Non-drug approaches grants Information for applicants

Parkinson's UK is the largest member-led charitable funder of Parkinson's research in Europe. So far, we've invested over £120 million in ground-breaking research.

Purpose and scope

We want to fund creative, innovative research into non-drug approaches that will play a vital part in helping people living with Parkinson's manage their daily challenges and take control of life living with Parkinson's. We want to focus on what matters most to people living with Parkinson's and provide solutions and deliver outcomes to improve quality of life as soon as possible.

There are lots of ways to manage the ongoing issues and challenges of life with Parkinson's. Non-drug approaches are important to people affected by Parkinson's. At some stages of the condition, these approaches are of equal or greater importance than pharmacological treatment.

We're looking for projects that, if successful, have a clear pathway to be made more widely available to people affected by Parkinson's as soon as possible. The proposed plan for the pathway to clinical adoption forms a major part of the grant assessment process.

We understand that some projects may be in the early stages of development. In this instance, it is important that applicants provide a detailed description of the practical proposed next steps of the project and its potential impact on people currently living with Parkinson's. Successful projects are welcome to apply to future rounds to support the next steps of their project development.

Applicants may wish to consider areas of unmet needs of people affected by Parkinson's. (please see research papers detailing the priorities of people with Parkinson's, including <u>Port et al., 2021</u> and <u>Deane et al., 2014</u>).

People living with Parkinson's want better treatments and hope for the future now. Find out more about how people can manage the ongoing issues and challenges of <u>life with Parkinson's.</u>

Details of the scheme

We're keen to receive applications from researchers working in the following areas, related to Parkinson's. This is not an exhaustive list.

- Physiotherapy
- Occupational therapy
- Speech and language therapies
- Mental health therapies (non-drug)
- Health and social care
- Complementary therapies
- Nutrition

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- Exercise, including dance
- Technology and devices
- The non-drug approaches grant scheme aims to test novel innovations such as apps, devices and exercise programmes which will directly improve quality of life for people living with Parkinson's . Applications related to improving healthcare services will not be considered in this scheme.
- The duration of a non-drug approaches grant is for a maximum of 24 months.
- There is no minimum value for the non-drug approaches grants, however, the maximum cost of applications is up to £200,000.
- Applications must be a research based project and be testing an innovation to improve life for people living with Parkinson's.
- We will not accept applications that are purely based on data gathering and evaluation studies.
- If the application involves a drug or preclinical testing, it should be submitted to the project grant scheme.
- If you have any queries on making an application in this area, please contact the team on <u>researchapplications@parkinsons.org.uk</u> prior to the submission deadline.
- Applications that are not within the remit of non drug approaches, and do not contain a research element, will not be considered.

Other grant schemes to consider

Find out more about other <u>Parkinson's UK grant schemes.</u>

The Excellence Network project grants scheme is for projects that aim to enhance the service of both health and care organisations for people with Parkinson's living in the UK. This could be through the development, testing or roll out of new clinical pathways or technology. Applications relating to the development of innovative healthcare frameworks, capacity building models and resources, clinical tools or data dashboards are welcome.

For more information, contact <u>excellencenetworkgrants@parkinsons.org.uk</u>.

Eligibility

- Applications must be directly relevant to people currently living with Parkinson's.
- Non-drug approaches grants are tenable at a UK university, NHS trust, statutory social care organisation or other UK research institution.
- Principal applicants should hold employment or honorary (if a clinical academic) contracts with the UK host institution that extend beyond the period of the grant.
- Principal applicants (as the grantholder) will be responsible for the intellectual leadership and overall management of the grant. Principal applicants must have the relevant skills and experience to carry out this role.
- Principal applicants based at UK universities must hold a post at the equivalent status of lecturer or above.
- Principal applicants who are healthcare professionals must hold a post at a senior level, such as lead physiotherapist. Applicants should contact the <u>Research grants team</u> if they are unsure whether their post is of a suitable level.
- Principal applicants who are funded by a fellowship must hold a senior level fellowship (a fellowship that has been extended beyond an initial 3 year term), and provide a letter of support for their application from the host institution. Individuals who hold a junior level fellowship (that is still within

its initial 3 years) are not eligible to apply as a principal applicant. Applicants should contact the Research grants team if they are unsure whether their fellowship is of a suitable level.

