

Participant Information Sheet

Graphic Scores: Using sound and art to bring together young people living with Parkinson's and improve mental health

This study is being run by Dr Jennifer Foley (Jennifer.Foley@ucl.ac.uk) and Alison Carlier (alison.carlier@icloud.com), funded by UCL Grand Challenges and approved by the UCL Research Ethics Committee (Project ID number: 25291/002)

We invite you to take part in a research study

- Before you decide, it is important for you to understand why the research is being done and what participation will involve.
- Please take time to read the following information carefully. Discuss it with others if you wish.
- You are free to decide whether or not to take part in this research.
- Ask us if there is anything that is not clear or if you would like more information.

Important things you need to know

- This project is a UCL-funded project, led by neuropsychologist Dr Jennifer Foley and artist Alison Carlier.
- We are exploring the social and psychological issues facing young people with Parkinson's, and piloting a new arts-based intervention to try to improve psychological wellbeing.
- In a small group of 10 participants of young people with Parkinson's, we will ask you to reflect upon certain psychological themes. We will ask you discuss your own experience pertinent to these themes and use words, drawing or imagery to express this.
- These words and images of each participant will then be added to one large musical score as graphic notation to depict the group's experience.
- With the support of professional musicians and composers with Parkinson's, you will decide how the musical score should be read and played, and what its name should be.
- The musical score will become a permanent artwork.
- We will then invite professional musicians to perform the musical composition at a UCL venue. The performance will be a public celebration of the group's work. At the event, we will display the musical score. You will be invited to attend this public event.
- During the workshops, we may photograph you and the group, if you consent to this. With your permission, these photos may be displayed publicly alongside the graphic score.

Why are we doing this study?

- We know that Parkinson's in young age can have a significant impact upon social and psychological wellbeing. We wish to explore the impact of an arts-based participatory intervention on feelings of social integration and mental health.
- This study is being led by Dr Jennifer Foley, a Parkinson's-mental health specialist at UCL Queen Square Institute of Neurology, and Alison Carlier, an artist who specializes in creating sound-based artworks. The project team also involves Dr Harry Costello and Dr Ella Burchill, who are both Parkinson's-mental health experts, Ms Gini Dellow, who is Parkinson's UK mental health policy lead and Sophia Davis who is a Research Assistant working on this project.

Why am I being asked to take part?

- We would like to recruit young people with Parkinson's.
- We are looking for people who are:
 - Aged between 18 and 50 years
 - Have feelings of anxiety and/or low mood and/or feel socially isolated
 - Willing to share their experience of living with the condition

- Able to communicate in English
- You do not need to have any previous experience of drawing, graphic scores or music-making.

What does taking part involve?

- This study will involve completing questionnaires asking about: how often you feel connected with others; how often you feel symptoms of low mood and anxiety; and how often you use various strategies to cope with stress.
- We will ask you to complete these questionnaires twice: once shortly before and once shortly after your participation in the arts-based participatory intervention. These can be conducted by email, telephone and/or video call, according to your preference. This should take up to 20 minutes each time.
- The arts-based participatory intervention will involve three in-person workshops held at UCL. At each of these two-hour workshops, you will be asked to reflect on your own experience of certain psychological themes. These psychological themes have been identified and prioritized by a UCL steering group comprising of other young people with Parkinson's, mental health experts and Parkinson's charities' representatives.
- At the workshop, you will be invited to use words, drawings or imagery to convey your own personal experience of these psychological themes. Each participant's contribution will be then added to one large musical score as graphic notation to depict the group's experience.
- Because of the personal nature of the workshops, we will ask you to sign a confidentiality statement, agreeing to maintain confidentiality of the information discussed during the workshops.
- With the support of professional musicians and composers, you will work as a group to decide how the musical score should be read and played, and what the composition should be called.
- The musical score will create a permanent artwork.
- You will be invited to attend a public performance of the group's musical composition at a UCL venue. At this event, professional musicians will be asked to perform the musical composition. At the event, we will display the screen-print of the musical score.
- The workshops and/or public event may be photographed. You will have the opportunity to opt-out of any photographs, and/or review and veto the use of these. If you do not want to participate in the photographs, the photographer will ensure you are not in any of these. If you do wish to be in the photos, these may be displayed alongside the graphic score, with your permission.
- Any travel expenses will be reimbursed via bank transfer upon receipt of completed claim forms and relevant receipts.

Project timeline

- We will conduct the workshops over the spring, and hold the public event in July 2025.

Are there any disadvantages or risks to taking part?

