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Understanding factors affecting access to and progression in doctoral research for STEM researchers with disabilities, including chronic illness and neurodiverse profiles

PARTICIPANT INFORMATION SHEET FOR SURVEY

Central University Research Ethics Committee Approval Reference: [R80402/RE001]

1. Introduction

You are being invited to take part in a research project, which is an opportunity for you to share your lived experience of studying at doctoral level. We value your perspective and aim to use your data to identify key areas and trends for deeper analysis.

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

2. Eligibility

To participate in this study you need to have been a PhD student at a UK university at some point in the last year, in the field of life sciences and/or STEM. You also need to identify as being disabled or be positioned as disabled under the Equality Act 2010.

Disabilities include mental health conditions, other chronic health conditions and forms of neurodiversity such as dyslexia. To have a disability means to have a “difference” or “impairment” which (in the UK context) significantly negatively impacts one or more of your everyday functions such as being able to read large amounts of text, concentrate, socialise, take notes, or do the dishes.

You do not need to have a diagnosis or have declared your disability to your university in order to fill out this survey. The survey is open to all disabled PhD student in STEM.

3. Why is this research being conducted?

This survey is intended to form a baseline to researching measures that can be taken to address inequality in access to, and progression within doctoral research for STEM researchers with disabilities. This includes individuals with chronic illness and with a neurodiverse profile. Your data will be used to begin the process of identifying key areas and trends that will then be developed alongside other data and condensed into a short report with recommendations for actions and further research.

This survey is being undertaken as a co-produced project between the University of Oxford, Pete Quinn Consulting Ltd and Disabled Students UK (DSUK) to reflect the lived experience of disabled doctoral students. Pete Quinn Consulting has a track record of providing reviews, critical friend support, mentoring and operational and strategic reviews and planning support based on prior experience of disability inclusion work at the Universities of Oxford, Edinburgh and York amongst others. DSUK has quickly grown to be the largest disabled student-led organisation in the UK. Born out of grassroots movements, DSUK now has over 500 contributors from 60 different universities.

4. Do I have to take part?

No. It is up to you to decide whether to participate in this study.

5. What will happen to me if I take part in the research?

Consent will first be obtained via the consent section of the survey before any data is collected. The survey will ask a set of eligibility questions before covering topics including admissions, funding, progression, placements / fieldwork, completion, and flexibility during your doctoral journey.

6. What are the possible disadvantages and risks in taking part?

These topics can be sensitive. Support is available through your university's support services (see Student Space below if uncertain of which services to use) and through a range of support providers including:

- Student Space via <https://studentspace.org.uk/>
- Mind via <https://www.mind.org.uk/information-support/> ,
- Samaritans via <https://www.samaritans.org/>
- Disability Rights UK via <https://www.disabilityrightsuk.org/how-we-can-help/helplines-0>

7. Are there any benefits in taking part?

While there are no immediate benefits for those people participating in the project, it is hoped that this research will lead to a better understanding of the issues faced by disabled doctoral students. The report recommendations, while not subject to mandatory implementation, will give stakeholders further tools in which to potentially improve the doctoral experience.

8. What information will be collected and why is the collection of this information relevant for achieving the research objectives?

We will not collect information which could identify you such as your name and email address and we ask that you do not include such information in your responses. If there is reason to believe you could be identified from the data, for instance if you are the only blind student at a specific university, we will take steps to ensure this data is anonymised. All published data, including any quotations from the survey and focus groups will be anonymised.

The findings from the research will be written up as a summary report which will be disseminated to UKRI and relevant committees of the University of Oxford and inform Research Councils and Doctoral Training Centres. The report itself may be internally available to individual institutions and publicly available to facilitate its use in future research, only if permission for it to be released is granted by the funder and lead organisation (UKRI-BBSRC and the University of Oxford).

All data will be stored on a secure cloud platform, with restricted access granted to only the researchers involved. Individual files will be password protected. Anonymised data will be stored for a minimum of 3 years after publication.

9. Data Protection

The University of Oxford is the data controller with respect to your personal data, and as such will determine how your personal data is stored and used. The survey platform JISC will be used to collect data. Pete Quinn Consulting Ltd, DSUK and The University will receive only anonymous data from JISC, for the purpose of the research outlined above. Research is a task that is performed in the public interest. Further information about your rights with respect to your personal data is available at <https://compliance.admin.ox.ac.uk/individual-rights>.

10. Who is funding the research?

UK Research & Innovation (UKRI) is a non-departmental public body sponsored by the Department for Business, Energy and Industrial Strategy (BEIS).

UKRI brings together the seven disciplinary research councils, Research England, which is responsible for supporting research and knowledge exchange at higher education institutions in England, and the UK's innovation agency, Innovate UK. The Biotechnology and Biological Sciences Research Council (UKRI-BBSRC) works to promote and support high-quality basic, strategic and applied research and related postgraduate training relating to the understanding and exploitation of biological systems

11. Who has reviewed this study?

This study has received ethics approval from a subcommittee of the University of Oxford Central University Research Ethics Committee. (Ethics reference: R80402/RE001).

12. Who do I contact if I have a concern about the research or I wish to complain?

If you have a concern about any aspect of this study, please contact *Professor Gail Preston* at gail.preston@dtc.ox.ac.uk, and we will do our best to answer your query. We will acknowledge your concern within 10 working days and give you an indication of how it will be dealt with. If you remain unhappy or wish to make a formal complaint, please contact the Chair of the Medical Sciences Interdivisional Research Ethics Committee at the University of Oxford who will seek to resolve the matter as soon as possible:

Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Boundary Brook House, Churchill Drive, Headington, Oxford OX3 7GB

13. Further Information and Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Mette Anwar-Westander
Disabled Students UK
Email: mette@disabledstudents.co.uk