**Information Sheet for Parents**

My name is Grace Sayers-Mcgowan. I am inviting you to take part in my dissertation research “*Experiences of Mental Health and Education in Young People with Vision Impairment”*. I am a master’s student at UCL’s Institute of Education, where I am studying Educational Psychology. I come from a teaching background and have a lot of experience working with children and young people in a variety of settings.

Research suggests that many young people with vision impairment experience anxiety and depression that can affect their academic and social experience at school. However, these factors have rarely been explored together. In particular there is a need to consider and center the perspectives of young people with vision impairment themselves, alongside parents and stakeholders. This study aims to explore and understand the unique experiences of young people with vision impairment in relation to their mental health and education.

The project is being overseen by Dr Jess Hayton, a Habilitation expert at UCL-IOE. I am also working alongside Vassilis Sideropoulos who is a specialist in mental health, also at UCL-IOE. This wider project has the eventual goal of creating best-practice guidelines for educators who work with young people with vision impairment.

I aim to use the following non-invasive measure to gather lived experiences of mental health and education from young people with vision impairment:

1. *Face-face interview*: (run by Grace via Zoom/face-to-face; 45-60 mins) a semi-structured interview with the young person to explore their educational and mental health experiences
	1. This will include a verbal *Medical History Questionnaire*: (completed by your child/ren, with you if they wish; 10-15mins), reporting diagnosis/es, medications (if any) that may affect mental health and education.

More details and some answers to frequently asked questions are below. If you require more details, please do contact me: grace.sayers-mcgowan.23@ucl.ac.uk. I really hope that you and your child/ren would like to take part in the project. If you wish to withdraw from the study please let me know by 8/07/24. You do not need to give a reason and there will be no negative consequences.

**Who is carrying out the reseach?**

Grace Sayers-McGowan is carrying out the research under the supervision of Dr Jess Hayton.

**Why am I doing this research?**

We know that a signficant proportion of young people with vision impairment are at a higher risk of anxiety and depression than their sighted peers. While this can affect both social and school engagement, we know very little about the specific ways vision impairment, mental health, and education connect. Crucially, I want to hear from young people themselves so I can consider their experiences in depth, as well as people who know them well or work alongside them.

**Why am I being invited to take part?**

You are invited as you are a parent/carer of a young person with visual impairment. You may have already expressed interest in taking part from our research advertisements or via word-of-mouth.

**What will happen if I choose to take part?**

First you will be asked to give consent for you, and your child to participate. I also ask that you speak with your child/ren about the project and confirm that they woud like to participate. Once I have written consent from you, you will be sent the link to the questionnaire electronically.

After this, you may be contacted again in order to request a face-face interview with your child/ren. I can arrange a virtual interview to make the project as non-invasive as possible.

For the interview, your child/ren can omit any information that they do not wish to disclose. This will not have any negative consequences. I want you and your child to be as comfortable as possible.

**Will anyone know I have been involved?**

I affirm your and your child(ren)’s right to confidentiality and anonymity. A limit to confidentiality is only in place if I have any concerns about the welfare of the participant/s. I would then be obliged to follow safeguarding procedures that are in place. I plan to anonymise you and your child(ren)’s data upon receipt (replacing names with codes) and the data containing personal information (i.e. names/dates of birth/medical information) will be destroyed securely.

**Could there be problems for me if I take part?**

As the project is examining experiences of mental health and education in young people with visual impairment some sensitive issues e.g. clinical diagnoses or upsetting experiences may show up in the research. It is my responsibility to ensure that you and your child/ren feel safe and comfortable while participating in this project. You and your child/ren have the right to stop taking part in the study without negative consequence, and the data will be destroyed; please inform me if you would like your data to be withdrawn by 08/07/24. If any sensitive issues do arise, I will handle this considerately and openly.

**What will happen to the results of the research?**

Once I have received the data, I will anonymise it and input it into a database. This makes the data completely depersonalised. I will then run analysis on the data set as a whole, looking for themes and variannces within the data. The depersonalised processed data will be used in my final dissertation project. The data may go on to be used in the wider project of Dr Jess Hayton and Vassilis Sideropoulos which may include a research article that will be published; potential conference presentations; and wider material to be sent to relevant organisations such as the Roynal National Institute of Blind People (RNIB). You are assured that neither you nor your child/ren will be identifiable in these research outputs.

**Do I have to take part?**

It is entirely up to you whether or not you choose to take part. I hope that if you do choose to take part that you will find it a valuable experience. If you choose not to take part, there are no negative repercussions.

**Benefits of the research for participants**

The research will contribute to a deeper understanding of how young people with vision impairment experience mental health and education, from their own perspective. This insight is sorely needed within the field to consider better the mental health and education experiences and needs of young people with vision impairment.

**Data Protection Privacy Notice**

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk.

UCL’s Data Protection Officer can also be contacted at data-protection@ucl.ac.uk. Further information on how UCL uses participant information can be found here:

[www.ucl.ac.uk/legal-services/privacy/participants-health-and-care-research-privacy-notice](http://www.ucl.ac.uk/legal-services/privacy/participants-health-and-care-research-privacy-notice)

The legal basis that would be used to process your personal data will be performance of a task in the public interest. The legal basis used to process special category personal data will be for scientific and historical research or statistical purposes/explicit consent.

Your personal data will be processed so long as it is required for the research project. I will always try to minimise the processing of personal data wherever possible and will anonymise and psyeudonimise 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 dataprotection@ucl.ac.uk.

**Contact for further information**

Grace Sayers-McGowan

grace.sayers-mcgowan.23@ucl.ac.uk

If you have any further questions before you decide whether to take part, you can reach me at grace.sayers-mcgowan.23@ucl.ac.uk.

If you would like to be involved, please complete the following consent form and return it to the email address above as soon as possible.

This project has been reviewed and approved by the UCL IOE Research Ethics Committee [insert reference number].

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