

ABN 15 211 513 464

**Hans Bogaardt PhD**  
*Chief Investigator*

Room S169  
Cumberland Campus  
The University of Sydney  
NSW 2006 AUSTRALIA  
Telephone: +61 2 9351 9334  
Email: [hans.bogaardt@sydney.edu.au](mailto:hans.bogaardt@sydney.edu.au)  
Web: <http://www.sydney.edu.au/>

## **SEVERITY OF SYMPTOMS IN PATIENTS WITH PARKINSON'S DISEASE: EVALUATION OF A DISEASE SPECIFIC QUESTIONNAIRE FOR SPEECH PATHOLOGY**

### **PARTICIPANT INFORMATION STATEMENT**

#### **(1) What is this study about?**

In this study, you are invited to complete an online survey. All identifying personal information will not be collected and responses will remain anonymous. The questions in the survey will include a range of relevant topics such as personal characteristics, physical and emotional well-being.

This survey will obtain information about your background health status and daily routines. This survey will explore the impacts of Parkinson's disease on everyday life and how these influence levels of physical and emotional comfort. Participating in this survey is voluntary and we appreciate your time when participating.

By giving your consent to take part in this study you are telling us that you:

- Understand what you have read.
- Agree to take part in the research study as outlined below.
- Agree to the use of your personal information as described.

You will be given a copy of this Participant Information Statement to keep.

#### **(2) Who is running the study?**

The study is being carried out by the following researchers:

- Zhi Ting Ho, student Speech Pathology, The University of Sydney, Sydney
- Hans Bogaardt, lecturer Speech Pathology, The University of Sydney, Sydney
- Natalie Allen, lecturer Physiotherapy, The University of Sydney

#### **(3) What will the study involve for me?**

You will be asked to go to a website which will show you an online survey. The questionnaire will also ask you some questions about your background. After two weeks you will be asked to complete a part of the previous online survey again, as this will allow researchers to investigate whether the questionnaire is stable through time.

If you don't have access to Internet or prefer to complete a paper version of the questionnaire, a paper version can be provided on request, if you contact the researchers.

**(4) How long will this study take?**

The survey is expected to take about 25 to 30 minutes to complete for the first survey and about 10 minutes to complete the second survey.

**(5) Who can take part in the study?**

Everyone who is diagnosed with Parkinson's disease can take part in this study.

**(6) Do I have to be in the study? Can I withdraw from the study once I've started?**

Being in this study is completely voluntary and you are not under any obligation to consent to complete the survey. Submitting a completed survey is an indication of your consent to participate in the study. You can withdraw any time prior to submitting your completed survey. Once you have submitted your survey anonymously, your responses cannot be withdrawn.

Submitting your completed questionnaire is an indication of your consent to participate in the study. You can withdraw your responses any time before you have submitted the questionnaire. Once you have submitted it, your responses cannot be withdrawn because they are anonymous and therefore we will not be able to tell which one is yours

**(7) What are the potential risks or costs involved in participating in this study?**

Apart from the time spent to complete the survey, there will not be any expected costs that may arise from participating in this study.

This survey does discuss health issues and diseases, which can be distressing. If you experience any distress, please seek appropriate psychological/emotional support. Examples of appropriate services in Australia include: Beyond Blue Ph: 1300 22 4636 (24 Hours/7 days per week) [www.beyondblue.org.au](http://www.beyondblue.org.au) and Lifeline Ph: 13 11 14 [www.lifeline.org.au](http://www.lifeline.org.au)

**(8) Are there any benefits associated with being in the study?**

For the first 100 participants who submit the questionnaire, *Shake It Up Australia Foundation* will receive \$5 for every completed response. *Shake It Up Australia Foundation* is a non-profit organisation that supports and funds research for Parkinson's Disease (PD). Research is aimed at enhancing treatments for patients with PD and ultimately finding a cure for it.

**(9) What will happen to the personal information that is collected during the study?**

Your answers to the electronic survey will be collected with help of SurveyMonkey. SurveyMonkey operates in accordance with the Health Insurance Portability and Accountability Act of 1996 (HIPAA), which is a United States law that regulates the collection and handling of protected health information. All SurveyMonkey information systems and infrastructure are hosted in world-class SOC 2 accredited data centers. Any sensitive user information, defined in the Privacy Act 1988 (Cth), collected through SurveyMonkey is used solely for the purpose of storing and processing it on behalf of the survey creator. By default, all communications using SurveyMonkey are sent over Transport Layer Security (TLS) connections, which protect communications by using both server authentication and data encryption. This ensures that user data in transit is safe and secure. SurveyMonkey also employs Forward Secrecy and only support strong ciphers for added privacy and security (SurveyMonkey, 2016).

Paper versions of the questionnaire will be stored in a secured cabinet at the Faculty of Health Sciences and only the investigators will have access to these files.

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

Your information will be stored securely and your identity/information will be kept strictly confidential, except as required by law. Study findings may be published, but you will not be individually identifiable in these publications

**(10) Can I tell other people about the study?**

Definitely, you can tell other people about this study.

**(11) What if I would like further information about the study?**

When you have read this information, dr. Hans Bogaardt will be available to discuss it with you further and answer any questions you may have. If you would like to know more at any stage during the study, please feel free to contact:

Dr. Hans Bogaardt  
Faculty of Health Sciences  
Discipline of Speech Pathology  
The University of Sydney  
Phone: +61 2 9351 9334.  
Email: hans.bogaardt@sydney.edu.au

**(12) Will I receive feedback on the results of this study?**

You have a right to receive the overall results of this study. If you wish to receive feedback and if you are willing to be contacted for future studies, you can leave your name and contact details at the end of the survey. Your details will be stored separately from the data collected in the survey. You will receive feedback in a one page lay summary, after the study is completed.

**(13) Who should I contact if I have any complaints or concerns about this study?**

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney (HREC 2017/200). As part of this process, we have agreed to carry out the study according to the *National Statement on Ethical Conduct in Human Research (2007)*. This statement has been developed to protect people who agree to take part in research studies.

If you are concerned about the way this study is being conducted or you wish to make a complaint to someone independent from the study, please contact the university using the details outlined below. Please quote the study title and protocol number.

The Manager, Ethics Administration, University of Sydney:  
Telephone: +61 2 8627 8176  
Email: ro.humanethics@sydney.edu.au  
Fax: +61 2 8627 8177 (Facsimile)