

We believe in involving people affected by Parkinson's in all stages of research. We know that partnerships between researchers and members of the public produce higher quality, more relevant research, and ensure that the benefits are felt by the people who need it most.

The Research Involvement Award aims to support this process, by offering the time and expertise of the members of the Research team to support researchers who have limited experience of patient and public involvement, to make the process simple and accessible.

### Purpose

- The Research Involvement Award aims to support researchers to involve people affected by Parkinson's to facilitate with:
  - Prioritisation of research topics
  - Preparing a research grant application
  - Design of research protocol
  - Management of studies
  - Data collection and analysis
  - Dissemination of findings
- This award aims to help researchers to overcome some of the common barriers to involvement, including not having the time, resources or 'know-how' and not knowing where to find the right people to involve.
- The award also aims to help researchers present a more compelling case for their study, if submitting an application to research funding bodies, as evidence of PPI is increasingly becoming a condition of funding.

### Scope

Successful applicants will receive:

- 1) Hands-on support and advice in developing appropriate patient and public involvement activities to meet the specific needs of the research. Including advice on;
  - Identifying who to involve
  - Selecting appropriate method/s of involvement
  - How to communicate with PPI contributors
  - Feeding back and maintaining relationships
  - Reporting on PPI activities
  - Acknowledging PPI contributors
- 2) Facilitation of the first meeting with PPI contributors, including;
  - Recruiting PPI contributors
  - Hosting the meeting at Parkinson's UK or room within your institution
  - Handling communications with the PPI contributors ahead of the meeting
  - Ensuring the meeting is accessible to people affected by Parkinson's
  - Helping with the structure and format of the meeting
  - Chairing and facilitating the meeting on the day
  - Reviewing lay materials to be used in the meeting, such as presentations and documents

- 3) Where funds for supporting PPI are not available to the applicant, Parkinson's UK will cover the cost of:
- Reimbursing patients, carers etc. for their reasonable travel expenses according to Parkinson's UK volunteer expense policy
  - Refreshment costs, including lunch, tea/coffee and snacks
  - Where possible, meetings are to be held at the Parkinson's UK Head office in London or at the applicant's institution. If this is not possible, Parkinson's UK will arrange a suitable venue and cover the cost of room hire.

## Duration

- The award will last according to the initial PPI activities planned by the applicant and Parkinson's UK staff. This will include planning, preparing and attending the first PPI meeting, as well as providing on-going support should it be required for an initial period of 6 months after the first meeting.
- Requests for support past this point for further activities will be considered on a case-by-case basis.
- The award aims to initiate PPI in the research process; groups formed in the initial meetings could be used to develop on-going relationships with people that can be sustained throughout the lifetime of the research study, or in the initiation of a new project.

## Eligibility

- Awards are tenable at a UK university, NHS trust, statutory social care organisation or other research institution.
- Applicants working across all fields of Parkinson's research, including those new to Parkinson's research.
- Applicants with limited experience of involving people affected by Parkinson's in their research.
- Applicants looking to involve people affected by Parkinson's at any stage of their research project, including when disseminating and implementing research findings
- Applicants who have not previously been awarded a research involvement award before.
- If applying for funding for an initial meeting, applicants must provide evidence that their host institution does not have PPI funding available to cover or share the cost with Parkinson's UK.
- Research projects based outside the UK will be considered on a case-by-case basis.

## Application procedure

Applications may be submitted at any time. All applications will be acknowledged within 5 days and applicants will be notified of a decision within 4 weeks from the stated submission deadline.

All researchers must submit their application via completing the research involvement award application form and returning it to [researchinvolvement@parkinsons.org.uk](mailto:researchinvolvement@parkinsons.org.uk)

Each application will be reviewed on a case-by-case basis by the Parkinson's UK Involvement Steering Group and research team.

An assessment will be made based upon the applicants:

- Motivations for involving people affected by Parkinson's in their project
- Demonstrated understanding of the potential benefits of PPI
- Previous experience of PPI
- The suitability of the project and it's likelihood of benefitting from PPI
- Enthusiasm for sustaining meaningful PPI in their research
- Available PPI support at applicants institution

## Unsuccessful applications

If we cannot support PPI in a project through an research involvement award, unsuccessful applicants will be provided with:

- PPI guidance and template documents
- The opportunity to connect with people affected by Parkinson's through our Research Support Network
- The opportunity to connect with a local research interest group

Applicants who are not successful will also receive written feedback, explaining the basis of the decision, and may be invited to apply in the next round.

If you have further questions about making an application, please contact the Research Involvement team.

**Call:** 020 7963 9327 or 020 7963 3964

**Email:** [researchinvolvement@parkinsons.org.uk](mailto:researchinvolvement@parkinsons.org.uk)