

# The CENTRE-PD Top 10 Survey

## *Getting to the Heart of Your Unanswered Research Questions;* Participant information Sheet

### Background...

In 2014, the James Lind Alliance and Parkinson's UK set up a Patient Setting Priority group to find the top 10 research priorities that people living with Parkinson's (PwP) and health and social care professionals would like to see answered. This was published in 2014 by Deane et al. The aim was to use this information to guide future research and make sure researchers focus on the most urgent needs of people affected by Parkinson's.

At an OPDC open day in 2016, Prof Michele Hu introduced the priorities and asked attendees what their preferences were from the top 26 identified in the original survey. The open day participants selected different priorities to those published in the original Top 10. In addition, there were a lot of free text answers pertaining to speech problems and therapies.

### Objectives...

We would like to update the survey to reflect what current participants in Parkinson's research and their friends/family would most like answered by research and how we, researchers and healthcare professionals, align with this. This will guide future research and how we communicate the results with the cohort.

We will be able to identify if the priorities change when considering: age/age at diagnosis, living arrangements, ethnicity, gender, socioeconomic status etc. by the collection of optional demographic information which will improve the understanding of if/how priorities change across different demographics.

Thanks to the collaborative work of CENTRE-PD, we will be able to survey people involved with similar cohort studies in Europe. CENTRE-PD is a European H2020 Twinning project whereby, University of Oxford and University of Tübingen are sharing knowledge and expertise with the University of Luxembourg (<https://www.centre-pd.lu>). We will pool the anonymous survey responses from all three sites, giving better statistical strength to our findings and to give comment on whether priorities change across different countries.

From this survey, we hope to find:

1. The top 10 research priorities for the management of Parkinson's;
2. How well the priorities of healthcare professionals and researchers align with PwP and their friends/family;
3. Potential differences in priorities across international geographical locations;
4. Whether current published/registered research projects are addressing the priorities adequately;
5. Guidance to form future research questions important to PwP and dissemination of research results.

For more information, guidance on completing the survey or any support and advice, please contact Francesca Bowring on:

01865 234 769 or [Francesca.Bowring@nhs.net](mailto:Francesca.Bowring@nhs.net)

**If you would like to complete the survey electronically, please either:**

- scan the QR code found in this box
- go to the following website: <https://tinyurl.com/centrepdtop10>
- or contact Francesca for more information



## Your help...

**Responses to this survey are completely voluntary and there is no obligation for you to take part.**

If you would like to help, we will first need your consent to pool your anonymous survey responses with those we collect from our colleagues in Europe. Data handling will be done here in Oxford and the European partners will only be able to see your anonymous survey responses if necessary.

The data we collect is completely anonymous, please answer them as best you can, they are not all mandatory.

Please read through the list of questions\* and rate how important each question is to you on a scale from **1 – 9**, where 1 is not important to you, and 9 is very important to you.

If you have a suggestion for a priority that is not on the list, you have the opportunity to add one in, remember to rate it also. You can **only add one** question and it is **not compulsory** to do so.

Once you have completed the survey, place the survey into the Freepost envelope provided and pop it in the post. Alternatively, you may scan it and email to [Francesca.Bowring@nhs.net](mailto:Francesca.Bowring@nhs.net)

If you would like to complete the survey electronically, please see the information in the box overleaf.

If you have any family members or friends that you think may be interested in participating, please share this with them. They can contact Francesca for a postal form or they can complete the form electronically using the information overleaf.

## Volunteer for the Panel...

During the first round of this survey, we are giving participants the opportunity to add a question they feel is not represented in the list of research priorities. These responses will be organised into themes and up to ten of the most common themes will be translated into appropriate research questions.

The volunteers of the panel will be presented the questions from the first round, plus the 10 new questions. The panel is then asked to rate all of the questions again including the new ones. There may need to be a few rounds of surveying before agreement is reached and they may need to do the survey a few times. After conclusion of the study, all email addresses will be deleted.

You can get more information or withdraw from the panel at any time point without giving a reason by contacting Ms Francesca Bowring.

\*The questions were identified during a project with Parkinson's UK and James Lind Alliance. For more information, please see the publication at: <http://dx.doi.org/10.1136/bmjopen-2014-006434>

## Consent Form for the CENTRE-PD Top 10 Survey.

Please read the all of the information available and then, read the statement in the box below carefully.