- We will not use your name or any identifiable information in the musical composition. If you agree to photographs and we use these, this risks exposure of your diagnosis and health status to the public. You can choose to opt-out of the photographs and/or veto the use of any of the photographs. If you have any concerns, we will not use the photographs.
- The workshops will cover personal health matters. The purpose of this is to reveal the impact of living with Parkinson's as a young person. However, it is possible that you might find this distressing or intrusive. We will design the workshops to avoid this and to be as sensitive as possible. You always retain the right to withdraw from the research at any point.
- If for any reason, you feel distressed by any of the workshops, it will be paused and you will be provided with support. A follow-up appointment with clinical neuropsychologist, Dr Jennifer Foley, will be arranged for further assessment and support, as necessary.

Are there any benefits to taking part?

- We hope that you will enjoy the arts-based participatory intervention. We hope that it might be useful to share personal experiences with others facing similar challenges, and work together to achieve a common goal. We hope that this process might enable participants to feel more connected with others and improve psychological wellbeing.
- We hope that you will enjoy the public performance and celebration of the group's work.

Do I have to take part?

- No, it is completely up to you. If you decide to take part, you will be asked to sign a consent form. You are free to withdraw from the workshops and or research at any time, without giving a reason. If you withdraw after completion of the graphic score, your contribution will be retained as it will not be possible to deduct this from the final work.

What happens when the research ends?

- The graphic score will be a permanent legacy of the group's work. We hope this will be installed at UCL and hosted online.

Who is organizing and funding the research?

- This research is funded by UCL Grand Challenges.
- The research is being led by Dr Jennifer Foley who is a clinical neuropsychologist, Honorary Lecturer at UCL and lead of Parkinson's UK Excellence Network for Mental Health.

Who has reviewed the research?

- UCL research is reviewed by an independent group of people, called a Research Ethics Committee, in order to protect participants' safety, rights, wellbeing and dignity. This trial has been reviewed and been given a favourable opinion [UCL Research Ethics Committee25291/002].

Who can I contact for further information?

- You can contact Dr Jennifer Foley, who is the Chief Investigator, if you have any questions or require any further information. Her details are: Dr Jennifer Foley, Department of Neuropsychology, National Hospital for Neurology and Neurosurgery, Queen Square, London W1N 3BG. Tel: 020 3448 3292. Email: Jennifer.Foley@ucl.ac.uk

What if there is a problem?

- If you wish to make a complaint, in the first instance please email Dr Foley (Jennifer.Foley@ucl.ac.uk).
- If the complaint has not been dealt with to your satisfaction then please email the Chair of the UCL Research Ethics Committee, ethics@ucl.ac.uk.

Local Data Protection Privacy Notice

Notice:

- The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk
- This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:
- For participants in health and care research studies, [click here](#)

- The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.
- The categories of personal data used will be as follows:
 - Name
 - Email address
 - Telephone
- The lawful basis that would be used to process your personal data will be performance of a task in the public interest.
- The lawful basis used to process special category personal data will be for scientific and historical research or statistical purposes.
- Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.
- If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

What should I do if I want to take part?

- Please take at least 48 hours to decide if you wish to take part.
- If you decide you wish to take part, please contact:

Sophia Davis, Research Assistant: Sophia.davis.22@ucl.ac.uk

Thank you for considering taking part in this research.

Participant Consent Form

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This study has been approved by the UCL Research Ethics Committee: Project ID number: 25291/002.

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking/initialling each box below I am consenting to this element of the study. I understand that it will be assumed that unticked/initialled boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

Please tick/initial each box

☐

1. I confirm that I have read the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. If I withdraw after the completion of the graphic score, I understand that my contribution will remain. ☐
3. I understand that my participation will involve being part of a small group sharing experiences of living with young-onset Parkinson's and I agree to maintain the confidentiality of all information shared by other group members during the session. I will not disclose any personally identifiable information about fellow group members outside of the group setting. ☐
4. I understand that photographs of the workshops may be taken and displayed alongside the final artwork. Please note that if you do not want your photograph taken, you can still take part in the research. ☐
5. I understand that I will have the opportunity to review and veto the use of these photographs. ☐
6. I understand that the photographs will be stored anonymously, using password-protected software and may be displayed alongside the final artwork, at art exhibitions and online. ☐
- I agree to my photograph being taken and used alongside the final artwork. ☐
 - I do not agree to my photograph being taken and used alongside the final artwork. ☐
7. I understand the potential risk of participating and the support that will be available to me should I become distressed during the course of the research. ☐
8. I am aware of whom I should contact, should I wish to lodge a complaint. ☐
9. I agree to take part in the above study. ☐

Name of Participant

Date

Signature

Name of Researcher

Date

Signature