

Supporting your research through involvement and participation

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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.

1. Our policy for research support

We fund and support high quality research to further our goals of finding better treatments and a cure and improving life for everyone affected by Parkinson's. We support research by working with people affected by Parkinson's to:

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

We also offer

- **Training and guidance for researchers and organisations** on working with people affected by Parkinson's to improve development, delivery and dissemination of research. We can also offer more general training and guidance if your research extends to other conditions as well.

2. How can we help you?

Parkinson's UK can promote and coordinate opportunities for people affected by Parkinson's to be involved in all stages of the research pathway – from basic science in the laboratory to use of drugs in the clinic.

We will ask for information about your project, study or trial and discuss with you how we can support you through our involvement and participation programmes. To do this we need to fully understand the purpose of the research and how the information gathered will be used. We assess each request for support to ensure it meets required research standards and that the support requested is covered by this research policy. It will be at the discretion of the Parkinson's UK research team to decide whether or not the research is eligible for support and if so how this is provided.

Once a request for support through patient and public involvement or participation is approved we will work with you to share the opportunity with our community of people affected by Parkinson's. The way we do this may include:

- Sharing the opportunity with the 3700+ members of our [Research Support Network \(RSN\)](#).
- Targeting communications to particular geographical regions or to our trained PPI volunteers who have an understanding of the research and development process and have experience of working with academic and industry partners.
- Sharing with our network of over 350 local groups across the UK.
- Promoting the opportunity through our digital channels, including our website, Facebook, and Twitter.
- Highlighting the opportunity to our wider membership through our magazines and/or e-newsletter.

For **patient and public involvement requests** we will target the most appropriate groups to meet your requirements but will not normally select specific individuals from the eligible contributors – these will generally be self-selected.

For **participation** requests we can work with sponsors and investigator site teams to help to recruit patients to clinical studies and trials we will work with you to build a strategy to minimise barriers to recruitment and to reach potentially eligible participants.

For patient and public involvement and participation support we recommend applications are made as early as possible and at least 4 weeks before the support is required. The first step is to submit the appropriate research support request form (see website and contact details below) and we will then be in touch within 5 working days to discuss the best options for supporting your research.

3. Find out more

Patient and Public Involvement in research

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

Participation in research studies

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

Letters of support

We will consider providing a letter of support for your research which can be presented to potential funders. Parkinson's UK letters of support confirm that the charity will support your research through involvement and participation as described in this policy but will not cover any financial support.

A letter of support would not commit Parkinson's UK staff to play a formal role in the research project, for example as a co-applicant or as member of a steering committee or advisory board. If you would like to discuss such a role for Parkinson's UK in your research please contact the Director or Deputy Director of Research at an early stage in the research planning process via our research inbox: Research@parkinsons.org.uk

Guidance and training

We offer training and guidance for your in-house research or clinical teams on working with people affected by Parkinson's or other conditions to improve development, delivery and dissemination of your research. For more information please contact:

researchinvolvement@parkinsons.org.uk

4. Types of research we can support

We welcome applications for support for of research projects from both commercial and non-commercial organisations.

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.

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 accept requests from an organisation contracted by an eligible sponsor to deliver research but will not undertake any work with third party organisations pre-contract (e.g. during the bidding process) however we can discuss the support which is available. 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 before undertaking any support activities.

- The charity expects all pharmaceutical company partners to work within [the ABPI code of practice 2016](#), particularly clause 27 (working with patient organisations). We will require a written agreement to be in place setting out exactly what has been agreed in line with the code of practice. Parkinson's UK will 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 where the organisation agrees to cover 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.

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 and in some cases facilitate involvement of people affected by Parkinson's in all stages of clinical research and development. Involvement in the early planning stages is supported with the understanding that that the planned studies will be approved by a research ethics committee prior to recruitment of participants and will be conducted in a NHS trust, University, or other appropriately accredited research institution. Support available includes: identifying and prioritising the most important research questions, providing input into funding applications or into research and development plans, designing and implementing studies, identifying barriers to participant recruitment and retention, recruiting members to a steering group, evaluating impact and communicating about your research.

Medical devices, (including software applications and living aids)

We can work with you to facilitate involvement and participation in the development of medical devices including:

- Standalone software applications which are considered to be medical devices according to the MHRA guidance: [MHRA Medical Device Standalone Software Including Apps](#)
- Living aids which are considered to be medical devices: [MHRA guidance decide if your product is a medical device](#)

We can support involvement and participation in planning and implementation of clinical investigations which will require research ethics committee approval and be conducted in a NHS trust, University, or other appropriately accredited research institution.

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 potential to benefit people affected by Parkinson's.

5. Types of research we cannot support

Non-medical devices (including software applications and living aids)

The development and assessment of software apps and living aids which are **not** categorised as medical devices under the MHRA definitions (see above) will be 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:

<http://www.ephmra.org/standards/code-of-conduct/code-of-conduct-online/>.

A key difference between research and market research is that market research involving healthcare professionals, patients, carers or members of the public **does not require** Research Ethics Committee approval

The research team doesn't support market research as defined in this code of conduct.

6. Governance

The researchers and their host institution/s 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.

7. When the project is completed

Feedback & acknowledgement

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

- Provide **feedback on the support received and the impact on your research** (by completing a short online survey) so that Parkinson's UK can assess and improve our Research Support Service.
- 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 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** within a year of the support activity.

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.

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