- Principal applicants who are healthcare professionals must hold a post at a senior level, such as lead physiotherapist. Applicants should contact the Research grants team if they are unsure whether their post is of a suitable level.
- Only one principal applicant can be listed on a non-drug approaches grant application.
- Principal applicants may submit more than one non-drug approaches grant application in a grant round.
- Applicants may be new to Parkinson's research, but the proposed team must include people with relevant Parkinson's expertise.
- Applicants may have previously spent time away from research (for example a career break, maternity / paternity leave, or long-term sick leave). Our reviewers will allow for this when the application is considered.
- A co-applicant is a person who will assist the grantholder (the principal applicant) in the management and leadership of the grant. Co-applicants must have the relevant skills and experience to carry out this role.
- Applicants must demonstrate that they have incorporated the appropriate roles and balance of expertise / experience to successfully undertake the project.
- Co-applicants and collaborators may be based at institutions outside the UK and / or at pharmaceutical or biotech companies. A maximum of five co-applicants can be added to an application. There are no restrictions on the number of collaborators.
- If you have a lay co-applicant, five or more co-applicants can be added to an application. A clear explanation is needed for their role within the project
- Please make sure you include all co-applicants and collaborators on your preproposal that would be included in a full application. Additional collaborators may only be added at the full application stage in response to suggestions from the reviewers
- Applicants should read <u>research grant terms and conditions</u> and the charity's <u>research grants costs</u> <u>guidance</u> before completing the application form.
- Applicants are also expected to ensure that they create a suitably diverse research team, taking into account issues such as race, ethnicity, gender, age, disability, sexual orientation, religion and belief. They will be asked to justify the team makeup in the application.
- Applicants should be directly relevant to the <u>charity's research priorities</u>.

Application procedure

- There is one application round per year. Closing dates for preproposal and full applications can be found on the <u>Parkinson's UK website</u>.
- Deadlines may be subject to change. Any changes will be shared widely via the charity website and relevant newsletters.
- Applications must be submitted by 4pm on the deadline dates.
- All applications must be made in English.
- Application is by a two stage process, consisting of a preproposal and a subsequent full application.
- Applicants will receive confirmation by email from the online applications system once a grant application is submitted.
- The full application stage is by invitation only for those applicants who have passed independent scientific and lay review at the preproposal stage.

- Both preproposal and full grant applications to Parkinson's UK are made through the charity's <u>online</u> <u>grant application system</u>.
- Applicants are not required to submit a hard copy application.
- In order to avoid formatting problems, text from other documents should be pasted into Notepad (or similar programme) before being copied into the online application form.
- Please make it clear if your project is a pilot study that requires future studies before it becomes available to people affected by Parkinson's.
- CVs should be submitted using the <u>Parkinson's UK template</u> and no personal information such as home addresses etc, should be included. At the preproposal stage, a CV should be included only for the principal applicant. At the full application stage, CVs should be included for all of the co-applicants, as well as the principal applicant.
- Details of any collaboration must be included and a letter confirming agreement from each collaborator should be submitted.
- If the project includes work with patients, please ensure a letter of written support is supplied from a clinical collaborator.
- Appendices for the preproposal stage you may submit up to two A4 pages of figures and / or pilot data. Any confirmatory letters should also be submitted as appendices but do not count towards this two page limit. The two page limit on appendices does not apply for the full application stage. Applicants are requested to only include information that is directly relevant information in the appendices.
- Any relevant 'in press' articles should be attached as appendices.
- Covering letters are not required.
- Use of generative artificial intelligence (AI) tools when developing proposals, applicants must ensure that any generative AI tools they utilise are used responsibly and in accordance with relevant legal and ethical standards where these exist (or as they develop). Any outputs from generative AI tools in applications should be acknowledged.
- Unless the charity requires further information, no correspondence will be entered into until the results are notified. Applicants are requested not to initiate contact with the Research team during the review process.
- At the preproposal stage, please include a plain English abstract, scientific abstract, objectives, preliminary budget, project background, experimental plan and details of the research team. This information is submitted as part of an online application form. There are word limits for each section of the online application form: Abbreviations (500 words max), Plain English summary please include the relevant information including a lay abstract, project background and impact (250 words max per section), Involvement of people affected by Parkinson's (200 words max), Scientific abstract (300 words max), Project background (450 words max), Experimental plan (400 words max)
- At the full application stage, the scientific research proposal should include the following information: background and plan of investigation which should explicitly cover study design, methods of data collection analysis and time schedule. The research proposal should be submitted as a PDF and should be no longer than 4,000 words. Research proposals longer than this will be rejected. A full list of references for the application should be listed within the research proposal section. Figures can either be embedded within the research proposal or included as an appendix. Any references and figure captions do not count towards the research proposal word count.

