TRACKING PARKINSON'S

APPLICATION FOR DATA & BIOSAMPLE ACCESS

1 Project Summary

Project title

Project acronym

Source of funding*

**If this is not part of a peer-reviewed grant, please provide evidence of institutional support and/or peer review*

Duration

Start date (dd/mm/yyyy)

Data requested (check all that apply)

- ☐ Clinical data
- ☐ Biosamples
- ☐ Both

Abstract / Lay summary

Please provide the necessary background, aims, justification for the type of data and/or sample requested, sample size and number of cases data/samples requested from, techniques to be used, result of pilot studies and expected benefits to Parkinson's disease research. This will be used to assess the value of the work against sample availability.

2 Applicant Details

Principal applicant	
Position	
Institution	
Department	
Email	
Phone	
Fax	

Collaborators outside main institution

Name	Institution

3 Research Plan & Data requested

Proposed research *Please describe the project hypothesis, experimental plan, methodology, key aims, plans for dissemination (500 words max)*

Clinical data *Please describe which clinical data requested and proposed research methods*

DNA samples *Please describe proposed research methods*

Frozen serum samples

Frozen samples are generally collected as 6 aliquots (2ml) per patient visit and stored at -80°C. Please describe the proposed use, volume of serum required and the number of times samples would be subjected to thawing and re-freezing.

Sample/Cohort request detail

Please indicate number of patient samples required

	Recent onset	Early onset	Relatives
DNA			
Frozen serum			

4 Terms and conditions for accepting data and/or samples

1. We accept the samples of blood/serum and confirm they will only be used for research. We acknowledge that they are provided without warranty as to their properties or fitness for any particular purpose and without any other warranty whatsoever, expressed or implied.

2. We acknowledge that the Tracking Parkinson's study does not screen the specimens that it procures for the presence of any infectious agents. We are aware of the potential risks in handling such material and hereby give assurance that all procedures employed in the handling, storage, use and disposal of the supplied material meet the appropriate standards. We, the recipient institution, will indemnify and hold harmless Parkinson's UK, Greater Glasgow & Clyde Health Board and University of Glasgow against any damages, dispute or injury arising from a failure to maintain such safeguards.

3. We agree to be held responsible for the use of the material supplied. We confirm that under no circumstances will the samples be used for a project other than the one described in this application nor will they be sold or transferred to a third party without having obtained prior approval from the Tracking Parkinson's Data & Biosample Access Committee.

4. We will provide, upon request by the Tracking Parkinson's Data & Biosample Access Committee, Parkinson's UK, NHS Greater Glasgow & Clyde or the University of Glasgow, information on the use and fate of the material received from the Tracking Parkinson's study, including the availability of any unused material.

5. We will provide a short written report of the work performed on the data and/or material supplied by the Tracking Parkinson's study, one year after receipt of same. On completion of the project, we undertake to provide results of assays and other assessments undertaken on the samples, and methods for deriving clinical variables and other information identified in relation to the samples, which will be used to enhance the core dataset for other future research projects.

6. If work performed on the material supplied by Tracking Parkinson's generates ideas, rights, processes or products of potential commercial value, the recipient institution will enter into a separate agreement with Parkinson's UK, NHS Greater Glasgow & Clyde and the University of Glasgow on all relevant intellectual property issues.

7. We will not sell or transfer to a third party any intellectual property rights arising from work performed on material supplied by the Tracking Parkinson's study without written agreement from Parkinson's UK and the University of Glasgow.

8. We acknowledge that clinical data, with or without associated biosamples, is provided as a working version at this time and that we should cite it as "Tracking Parkinson's (PRoBaND) dataset, version X.X, YYYYMMDD."

9. We agree to cite the contribution made by the PRoBaND Clinical Consortium, the NHS Clinical Research Network, and Parkinson's UK in one or more of "Materials and Methods" and "Acknowledgements" sections of all publications arising from research performed on the material that it has supplied, and we will make available copies of such publications.

   The Tracking Parkinson's study should be acknowledged in the following manner:

   "Samples and associated clinical data were supplied by the Tracking Parkinson's (PRoBaND) study, funded by Parkinson's UK (Grant ref J-1101), a charity registered in England and Wales (2581970) and in Scotland (SC037554), with the support of the Comprehensive Local Research Network."

   Members of the Tracking Parkinson's (PRoBaND) consortium may request co-authorship when the provision of samples has required use of their time and expertise in supporting the recipient project.

10. Our right to undertake the obligations detailed in these Terms and Conditions is confirmed by the signature of the representative below.

5 Signature of applicant

Applicant

Name and position	Signature	Date

On behalf of receiving institution

Name and position	Signature	Date

6 Publication of research programme (optional)

If successful, we encourage applicants to allow their abstract and contact details to be listed on our website to facilitate collaborative research and to publicise the impact of the study's data.

The applicant named above consents to the following information being published on trackingparkinsons.org.uk

- ☐ Name
- ☐ Institution
- ☐ Abstract