**Participation is completely voluntary and there is no obligation for you to take part. You may discontinue or stop the survey at any point without giving a reason.**

The data you provide in the survey will be anonymised and used to establish the top 10 research priorities for the management of Parkinson's. You are not obliged to complete all demographic information and it is not compulsory to give your email address. Your anonymous survey data will be inputted on to the database and pooled with other responses at the University of Oxford for analysis.

No personal information will be collected or shared with any researcher outside of your local institute. Anonymous data with no personal identifiable information may be shared with external researchers to verify our findings and for peer review when published.

Participation in the Delphi panel is optional and you may continue to the survey **without** agreeing to **Section 2**.

Read each statement and **tick** the boxes only if you agree.

If you have any questions or doubts, please contact Ms. Francesca Bowring for more information.

**Tel:** 01865 234 769; **Email:** Francesca.Bowring@nhs.net.

### 1. Survey Consent

**By ticking this box, you consent to participate in the CENTRE-PD Top 10 survey and for your anonymised survey responses to be analysed at the University of Oxford.**

## Optional- Consenting to Participate in the Delphi Panel

**This consent form should only be completed if you are interested in the possibility of being randomly selected for the panel.**

If you do not wish to participate in the additional surveys, please skip to the survey.

If you volunteer for the panel, you may withdraw at any time without giving a reason. Any email addresses provided will be used only for the purpose of participating in the Delphi panel. Your email address will be separated from your survey responses and stored securely once you are randomised. You may ask for your email to be deleted at any time and all email addresses will only be kept whilst the Delphi panel is in operation. Thereafter, all will be removed from the University of Oxford system. If you are not selected for the panel, your email address will be deleted.

If you would be happy to complete this survey again, please read the Delphi Consent form and leave your email address there so that if you are selected, we can send you an electronic link to repeat the survey in the near future.

**You may continue with the survey without giving your email address. If you would prefer to skip to the survey go to the next page.**

### 2. Delphi Panel Consent

By ticking this box, you consent to give your email address so that you may be randomly selected for the Delphi panel. You understand that there are only 50 places and by giving your email address you will not definitely participate in the panel. You understand that if you are selected for the panel, you may withdraw at any point and ask for your email address to be deleted.

**By ticking this box, you agree to give your email address for Delphi panel randomisation.**

**Email Address\*:**

.....  
*\*only complete if you have consented above.*

# Research Priorities for the Management of Parkinson's Disease

**\*Please only complete this survey ONCE\***

## SECTION 1 – All participants Please: Demographic Information

**Which of the following best describes you?**

Person with Parkinson's

Carer/former carer of someone with Parkinson's

Friend/family member of someone with Parkinson's

Health/social care professional/researcher (specify below)

.....

**Gender:**

Male

Female

Other

Prefer not to say

.....

**What is your ethnic background?**

Asian/Asian British (please specify below)  Arab  Black/Black British  Hispanic/Latino

White  Mixed/multiple ethnic groups (please specify below)  Prefer not to say

Other/Specify .....

**Have you ever participated in research (as participant or researcher)?**

Yes  No  Prefer not to say

## SECTION 2 –People with Parkinson's Only: Information

We would like this information to establish whether there are differences in priorities when you consider these different variables, for example, do those on a lower income have priorities related to being able to work rather than improve quality of life? Do priorities change amongst newly diagnosed and those whom have had Parkinson's for some time?

**What age are you today?** .....

**Age at Diagnosis of Parkinson's:** .....

**What are your living arrangements?**

Prefer not to say  Own home (independently)  Own home (supported by family)

Own home (supported by carers)  Residential home  Nursing home  Other.....

**What is your highest level of education?**

Level 1 – Level 2 (up to: O level, GCSE, intermediate apprenticeship, music grades)

Level 3 - Level 4 (includes: higher apprenticeship, higher certificate, A/AS levels)

Level 5 - Level 6 (includes: any degree, higher/graduate diploma)

Level 7 - Level 8 (includes: postgraduate degree/certificate/diploma, PhD or DPhil)

Prefer not to say

**Is your annual household income below or above £15,392?\***

Less than or equal  Above  Prefer not to say

\*If you live in shared accommodation, please select the option that best describes your individual financial status.

Please turn over ►