Costing the full application

• Please read our guidance on allowable and non allowable research costs.

- In line with the Association of Medical Research Charities guidelines, Parkinson's UK will only reimburse directly incurred research costs for awarded grants as per the application submitted.
- Applicants must justify the funds requested.
- Applicants must apply for funding in British pounds sterling
- The research budget in the preproposal should be realistic. If the proposal proceeds to the next stage, the overall costs included within the full application are required to be within ±10% of the overall costs stated in the preproposal application. Please note, costings at the preproposal stage do not need institutional approval.
- Applicants who are successful at the preproposal stage will be invited to submit a full application..
- At the full application stage, further details are required to be submitted on the budgeted costs within the 'justification for the support requested' section.
- Applicants should seek the advice of their institution's Finance or Research Office on costing the full application well in advance of the application deadline. When a full application is submitted via the online application system, it is sent directly to Parkinson's UK.
- Staff costs: Basic salary should be stated for each individual. Provision for London weighting, superannuation and National Insurance should be shown separately in the space provided. An appropriate grading and salary must be quoted even where a named assistant cannot be specified. Both the grading and salary should have the approval of the appropriate administrative officer of the institution where the assistant would be employed. Parkinson's UK will not pay salaries for principal investigators, co-applicants or collaborators named on the funding applications unless their salaries are dependent on grant funding. In these cases the charity would require a letter from the Institute confirming this to be included in the appendices at both the preproposal and full application stage. If appropriate, applicants can apply for support costs for PhD students as outlined in the <u>research costs</u> <u>guidance</u>. PhD positions must not be the primary position funded to work on the proposed research project but can be a secondary funded position as part of a wider project. The main focus of the project grant scheme is the investigation of major research challenges.
- **Research expenses:** Details must be given. Grants do not cover administrative expenses or costs for attending conferences. The charity funds UK based research posts only, however research expenses can be requested of up to £10,000 for overseas research work essential to the success of the proposed project. Detailed justification for this must be provided.
- **Open Access Publications:** Costs related to open access publishing may be included. Please see our guidance on <u>open access publishing</u>. The costs requested must be fully justified.
- **Research involving human participants:** Please give details of what will be expected of study participants and the costs involved. You may find it helpful to carry out <u>patient and public involvement</u> (<u>PPI</u>) during the design of your study to ensure that you have considered the unique needs of people affected by Parkinson's.
- **Patient and public involvement (PPI):** You may include costs for any planned patient and public involvement (PPI) activities in your application for all types of research projects, for example travel expenses for a face-to-face meeting. Please see <u>our PPI guidance</u> on how to involve patients and the public in your research in a meaningful way.
- Equality, diversity and inclusion (EDI): You may also include costs for any planned activities in relation to EDI, for example consultation with an EDI specialist on delivery support and advice. Please see our <u>Race Equality in Research project webpage</u> for guidance on how to think more about ethnicity and inclusion when planning and designing your research.
- **Equipment:** Please specify each piece of equipment requested.

• Inflation: Inflation will not be paid in year one. Inflation in years two and three is allowable up to 3%. In the financial schedule of the application form, inflation should be shown separately from the research costs. The research costs should be entered into the application form excluding inflation. The level of inflation requested for years two and three can then be added separately for the 'Salaries and related costs', 'Research expenses' and 'Equipment' sections (applicants can select none, 1%, 2% or 3%). The inflation will be calculated automatically at this rate and the correct amounts will be added on to the costs as a separate 'Inflation' line in the table.

