# **Patient and public involvement (PPI)**

Support request form

We support good quality research that has the potential to benefit people affected by Parkinson’s. You will be asked to agree to the conditions of our support, which are outlined in our PPI Support Agreement. It will be at the discretion of Parkinson's UK as to whether the research is eligible for support and how this is provided. For more information about the types of research we support, see the Research Support Policy on the [PPI webpage](https://www.parkinsons.org.uk/research/patient-and-public-involvement-ppi).

By helping you to involve people affected by Parkinson’s in your research, Parkinson’s UK is not taking any responsibility for the research and is therefore not liable for any claims concerning negligence, harm or oversight that might arise during the course of the research.

Before completing this form, we recommend you read our [PPI Guidance for Researchers](https://www.parkinsons.org.uk/sites/default/files/2018-11/PPI%20Guidance%20for%20Researchers.pdf) which gives you practical advice on involving people affected by Parkinson’s in research. [This website](https://sites.google.com/parkinsons.org.uk/ppi-in-lab-based-research/home) also gives additional guidance for lab-based researchers.

Please return your completed form toresearchinvolvement@parkinsons.org.uk

**Contact details**

|  |  |
| --- | --- |
| **Principal applicant** |  |
| **Job Title** |  |
| **Research Institution & department**  |  |
| **Phone number**  |  |
| **Email** |  |
| **Co-applicants (if any)** |   |
| **Where did you hear about our PPI support?** |  |

**Background to your research**

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| --- | --- |
| **Plain English title** |  |
| **A plain English description of the study and its aims** (max 250 words, including research area, projected study length if known and any suitable links to online information about the research) |
|  |
| **How will your research help people affected by Parkinson’s in the future?** (in ~100 words) |
|  |
| **What stage are you currently at with your research?** Have you secured funding for your research?If yes, who is the funder?If no, when and where are you applying for funding? |
|  |

 **PPI in your research**

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| **At what stage of your research would you like to involve people affected by Parkinson’s?** (highlight all that apply) |
| * Identifying and prioritising your research question
* Writing your plain English summary
* Designing your study
* Evaluating study documents (information sheets, consent forms etc.)
* Managing the research (as part of a steering group or advisory committee)
* Undertaking the research
* Disseminating the research
* Evaluating impact
* Other (please specify):
 |
| **How would you like to involve people affected by Parkinson’s in your project?** (such as completing a survey, attending focus/steering groups, reviewing documentation) |
|  |
| **When would you like the PPI activity/activities to start?**  | **What will be the expected time commitment for PPI contributors?** |
|  |  |
| **How would you like Parkinson’s UK to support you with involving people affected by Parkinson’s?** (For example, by advising on PPI activities, connecting you with PPI contributors, facilitating a meeting or in another way.)  |
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**PPI in your research - who are you looking to involve?**

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| **Are you looking for people with specific characteristics or experience?** (such as early-onset, experience of participating in research) |
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| **How many people fitting the criteria are you looking for?** | **Are you looking for people who live in a specific location?**  |
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**PPI in your research - ethics and payment**

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| Whilst you should make sure and PPI activities are carried out in an ethical way, you do not need ethical approval for PPI - see this [HRA webpage](https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/what-do-i-need-do/) for more info.  |
| Any expenses incurred by PPI contributors must be reimbursed. You should also explore whether you are able to offer an honorarium payment to PPI contributors. Please see our [Guidance on Expenses and Payments here](https://www.parkinsons.org.uk/sites/default/files/2021-03/Guidance%20for%20researchers%20on%20payment%20and%20recognition%20%282%29%20%282%29.pdf).  |
| **Will expenses incurred by PPI contributors be reimbursed?** | **Will you be offering an honorarium payment to PPI contributors in recognition of their time and expertise?**  |
| * Yes
* No
* N/A
 | * Yes
* No
 |

**Your experience of involvement**

|  |  |
| --- | --- |
| **What is your previous experience of patient and public involvement, relating to this project or any previous work?**  | * No previous experience
* A little experience
* Some experience
* A lot of experience
 |
| **Please provide a brief explanation of any previous involvement experience:** |
|   |

**Feedback and acknowledgement**

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| **How do you plan to feedback to the PPI contributors on the impact they have had?** |
|   |
| **How will you inform PPI contributors of the research outcomes once the study is complete?** |
|  |
| **How do you plan to acknowledge the PPI contributors?** As a contributor, co-applicant, authorship?  |
|  |

**Get connected via Synapse**

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| Synapse is our monthly e-newsletter for Parkinson's researchers. Sign up to be the first to find out about funding opportunities, research events and other news and opportunities from Parkinson’s UK. |
| **Enter your email to sign up:**  |  |

By signing up you agree to receiving the latest Parkinson's UK Synapse updates. We will not sell your details to third parties. At Parkinson’s UK we want to be very clear about how we use, store and protect your personal data, which you can read about at www.parkinsons.org.uk/privacy. If you would like to change your subscription please let us know by emailing research@parkinsons.org.uk.