

PARTICIPANT INFORMATION SHEET (SURVEY)

1. Title of the project

The exogenous and endogenous use of music for mood and movement management among people with Parkinson's.

2. Introduction

We would like to invite you to participate in a study designed to explore the use of music for movement and mood management among people with Parkinson's. Before you decide for or against participation, we would like to inform you about the study, the scope of your participation and how we handle your data. Therefore, we ask you to read the following information. If you have any questions or uncertainties, you can also contact us at any time. Thank you for reading this document carefully.

3. What is the aim of this project?

With this study we want to investigate how, why and when people with Parkinson's use music in relation to activities and feelings. This is a collaborative research initiative extending initial research in this area that was funded by Parkinson's UK. It is our aim that by involving people with Parkinson's in the research process, we can work to provide better recommendations related to how best to use music both on an individual basis, and in group activities for example, for rehabilitation.

4. Do I have to participate?

No, you do not have to participate. If you decide to participate, you will be asked to give your consent. You can withdraw from participating in the study at any time and without giving any reason. This will not have any consequences for you at all. In addition to participating online, we offer assistance with completing the survey with our help by phone or video call. This is in response to consultation with people with Parkinson's who have explained that completing surveys online can be tiring and/or frustrating. However, we acknowledge that not everyone feels comfortable on the phone, so this is only one of several options; of course, you can complete the survey yourself online.

5. Can I participate in this study?

You can take part in this study if you are over 18 years old and have been diagnosed with Parkinson's by a medical professional, such as a neurologist.

6. How long does the survey take?

Test runs have shown that the survey will take about half an hour to 45 minutes.

7. What questions will I be asked in the survey?

The first part of the survey is about demographic data (e.g. age, sex, education), and about your Parkinson's (e.g. stage, duration, medication). These allow us to gain an overview of the participants. The second part of the survey includes questions about your use of music in relation to activities and feelings, and also about your current wellbeing.

8. Will I suffer any disadvantages or risks from my participation in this study?

There are no risks for you and your participation will not lead to any disadvantage, though we appreciate you may find it tiring to complete the survey.

9. What contribution can my participation in this study make?

Your participation can provide important information about how people with Parkinson's use music to manage their moods and movements that we can then share with other people with Parkinson's, as well as medical and health professionals. This is important in terms of being able to individualise care and also for new forms of social prescribing, such as dancing, singing and other activities that may benefit from including music for people with Parkinson's

10. How is the confidentiality of my information in this study guaranteed?

The personal information we collect allows us to make general statements about the composition of the sample. The data will be anonymised directly during the collection process, so that it will not be possible to draw conclusions about the answers of individual participants. Copies of the anonymised data will be stored on encrypted data carriers as is usual in scientific studies and only the research team will be able to access this information. Data will only be shared through institutionally approved communications programmes.

11. What happens to my data?

Hard copy and electronic (i.e., online) data from the survey are stored securely, with only the research team having access to the data. All electronic data is stored and kept on encrypted data carriers. The data will form the basis for a planned scientific publication and, wherever possible, publications via other channels and formats, as this is of public interest. In all cases of exploitation, the data is anonymised, and it is not possible to draw conclusions about the test persons. Depending on the requirements of the publication formats (research report, publication in scientific journals or public media), the data is stored securely for a certain period of time. In line with developing practices in the research community, to enable transparency and improve scientific standards, this study will be logged with the Open Science Framework, and anonymised data will be made available to other researchers to explore the use of music among people with Parkinson's. All identifying text (e.g., quotations in relation to question answers) will be removed prior to any data sharing protocols.

12. Who has reviewed the research project according to ethical standards?

This project has been reviewed and approved by the Ethics Committees of the Lucerne University of Applied Sciences and Arts in Switzerland.

13. Who can I contact if I have questions about the study?

For questions and further information, or if you have concerns about the research project, please contact: Dr. Dawn Rose (dawn.rose@hslu.ch).

If you feel that your concern has not been dealt with to your satisfaction, you can contact the HSLU Ethics Committee via email at nicolas.schulthess@hslu.ch.

Thank you very much for reading these documents carefully and for your interest in participating in the study.