Review procedure

- Preproposals and full applications will be independently reviewed by three scientific members of our <u>College of Experts</u> and a group of lay grant reviewers, who are people affected by Parkinson's.
- The scores from the scientific reviewers and lay grant reviewers are given equal weighting in the assessment of grant applications
- All applications are reviewed using a ten point system, with 0=Unfundable and 10=Highly fundable / Highly competitive at International Standard (see Appendix).
- Applicants submitting preproposals with substantive scientific merit, that are also viewed to be important and relevant to people with Parkinson's, will receive an email notification inviting them to submit a full application. This invitation will include feedback from the scientific reviewers.
- Applicants submitting preproposals which lack scientific merit or which are scored unfavourably by people affected by Parkinson's, will receive an email stating they are not being invited to submit a full application and feedback on why they have been unsuccessful at this stage.
- All proposed research projects should be in the best interests of people affected by Parkinson's, who are also a key audience for your research. A good plain English summary is essential for a successful submission, as the lay evaluation of applications depends on the lay grant reviewers being able to read and understand your application. The plain English language sections must use an appropriate level of lay rather than technical language and give a realistic representation of scientific sections of the project in terms of potential outcomes and timescales. We strongly recommend that applicants seek lay input on their plain English summary in advance of submitting your application. Applicants can request lay feedback on their plain English section prior to applying by contacting our <u>patient and public involvement</u> (PPI) programme at least three weeks prior to the application deadline.
- For full applications, the mean review scores from both the College of Experts scientific reviewers and lay grant reviewers will be used to identify a shortlist of highly ranked applications for further discussion at a panel meeting.
- Feedback from College of Expert scientific reviewers and lay grant reviewers will be sent to principal applicants of shortlisted applications and will be reviewed at the panel meeting. Applicants will have at least one week to reply to the queries raised or provide clarification. Principal applicants will receive an email alerting them to the timing of the 'right-to-reply' period. 'Right-to-reply' responses from applicants should be no longer than two sides of A4.
- The grants assessment review panel of scientists and lay grant reviewers which is made up of members of the College of Experts will discuss and score the shortlisted applications. The mean review scores submitted from both the College of Experts scientific reviewers and lay grant reviewers will be used to identify applications that they will then recommend for funding to the Parkinson's UK Chief Executive Officer.
- Successful applicants may be given feedback from the panel meeting and the opportunity to respond and develop areas of the application, with input from appropriate experts as necessary.

- Funding may be awarded on the condition that particular areas of the application are developed as suggested by the funding panel.
- Successful applicants (grantholders) will submit annual and final reports as per the Parkinson's UK research grants terms and conditions, which will be reviewed by appropriate members of the College of Experts.
- Applications will be judged by three scientific members of the College of Experts against the following criteria:
 - importance and relevance of the research
 - potential impact of the research for people affected by Parkinson's
 - likelihood of the research being rolled out for people affected by Parkinson's
 - scientific quality of the proposal
 - quality of the researcher and team
 - diversity of the research team
 - value for money
 - budget and infrastructure
- Applications will be judged by lay grant reviewers against the following criteria:
 - the importance and relevance of the research for people affected by Parkinson's
 - the likelihood of potential benefit of the research for people affected by Parkinson's as soon as possible
 - if the proposed research involves human participants, whether they think people would be likely to take part
 - whether the proposed project includes a clear pathway to being made available to people affected by Parkinson's

Patient and public involvement

Applications must be driven by strong research evidence and supported by meaningful patient and public involvement (PPI). Applicants must work with people affected by Parkinson's in the development of an application in a way that adds value to the project and, if successful, throughout each stage of the research process.

Patient and public involvement is essential in the non-drug approaches grant scheme.

