

Supporting your research through involvement and participation of people affected by Parkinson's.

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In this policy:

Patient and public involvement (PPI) or 'involvement' is defined as:

Researchers and people affected by Parkinson's work in partnership to plan, design, implement, manage, evaluate and/or disseminate research.

Participation is defined as:

People affected by Parkinson's or healthy controls take part as subjects in a research study – this may be clinical trial, interventional or observational study.

Introduction

We support research to further our goals of finding a cure and improving life for everyone affected by Parkinson's. We can spread the word about your research if you need people affected by Parkinson's to:

- Help shape your research as **Patient and Public Involvement** contributors
- Participate in your **Research Study**

Our policy for research support

We can support good quality research which has the potential to deliver benefits for people affected by Parkinson's. We assess each request to ensure it meets our required standards. We need to fully understand the purpose of the research and how the information gathered will be used. Ultimately it will be at the discretion of the Parkinson's UK research team whether the research is eligible for support and how this is provided.

The researchers and host institution are responsible for ensuring adherence to all relevant research governance requirements including regulatory requirements.

Parkinson's UK will not pass on contact details of members, volunteers or research supporters to a third party until documented consent to contact has been obtained.

The use of the Parkinson's UK name or logo must have prior written agreement. We will also seek permission before using any partner name or logo.

Parkinson's UK is not responsible for, and therefore is not liable for, any claims concerning negligence, harm or oversight that might arise during the course of your research. The host institution is responsible for maintaining appropriate policies of insurance covering personal indemnity, public liability and employer's liability insurance.

The researchers and host institution are responsible for ensuring that the people affected by Parkinson's involved in the research are notified and aware of any information of a confidential nature that cannot be shared.

This policy has been reviewed by people affected by Parkinson's who are members of our Research Support Network. This policy will be reviewed on an ongoing basis.

How can we help?

Parkinson's UK can help promote opportunities to participate or be involved in your research to people affected by Parkinson's. If your request is approved we will share the opportunity through our communications and networks. We are not responsible for selection of individuals – these will generally be self-selected.

Once we receive your completed research support request form we will be in touch within five working days to discuss how we can support your research. We recommend applications for support are made as early as possible and at least four weeks in advance.

How we share the opportunity varies depending on a number of factors and is at the discretion of the Parkinson's UK research team but may include:

- sharing the opportunity with the 2300+ members of our [Research Support Network \(RSN\)](#)
- targeting communications to particular geographical regions or to our trained 'RSN volunteers' who have an understanding of the R&D process and have experience of working with academic and industry partners
- sharing with our local networks, which includes over 350 groups across the UK
- promoting the opportunity through our digital channels, including our website, Facebook, Twitter and online discussion forum
- highlighting the opportunity to our wider membership (around 37,000) through our magazines or e-newsletter

Types of research we can support

We welcome applications for support of both non-commercial and commercial research subject to the following criteria:

Non-commercial research

Researchers/research teams must be affiliated with a university, NHS trust or other appropriately accredited research institution which has agreed to sponsor your research.

- Parkinson's UK strongly recommends that research support requests include the intention to refund reasonable out-of-pocket expenses incurred by research contributors.

Commercial research

This covers research and development undertaken by pharmaceutical, biotechnology, medical diagnostic and device industries.

We will consider requests from an organisation contracted by an eligible sponsor to deliver the research. We will not work with third party organisations pre-contract (e.g. during the bidding process). Parkinson's UK will need to know the name of the sponsor and the purpose of the research for delivering benefit for people affected by Parkinson's.

- The charity expects all pharmaceutical company partners to work within [the ABPI code of practice 2016](#), particularly clause 27 (working with patient organisations). Parkinson's UK will also comply with this Code of Practice and follow the [AMRC guide for charities working with industry](#).
- Similarly, other commercial organisations should work according to their industry code of practice.
- Parkinson's UK will only support commercial research that covers all reasonable out-of-pocket expenses incurred by research contributors.
- We will not undertake any support which may suggest that the Parkinson's UK research team is recommending a product to the community of people affected by Parkinson's.

Research projects based outside the UK will be considered on an individual basis if associated with an accredited research institution or an eligible commercial partner.

For both commercial and non-commercial organisations we welcome enquiries about support for basic research and clinical research and development.

Basic research

We can support your research by facilitating involvement of people affected by Parkinson's. This includes: identifying and prioritising the most important research questions for people living with Parkinson's, providing input to funding applications, evaluating potential impact and communicating about your research.

Clinical research and development

We can support research by facilitating involvement of people affected by Parkinson's in all stages of clinical research and development. This includes: identifying and prioritising the important research questions, providing input into funding applications or into research and development plans, designing and implementing studies, identifying barriers to recruitment and retention, being a member of a steering group, evaluating impact and communicating about your research.

For the purposes of this policy we will consider support for clinical studies (including the early planning stages of one or more clinical studies) which will be conducted in an NHS trust, university, or other appropriately accredited research institution and will require research ethics committee approval prior to recruitment of people affected by Parkinson's.

Participation in clinical research studies

We can support sponsors and investigator site teams to recruit participants to both commercial and non-commercial studies. Parkinson's UK will not be involved directly in the consent process for clinical studies.

Digital applications and daily living aids

- We can work with you to facilitate involvement and participation in the development of standalone software apps which are considered to be medical devices according to the MHRA guidance: [MHRA Medical Device Standalone Software Including Apps](#)
- Similarly, we can support development of daily living aids which are considered to be medical devices: [MHRA guidance to decide if your product is a medical device](#)

We can support involvement and participation in planning and implementation of clinical investigations which will be conducted in an NHS trust, university, or other appropriately accredited research institution and will require research ethics committee approval prior to recruitment of people affected by Parkinson's.

It is the responsibility of the applicant to ensure that all the above criteria are satisfied, and to provide clear evidence that the research activities are rigorous and have the potential to benefit people affected by Parkinson's.

Types of research we cannot support

Non-medical device software apps

The development and assessment of software apps and daily living aids which are **not** categorised as medical devices under the MHRA definitions (see above) will not be considered for research support.

Market research

A useful document regarding definitions of research/market research is the [European Pharmaceutical Market Research Association Code of Conduct](#).

For the purposes of this policy we will not consider support for market research (for example user needs assessments, first hands on assessments, post market evaluations etc) which does not require research ethics committee approval prior to participation of any person affected by Parkinson's.

Where can I find more information?

If you are looking for people affected by Parkinson's to help shape research as **Patient and Public Involvement** contributors, find out more from:

Web: www.parkinsons.org.uk/researchinvolvement

Email: researchinvolvement@parkinsons.org.uk

If you are looking for people affected by Parkinson's to **participate** in your research, find out more from:

Web: www.parkinsons.org.uk/participation

Email: participation@parkinsons.org.uk

When the project is completed

Feedback and acknowledgement

If we agree to support your research, we require you to:

- send a **plain English summary** (Parkinson's UK can help you to draft this) of the research findings or decisions and recommendations resulting from this support to your contributors/participants and Parkinson's UK. We recommend researchers provide this summary to the volunteers as soon as possible following their involvement and definitely within a year of their involvement
- **acknowledge** Parkinson's UK's support in any relevant research publications
- provide Parkinson's UK with a copy of **any relevant research publications**. We also request advance notice of any related **media releases** which happen within the next year
- complete a research support feedback form so that Parkinson's UK can assess and improve our research support service

Payments

Parkinson's UK does not currently request any payment for the use of our resources in supporting your research. This may be reviewed in the future.

Any additional payments made to people affected by Parkinson's beyond out-of-pocket expenses are outside of the remit of Parkinson's UK.