



“Minding the gaps: The role of community co-creation in improving medical and social care for young adults with cerebral palsy”

Information Sheet

You are being invited to contribute to a public involvement collaborative research project developed by the Faculty of Medicine & Health at the University of Leeds, and the Business Schools at both the University of Leeds and the University of Durham. Please take the time to read the following information carefully. Do not hesitate to ask if there is anything that is not clear or if you would like more information.

What is the study about?

Cerebral palsy (CP) is a lifelong condition that affect patients' movement and co-ordination. While medical care is core to the quality of life for people with CP, we believe a holistic approach is needed to understand the role of professional and non-professional support ranging from medical, physio, speech, and occupational therapies, to social care, schooling, university, sports, and arts, amongst others. We call upon the ideas and experiences of people from these different segments to share ideas and experiences in order to create and nurture a community able to improve medical and social care for those with CP.

Why have you been invited to participate?

You are invited to participate in the research because you are part of the aforementioned communities that surround people who have CP. Your participation can be invaluable in identifying the challenges young adults with CP face in receiving and accessing care and support during and after transitioning from adolescence to adulthood. It is entirely your choice to decide whether or not you would like to collaborate, and if you decide to take part you are free to withdraw at any time and without giving a reason. All you need to do is to send an email to Dr Simon Williams email address (s.c.williams@leeds.ac.uk).

What will happen if you take part?

As a participant in this study, you are being asked to take part in a workshop held at Leeds University Business School in November 2019 (Wednesday 6th of November -10:00 to 16:00h; and Thursday 7th of November- 13:30 to 16:00). During this workshop, you will be asked to take part in group discussions to share your views on various aspects of accessing and receiving social and medical care relevant to people with CP. We will observe and take notes during the workshops. In group discussions, we cannot guarantee absolute confidentiality as other participants will be in the room, however, we guarantee that all contributions will be anonymised in our notes and kept securely in the university servers. Anonymised quotations from your interventions may be used in the reports/publications from the study but you will be consulted prior to publication if there is any concern regarding anonymization or confidentiality. Data submitted to the research team will be evaluated and catalogued but not shared with third parties without explicit consent to do so.

What are the possible benefits of taking part?

The research project is an opportunity to engage young adults with CP, and other stakeholders, in a conversation which can identify some of the challenges they face in accessing social and medical care. Further, some participants may benefit from the opportunity to exchange experiences and best practice.



What will happen to the results of the research study?

It is expected that workshop outputs will lay the foundation for follow-up research proposals and applications for research funding aiming to improving the overall quality of social and medical care provided to people with CP especially during their transition from adolescent to adult stage.

Who is organising the research?

The research team comprises of faculty members from the Faculty of Medicine & Health at the University of Leeds and from across the Business Schools of both the University of Leeds and the University of Durham.

The researchers involved are:

1. Joana Pereira (Lecturer in Strategy, Leeds University Business School)
2. Rory O'Connor (Pro-Dean Research and Innovation Faculty of Health and Medicine)
3. Tyrone Pitsis (Professor in Technology, Strategy and Society, Durham University Business School)
4. Samit Chakrabarty (Lecturer in Neuroscience at the School of Biomedical Sciences)
5. Lena Jaspersen (University Academic Fellow in Innovation Management)
6. Josh Morton (Lecturer in Strategy, Leeds University Business School)
7. Tabish Zaman (Research Assistant at Leeds University Business School)
8. Simon Williams (Associate faculty at Leeds University Business School)

The research team may be assisted by other research assistants at various stages of the project.

Who has reviewed the study?

The research project has been reviewed by the University Research Ethics Committee, University of Leeds.

Contact for Further Information

For further information please contact project lead Dr Joana Pereira (contact details above) or, if you prefer an alternative contact, Jennifer Blaikie, Senior Research Ethics Administrator (j.m.blaikie@leeds.ac.uk; Research & Innovation Service, University of Leeds, Leeds, LS2 9LJ, United Kingdom).

Thank you for taking the time to read this information sheet.

Dr. Joana Pereira
Leeds, 24.09.2019