- Patient and Public Involvement (PPI) is when researchers and people affected by conditions work in partnership to plan, design, manage, evaluate and communicate about research.
- Applicants are strongly advised to seek lay input on their research proposal as early as possible when devising their research questions, study design and PPI plans.
- PPI in research leads to higher-quality, more efficient research focused on what matters most to those living with the condition.
- All applicants are expected to work with people affected by Parkinson's in the development of an application for funding and, if successful, as much as possible throughout the research process. There are a number of ways that applicants can involve people in their research, including, but not limited to, in identifying and prioritising research questions, shaping study design and helping to write plain English summaries. Read <u>this article</u> for more information on how PPI can strengthen your application.

- Parkinson's UK can support researchers to involve people affected by Parkinson's through our <u>patient</u> <u>and public involvement</u> (PPI) programme, including by helping to plan meaningful involvement activities and find people to involve.
- Remember to include costs for any planned PPI activities in your application. This includes necessary
 expenses incurred by PPI contributors as a result of being involved in a PPI activity. Parkinson's UK
 also considers it best practice that PPI contributors are offered an honorarium for their involvement in
 research where the PPI activity requires a substantial time commitment. For more information please
 read our guidance for researchers on payment and recognition and INVOLVE's <u>'Budgeting for
 Involvement' document and 'Cost Calculator'</u>.
- See our <u>PPI Guidance for researchers</u> and also our <u>PPI tools for lab based researchers</u> for more information, and get in touch with the team for support with PPI at <u>researchinvolvement@parkinsons.org.uk</u>

Please also see the **patient and public involvement flow chart at the end of** this document, which illustrates how you can involve people affected by Parkinson's in every stage of your research.

Recruiting participants and staying connected

Parkinson's UK can help researchers to find participants for their research studies.

Researchers are expected to keep participants up to date with the progress of their study, as this makes them more likely to take part in future research and helps to increase the quality of the research. Use this simple, free communication <u>toolkit</u>, co-produced with researchers and the Parkinson's community to stay connected with your participants. The toolkit was developed with the HRA (Health Research Authority) and RECs (Research Ethics Committees). Please contact <u>participation@parkinsons.org.uk</u> if you have any questions.

Equality, diversity and inclusion (EDI)

Parkinson's UK is here for everyone in the Parkinson's community. The <u>Parkinson's UK Equality, diversity</u> and inclusion (EDI) strategy sets out our overarching goal, ambitions and EDI promise. The charity wants equity for everyone who lives with Parkinson's, and the people in their lives, in the UK. Parkinson's affects all sections of the community, irrespective of race, ethnicity, gender, age, disability, sexual orientation, socioeconomic group, religion or belief. Responses to Parkinson's treatment can be different depending on a range of factors. We believe Parkinson's research should involve, include and represent all members of the community. By having a diverse network of people involved with research, we're more likely to make breakthroughs that change the lives of all people with Parkinson's.

All applicants are encouraged to use an inclusive research design approach. If you are involving human participants or tissues, please address how these factors will be considered in your experimental plan. The charity's <u>Race Equality in Research project</u> sets out our long-term strategy to increase engagement and participation in Parkinson's research with people from Black, Asian and Mixed Race backgrounds. Please see the 'Writing a research grant application' section within the Appendix to this document for further details on how to consider equality, diversity and inclusion in all aspects of your research.

We actively encourage people from all sections of the community, irrespective of race, ethnicity, gender, age, disability, sexual orientation, socioeconomic group, religion or belief. Please explain how you have considered these issues when creating a diverse research team. EDI data will be collected for all staff and students named in the research team via an online survey as part of the charity's monitoring processes.

We understand that different people choose different career paths, so we want to provide flexible research career opportunities. If you're funded by us, you can request flexible and part-time working. We always try to accommodate requests, as long as they fit in with the needs of employing organisations.

We consider the needs of everyone who applies for a grant at Parkinson's UK. If you have a disability, long-term health condition, mental health condition, are neurodivergent, or have care responsibilities and need support at any point during the application process, please get in touch and we'll be happy to help. You can email <u>researchapplications@parkinsons.org.uk</u>.

Unsuccessful applications

- Comments from the reviewers will be made available to unsuccessful applicants. No further discussion with Parkinson's UK staff or the College of Experts is allowed.
- On occasion, applications may receive high review scores but still be unsuccessful. Parkinson's UK are within their rights to choose to fund the application that will have the most impact and most closely aligns with the charity's strategy and has the most potential benefit to people affected by Parkinson's, based on the recommendations of the funding panel.

