Supporting research through involvement and participation

As the largest European charitable funder of Parkinson's research, we've invested over £100 million in vital research that has delivered groundbreaking discoveries, new medications and better care. Alongside our research funding, we provide expert participant and involvement support to help your research achieve its goals.

Together we are a powerful global movement of scientists and supporters, investors and innovators. Driven by people with Parkinson's every step of the way. We can find a cure, and improve life for everybody affected by Parkinson's.

This document sets out how we support research via community involvement and participation.

Document details: Supporting research through involvement and participation - March 2025
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Review date: March 2027

What do we mean by involvement and participation?

- **Patient and Public Involvement (PPI) or 'involvement'** is when researchers and people affected by Parkinson's work in partnership to plan, design, implement, manage, evaluate and/or disseminate research.
- **Participation** is when people affected by Parkinson's or healthy controls take part as subjects in a research study.

1. Our support

As well as funding pioneering Parkinson's research through our research grants and unique Virtual Biotech programme, we also support high quality research by enabling the Parkinson's community to:

- Inform, develop and guide research through our sector-leading Patient and Public Involvement (PPI) programme
- Take part in research studies by promoting participation via our website, communication channels and networks

You can find further information about the support available and the relevant forms to apply for support on our website:

Recruit participants to your study

https://www.parkinsons.org.uk/research/recruit-participants-your-study

Patient and Public Involvement in research

https://www.parkinsons.org.uk/research/patient-and-public-involvement-research

Letters of support

We can provide a simple letter of support to confirm that the charity will support your research through involvement and participation as described in this policy. Please see further information and the form to request a letter of support on our website.

Please note, a letter of support does not commit Parkinson's UK to play a formal role in the research, for example as a co-applicant or partner. If you would like to discuss such a role for Parkinson's UK in your research please contact us at an early stage in the research planning process via our research inbox: research@parkinsons.org.uk

2. What research do we support?

We support both commercial and non-commercial projects and studies. This includes research and development undertaken by pharmaceutical, biotechnology, medical diagnostic and device industries.

To be eligible for our participation or involvement support, projects / studies must:

✅ Have potential to benefit people living with Parkinson's and/or their loved ones
✅ Be high quality and rigorously planned
✅ Be affiliated with a University, NHS Trust or other recognised research institution
✅ Be aware of and abide by relevant codes of practice*
✅ Pay any out-of-pocket expenses incurred by participants or PPI contributors
✅ Consider paying PPI contributors for their time*
✅ Consider equality, diversity and inclusion in research*
✅ Commit to sharing learnings/results as widely as possible
✅ Have a plan for managing and sharing the data generated

** supporting documents can be found in the appendix.*

International and masters level projects will be considered on a case-by-case basis.

It is the responsibility of the applicant to ensure that all the above criteria are satisfied.

3. What research do we <u>not</u> support?

To ensure we are only supporting high quality, impactful research and to avoid overburdening the Parkinson's community with requests, we do not support:

❌ Undergraduate level research projects (or equivalent)
❌ Projects that unnecessarily duplicate previous research
❌ Market research
❌ Projects where the sponsor/funder is not named
❌ Projects which may suggest the charity is recommending or endorsing a product

Parkinson's UK maintains discretion on whether or not to support participation and involvement requests and will be guided by the criteria above. Our ability to provide support may be limited by capacity. Please note it may take up to 8 weeks, from receiving your request and all documents, to share your research with the community.

4. Governance

- 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.
- Researchers are responsible for ensuring that people affected by Parkinson's are notified of any information of a confidential nature that cannot be shared.

5. Communication, feedback, acknowledgement

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

- Promptly respond to all people who express interest in taking part or being involved in your research, both before and after you have completed recruitment
- Provide feedback on the support received and the impact on your research.
- Communicate with participants / contributors at regular intervals as well as provide a summary of findings and outcomes. You can find guidance and templates to assist with this by using our staying connected toolkit.
- 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.

6. Cost recovery when supporting commercial organisations

From 2025, to help support the sustainability of our Patient & Public Involvement (PPI) programme, Parkinson's UK will charge for staff time when supporting commercial organisations with PPI. This is in line with new guidance for Fair Market Value for Charities in Partnership work developed by UK charities. For further information get in touch with our Research Involvement team: researchinvolvement@parkinsons.org.uk

All other support with Participation and Patient & Public Involvement remains free.

Get in touch | research@parkinsons.org.uk
If you have any questions or would like to discuss how best to work with the Parkinson’s community in your research please get in touch.

Appendix

Parkinson’s UK resources to support your research:

- Recruit participants to your study: https://www.parkinsons.org.uk/research/recruit-participants-your-study
- Patient and Public Involvement in research: https://www.parkinsons.org.uk/research/patient-and-public-involvement-research
- Race equality in research: https://www.parkinsons.org.uk/research/race-equality-research
- Staying connected with your participants: https://www.parkinsons.org.uk/research/staying-connected-your-participants
- Parkinson’s UK (2021) Guidance on expenses and payment for PPI contributors: https://www.parkinsons.org.uk/sites/default/files/2021-03/Guidance%20for%20researchers%20on%20payment%20and%20recognition%20%282%29%20%282%29.pdf
- Guidance on feedback to Patient and Public Involvement contributors: https://docs.google.com/document/d/1KvXmwdN-PJ9CL4UP8okA16F736NtLPfLZusoQHKhaOA/edit
- Parkinson’s UK data management and sharing: https://www.parkinsons.org.uk/research/data-management-and-sharing

External resources to support your research:

- UKRI guidance on the regulations and approvals that may be required for specific types of research. Available at: https://www.ukri.org/councils/mrc/guidance-for-applicants/5-ethics-and-approvals/ (April, 2023)
- NIHR (2020) Improving inclusion of under-served groups in clinical research: Guidance from the NIHR-INCLUDE project. UK: NIHR. Available at: www.nihr.ac.uk/documents/improving-inclusion-of-under-served-groups-in-clinical-research-guidance-from-include-project/25435 (April, 2023)

- ABPI (2021) ABPI 2021 Code of Practice. UK: ABPI. Available at: https://www.abpi.org.uk/reputation/abpi-2021-code-of-practice/ (April, 2023)
- Fair Market Value for Charities in Partnership work: https://pifonline.org.uk/resources/fair-market-value-for-charities-in-partnership-work/