**Information Sheet – VERSION: DAIE\_SUR\_MG2021**

**The title of the research project**

Disability Activism in Europe: Online Survey Exploring Young Disabled People's Views and Experiences

**Invitation paragraph**

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to review the following information carefully and discuss it with others if you wish. Please contact the researcher, Miro Griffiths (details at the end of this document) if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

**What is the purpose of the project?**

This project aims to explore young disabled people's experiences of disability activism and disability politics across Europe. The project will explore the opportunities and challenges encountered by young disabled people as they participate in disability activism across Europe, and the importance of disabled people's social movements.

**Why have I been chosen?**

In order to participate in the survey, you will need to confirm the following:

– your age is within the range of 18 to 35;

– you identify as a disabled person;

– you have experience/are interested in disability activism and disability politics;

– you identify as living in a European State.

**Do I have to take part?**

It is up to you to decide whether or not to take part. If you decide to take part, please download and keep a copy of the information sheet and consent form. Your participation in this study is voluntary entirely and you can withdraw at any time and without explanation. During completion of the survey, you do not have to answer any questions you do not want to and you can close the survey window at any time. If you want to withdraw part or all of your data after completing the study, please email Miro Griffiths with your unique response number (provided at the end of the survey) and outline what you would like removed. Please note: you will need to contact Miro Griffiths with a withdrawal request within one month after completing the survey.

**What do I have to do?/ What will happen to me if I take part?**

It will take, approximately, 10 to 30 minutes to complete the survey. You will only need to take part in the survey once. The survey can be accessed through an Internet connection on a computer, laptop, mobile phone, or tablet. It will be available in English, English Easy Read, French, Spanish and German. The survey is compatible with screen reader technology, and all images have an alternative text description.

During the survey, you will be asked questions with regard to your personal experiences of disability activism and social movements, as well as your opinion on improving participation within European disabled people's social movements. Some of the questions will give you an option to type further comments. At the end of the survey, you will have the option to type an email address. Please type your email address if you would like to be considered for future research on disability youth activism across Europe (for example, online interviews).

**What are the possible disadvantages and risks of taking part?**

The survey will ask questions about accessibility and participation within activist networks and social movements. Reflecting on experiences of barriers is a sensitive topic, it may cause some discomfort and/or upset.

**What are the possible benefits of taking part?**

Whilst there are no immediate benefits for those people participating in the survey, it is hoped that this work will provide an original and important exploration of young disabled people's experiences of disability activism across Europe.

**Use, dissemination and storage of research data**

The survey data collected will be stored on a University of Leeds password protected cloud storage platform and the Jisc Online Surveys password protected platform. If you decide to type an email address so that you are considered for future research on disability youth activism then your email address will be stored on the University of Leeds and Jisc platforms. The data stored on these platforms will be deleted by October 2028. This will be five years after the research has concluded.

Your survey responses will be combined with the responses from other participants and then analysed by Miro Griffiths. Your email address and unique response number will not be included in the analysis phase of the research. Description and summaries of all the survey responses collected will be used in future publications, such as conference papers, journal articles, and books. The research will also be stored in the University of Leeds research data repository, which will help other researchers exploring similar topics.

The research abides by the terms and conditions outlined in the [University of Leeds Privacy Notice](https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2020/11/Research-Participant-Privacy-Notice.docx) and [Data Processing Agreement](https://www.onlinesurveys.ac.uk/terms-and-conditions/) with Jisc Online Surveys. If you would like to discuss the terms and conditions surrounding privacy and data processing then please get in touch with Miro Griffiths.

**What will happen to my personal information?**

The survey does not ask any questions associated with direct identifiers, such as name, date of birth, or postal address. You will have the option to provide an email address if you would like to be considered for future research on disability youth activism. You will be contacted by Miro Griffiths with further details before October 2023.

Your email address will not be included in the analysis phase of the research, nor will it be intentionally shared with anyone other than Miro Griffiths.

**Who is organising/ funding the research?**

Miro Griffiths is a paid employee of the University of Leeds. The Leverhulme Trust has partially funded Miro to carry out this research, and contributed towards research expenses.

**Contact for further information**

If you would like to contact Miro about the research project, please use any of the following methods:

Email – [m.griffiths1@leeds.ac.uk](mailto:m.griffiths1@leeds.ac.uk)

Phone – 0044 7835 413 238

If you would like to contact somebody to complain about Miro's conduct during the research project, please contact Dr Angharad Beckett using any of the following methods:

Email – [A.E.Beckett@leeds.ac.uk](mailto:A.E.Beckett@leeds.ac.uk)

Phone – 0044 113 343 4409

**Finally ...**

Thank you for reviewing this information sheet. It is important to review the consent form prior to participating in the survey. The consent form can be accessed via the survey home page, accessed: <https://disabilityactivism.leeds.ac.uk/getting-involved-in-the-research-2/survey-disability-activism-in-europe/>

Please download a copy of the information sheet and consent form.