Resubmissions

Only one resubmission is allowed. This includes instances where the application has previously been submitted via another Parkinson's UK grant scheme.

For unsuccessful applications, it is possible to submit a revised application at the preproposal stage of the following year's non-drug approaches round (if it still fits within the scheme's remit). Resubmitted applications must be significantly different from the original application and incorporate changes based on the feedback provided during the review process.

- Applicants are required to note in the declarations for the application that the proposal has previously been submitted to Parkinson's UK.
- Applicants must specifically include as an appendix an annotated version of the research proposal, showing where changes have been made, and a list of bullet points indicating the changes.

Further information and support

Read the slides from our <u>recent non-drug approaches workshop</u> for researchers and people affected by Parkinson's.

Visit the <u>Parkinson's UK YouTube channel</u> to see videos from people with Parkinson's, scientists and supporters, fundraisers and families, carers and clinicians. Impatient for change. We're taking a stand, speaking out, chipping in, and playing our part.

Contact us

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

Email: researchapplications@parkinsons.org.uk

Writing a research grant application

We only fund the best quality research so that every penny donated towards research will benefit people with Parkinson's. We receive a high volume of applications in each grant round, so it's vital that you make your application stand out from the crowd. Below are some tips and pitfalls to avoid when preparing your grant application to give yourself the best chance of success.

Make a good first impression

- Ensure that you are fully familiar with all sections of the 'Information for applicants' document.
- Read the Parkinson's UK research grant <u>terms and conditions</u> and <u>costs guidance</u> make sure your requests are allowable by Parkinson's UK.
- Give all the information required in the correct format Arial typescript, size 11pt.
- Ask at least one independent person to proofread your application reviewers dislike typographical and grammatical errors.
- Ensure figures make sense and are correctly referenced in the text.
- Make sure everything in your research proposal is correctly referenced.
- Even if your ideas are excellent, a badly presented application may make reviewers wonder if this is an indication of how the research will be conducted.

Write a good plain English summary

- It is important that you think carefully about your lay reader when writing your plain English summary.
- Lay grant reviewers may have considerable personal experience of Parkinson's but little specialised scientific knowledge.
- The plain English summary must accurately reflect the research proposal and scientific abstract.
- Although the summary should be written in simple terms, please make sure that it contains enough detail for a lay grant reviewer to make an informed decision about the project.
- Applicants should be realistic about the potential outcomes of their research and the likely timescales involved.
- Avoid using jargon, abbreviations and technical terms wherever possible if you have to use them provide a clear explanation and include a good glossary.
- Avoid complicated English or uncommon words.
- Avoid elaborate explanations of 'what is Parkinson's'. Lay grant reviewers are very likely to know a lot about this already but want to know about the particular research project.
- Use active not passive phrases, for example say 'we will do it' rather than 'it will be done by us'.
- Keep sentences short try not to use more than 15 to 20 words per sentence.
- Break up the text, for example by using bullet point lists.
- If your study involves participants ensure you have included details of what will be involved for them and how they will be supported.
- Ask someone without a scientific background to read your draft and advise if anything is unclear.
- Applicants can request lay feedback on their plain English section by contacting our <u>patient and</u> <u>public involvement</u> (PPI) programme at least three weeks prior to the application deadline.
- You can find more tips on writing a good plain English summary on the <u>'make it clear' campaign</u>.

Clearly demonstrate how your research relates to Parkinson's

• Parkinson's UK only supports research into Parkinson's and Parkinson's like disorders. We want to fund research that has the greatest chance of improving the lives of people with Parkinson's.

- Applications for lab-based projects must clearly demonstrate how their research relates to Parkinson's and how it could provide valuable insights for future research.
- Scientific and lay grant reviewers have a lot of knowledge of Parkinson's and will usually have considered many applications over the years. They expect applicants to demonstrate a good understanding of Parkinson's. Applicants whose expertise and publications record primarily relates to another field should seek to collaborate with relevant experts in Parkinson's and people affected by Parkinson's where necessary.
- Parkinson's UK will consider applications which may provide insights into a number of neurodegenerative conditions, but again you will need to show the particular relevance to Parkinson's.

Ensure your research proposal is clear and logical

- Make sure your hypotheses are clear and firm and are reflected clearly in the methodology.
- Consider the practical implications of people affected by Parkinson's in your research.
- Show how the various experiments and stages of proposed research relate to each other.
- Give clear information on what the outcome measures will be.
- Identify and address any potential challenges or pitfalls what will you do if your first proposed experiment doesn't result in the outcome you expected? Or if you have challenges with recruitment or retention of participants?
- Provide sufficient detail on the experiments and how they will be carried out to show your understanding of what you're doing.
- Give realistic sample sizes and power calculations based on evidence.
- Clearly describe the future clinical benefits and timescales of practical improvements that could result from the research.
- Ensure your application includes details of how the results of your research will be made available to others.

Consider equality, diversity and inclusion in all aspects of your research

Parkinson's UK is here for everyone in the Parkinson's community. The <u>Parkinson's UK Equality, diversity</u> and inclusion (EDI) strategy sets out our overarching goal, ambitions and EDI promise. The charity wants equity for everyone who lives with Parkinson's, and the people in their lives, in the UK. Responses to Parkinson's treatment can be different depending on a range of factors. We believe Parkinson's research should involve, include and represent all members of the community. By having a diverse network of people involved with research, we're more likely to make breakthroughs that change the lives of all people with Parkinson's. The <u>Parkinson's UK Race Equality in Research project</u> sets out our long-term strategy to increase engagement and participation in Parkinson's research with people from Black, Asian and Mixed Race backgrounds.

Parkinson's affects all sections of the community, irrespective of race, ethnicity, gender, age, disability, sexual orientation, socioeconomic group, religion or belief. There are also a broad range of factors that can impact the metabolism and response to treatments including physiology and genetics. These differences in response to treatments can be related to issues such as race, ethnicity (Ben-Joseph et al., 2020) and Sauerbier et al., 2018) and gender (Cerri et al., 2019). There can also be biases in medical devices and technologies against individuals of different ethnicities, genders and other socioeconomic groups that may need to be mitigated. For example, some devices employing infrared light or imaging may not perform as well in people with darker skin pigmentation - this would need to be taken into account in the development and testing of the devices. The social aspects of diversity also need to be considered, especially in relation to how this impacts on the way individuals are diagnosed and treated. Without a

diverse group of individuals participating in research, researchers will not know if their results can be applied to all people equally.

Parkinson's UK is committed to supporting research that is inclusive, in both design and practice, and gives appropriate consideration to equality, diversity and inclusion issues to be beneficial for everyone. Applicants are therefore asked to consider and explain how they have taken these factors into account in all relevant aspects of their work. Depending on the type of research, this could include the following aspects of the application:

- Inclusive research design When designing research projects with human participants, applicants
 must consider factors such as gender, age, ethnicity in their research questions, methods,
 implementation, outcomes and reporting. Applicants may wish to refer to the guidance provided by
 the MRC on <u>sex in experimental design</u>, and also the toolkit produced by NIHR and CEHR that
 includes help in developing research questions that are more relevant to ethnic minority communities.
- Participation and use of human tissue Applicants must consider how they will ensure that the participant groups and human tissue samples used reflect the diversity of the population. This could include carefully considering the eligibility criteria for study participants and the recruitment processes; developing study materials with inclusion in mind; ensuring the research team is aware of relevant cultural issues; and building partnerships with community organisations / trusted advocates. Applicants should consider if there are any issues that would impact the diversity of people with Parkinson's that would be willing and comfortable to take part (are there any barriers that would stop certain sections of the community from participating). Please refer to the guidance produced by the NIHR INCLUDE project on improving inclusion of under-served groups in clinical research and the NHS guidance on increasing diversity in research participation.
- **Research team** Applicants should consider the expertise required to carry out inclusive research and the diversity of their team, including a balance of gender, ethnicity and career stage. Researchers from under-served groups are more likely to be familiar with, and motivated to develop solutions for, health issues facing the demographic groups to which they belong. If appropriate it may be helpful to include those researching social and health disparities in under-served groups in your team. If relevant to the study, then it can also be helpful to include bilingual staff in the research team. When recruiting to your team you should consider diversity and follow best practice as advised by your Institution's HR department, including mitigating the impact of unconscious bias. It can also be helpful to consider how you will build an inclusive team environment where all feel valued and supported, with equal access to development opportunities.
- **Patient and public involvement (PPI)** Applicants must consider how they will involve the Parkinson's community in their research. When planning involvement activities, applicants should consider diversity and take steps to ensure they are as inclusive and representative as possible.

You can also learn more in the Parkinson's UK <u>blog post on increasing diversity in research</u>. Please find below some specific examples of steps that researchers can take to increase diversity in Parkinson's research:

- Recruiting staff (clinicians, coordinators, researchers) who reflect under-served communities.
- Developing relationships with communities over the long term.
- Engaging with communities early to make sure the research questions asked are things that the community really wants to see addressed.
- Going beyond translating clinical tests and resources by also making sure they are <u>culturally</u> <u>appropriate</u>.

- Having open lines of communication to ensure people can discuss their concerns about taking part.
- Recruiting diverse teams of clinicians and researchers from the local community and training them.

Non-drug approaches - Parkinson's UK Scientific reviewer scoring system

The listed characteristics are for guidance only. The characteristics are general statements on the overall quality of the application in each funding category. They are not a checklist of minimum criteria for the funding category.

Funding category	Characteristics for Scientific Members	Rating scale	
Highly fundable	• Very important research questions; likely to result in advancement in the scientific understanding of Parkinson's or significant benefit for people affected by Parkinson's by addressing the priority research areas for improving everyday life.	Exceptional	10
	 Very clear pathway to impact and delivery for people living with Parkinson's Excellent and appropriate methods and research design. Very strong, internationally competitive and diverse team, 	Excellent quality research	9
	 containing all relevant disciplines. Very good value for money. Clear and well written proposal. Strong evidence of meaningful and well-planned patient and public involvement including the consideration of diversity, with activities integrated at relevant points throughout the project Plain English summary accurately reflects the research proposal and is realistic about potential outcomes and timescales involved. 	Very good, bordering on excellent	8
Potentially fundable	• Relevant research questions; likely to result in advancement in the scientific understanding of Parkinson's, or benefit for people affected by Parkinson's by addressing the priority research areas	Good quality research	7
	 for improving everyday life. Clear pathway to impact and delivery for people living with Parkinson's Good quality and appropriate methods and research design. Competent, appropriate and diverse research team containing all 	Above average quality research	6
	 key disciplines. Good value for money. All key aspects of application are clearly presented Some evidence of patient and public involvement including the consideration of diversity, with activities well planned and integrated at relevant points. Plain English summary accurately reflects the research proposal and is realistic about potential outcomes and timescales involved. 	Acceptable quality	5
Not fundable (without significant changes)	 Research questions are not directly relevant to the scientific understanding of Parkinson's or do not address the priority research areas for people affected by Parkinson's. Unclear pathway to impact and delivery for people living with Parkinson's 	Borderline quality research	4
	 Inappropriate methods and research design of only modest or poor quality. Applicants without relevant research experience or key disciplines not represented. Poor value for money. 	Below acceptable quality	3

	 Key elements of the application are unclear. Limited evidence of patient and public involvement including the consideration of diversity, with unclear plans. Plain English summary is unclear, does not accurately reflect the research proposal and is unrealistic about the potential outcomes and timescales involved. 		
	 Irrelevant research questions. Poor pathway to impact and delivery for people living with Parkinson's Poor/flawed/duplicative methods and research design. Kow skills missing from the research team 	Many identified flaws	2
Definitely not fundable	 Key skills missing from the research team. Very poor value for money. Unclear application. No or limited evidence of appropriate patient and public involvement including the consideration of diversity in the research. Plain English summary is unclear, does not accurately reflect the research proposal and is unrealistic about the potential outcomes and timescales involved. 	Serious weaknesses or major concerns	1

Patient and public involvement support flowchart

