



Participant Information Sheet For Parents and Carers

UCL Research Ethics Committee Approval ID Number: 20633/001

The data registration reference is Z6364106/2021/05/25

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

School attendance and home learning experiences of children with intellectual disability and/or on the autism spectrum a year after the COVID-19 pandemic

Department: Division of Psychiatry, University College London (UCL)

Name and Contact Details of the Researcher: Ms Nancy Kouroupa, athanasia.kouroupa.12@ucl.ac.uk

Name and Contact Details of the Principal Researcher: Dr Vaso Totsika, v.totsika@ucl.ac.uk

Collaborators

Professor Kylie Gray, University of Warwick, UK

Professor Richard Hastings, University of Warwick, UK

Professor Bruce Tonge, Monash University, Australia

Dr Glenn Melvin, Deakin University, Melbourne, Australia

Dr David Heyne, Leiden University, Netherlands

Ms Amanda Allard, Council for Disabled Children, UK

Ms Victoria Jane Nicholls, University College London (UCL), UK

Study collaborators work with the UCL researchers to design and manage the study, recruit, interpret, and disseminate study findings.

1. Invitation

We would like to invite you to take part in this 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 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 or not you wish to take part.

2. What is the project's purpose?

The COVID-19 pandemic brought many disruptions to children's education. Autistic children and children with an intellectual disability are vulnerable. The study aims to investigate the educational experiences of children with intellectual disability and/or autism in spring/summer 2021, approximately one year following the start of the COVID-19 pandemic in the UK.

The study will investigate the educational experiences of 5-15 year-old autistic children or children with an intellectual (learning) disability, whether they are registered with a school or not.

The study will ask these questions:

- What are the reasons for missing school?
- What helps or hinders school attendance?

- When are parents' experiences of home learning?

The study findings will provide evidence on the impact of COVID-19 on school attendance and absenteeism, as well as home education, highlighting areas for improvement in UK educational policy and practice.

3. Why have I been chosen?

You have an autistic child or a child who has an intellectual disability, or both conditions. Your child may have other conditions too (or not).

Your child is school-aged: between 5 and 15 years-old. This is about the same as Reception (Year 1 in Northern Ireland or P1 in Scotland) and Year 10 (S4 in Scotland).

Your child may be registered to attend a school (any school: mainstream, special, alternative) or may be home educated (Elective Home Education).

You may be the child's parent (biological, foster, adoptive, step, co-parent) or carer.

4. Do I have to take part?

Taking part in the study is voluntary. You do not have to agree to take part, and nobody will know if you decide not to. If you do not agree to take part, it will not affect your rights in any way.

It is up to you to decide whether or not to participate. Read the information here and keep it, if you decide to take part. If you take part, you will be asked to consent (without providing your name).

You do not have to answer any questions in the survey that you do not want to. Agreeing to join the study does not mean that you have to complete it. If you start the survey, it is your right to stop at any point before the end: this will not affect your rights in any way. To withdraw from the study, just close the browser window without submitting your responses.

Following consent, if you close the browser window without having responded to any of the listed questions, any saved information will be deleted. If you respond to at least one question in the survey, your data will be saved and retained to the database.

If you take part, we will not ask for your name, contact information, and we will not save your IP address: this means that if you decide to withdraw from the study after completing the survey, we will not be able to delete the data you have provided because we will not know it is your data.

5. What will I need to do if I take part?

You will be asked to fill out an online survey. The first step is giving your consent to participate, by clicking some 'Agree' statements.

You will then be asked some questions about (a) your child, (b) their school attendance in May 2021 or their home schooling and (c) about you and your family.

It takes approximately 20 minutes to complete the survey.

If you have more than one child with intellectual disability and/or on the autism spectrum, please complete the survey for only ONE of your children. If you have spare time, please fill in a new survey for another child separately.

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

We will not ask for any information that can identify you (no name, contact details or IP addresses will be saved). If your child goes to school, we will not ask for the name of the school. We will ask about your child's diagnosis (the conditions you have been told your child has). To minimise the risk of identification, we will group some of the information we ask off you: for example, if your child has a rare genetic syndrome, you can tell us so without specifying the name of the syndrome.

We will ask about your child's mental health and anxiety feelings: there is a possibility you might feel distressed thinking about your child's mental health, or anxiety, or schooling situation. If you want to find out more about children's mental health or how to get help, you could read [this guide by the NHS](#), this [guide by the Mental Health Foundation](#), get in touch with your GP, or your local charity that supports families of children with intellectual disability or autism.

What are the possible benefits of taking part?

There will be no direct benefit to you by taking part in this study. There is no reimbursement for taking part in the study.

However, you will be helping to establish a better understanding of the educational experiences of children with intellectual disability or autism a year after the start of the COVID-19 pandemic. As a result, we will make recommendations for UK school policies for children with Special Educational Needs and Disabilities (SEND) and it is likely that this study will be taken into account in future policies.

7. What if something goes wrong?

If you have a complaint about the study or a complaint about your treatment from the researcher, please email the Principal Researcher (Dr Vaso Totsika v.totsika@ucl.ac.uk) including the study administrator in your email (Ms Paula Beharry p.beharry@ucl.ac.uk). This is to help us make sure that we receive your email in a timely manner. We will aim to respond to your email within a week of receiving it.

If you feel that the complaint has not been handled to your satisfaction through the above process, you can contact the Chair of the UCL Research Ethics Committee – ethics@ucl.ac.uk.

8. Will my taking part in this project be kept confidential?

The information in this study will be used only for research purposes and in ways that will not reveal who you are. National laws may require us to show information to university or government officials (or sponsors) who are responsible for monitoring the safety of this study. You will not be identified in any publication from this study.

Here are the steps we will take to protect your confidentiality:

- We will **not** ask personal information that can identify you directly: we will not ask for your name, address, contact details, your child's name, or your child's school if they go to one.

- We will **not** ask for personal information that could identify you indirectly: We will not save the IP address of the machine you use to complete the online survey.
- Some of the information you will be asked to provide is considered sensitive (ethnicity, health conditions). Such information will either be collected in aggregate format (e.g. rare health conditions) and/or will be reported in aggregate format (child diagnosis, child ethnicity). In this way, no one will be able to identify you or your child either by looking at the data or by looking at the published results.
- The survey is completed in Qualtrics. We selected Qualtrics because it is [secure](#). UCL has a Master Agreement with Qualtrics which means UCL's Legal and Data Protection Teams have reviewed it.
- During the study, we will keep all data in a secure environment at UCL. Access to the data for editing and analysis will be from password-protected computers.
- During the study, data will not be shared with members of the research team who are outside the EU.
- At the end of the study, data may be deposited for future re-use with the UK Data Archive if the research funder (see q. 12) requires it: before sharing data for future re-use, data will be reviewed again to ensure that any information that might identify you has been removed or changed. Agreeing to your data being deposited to the UK Data Archive is optional. You can still take part in the survey even if you do not agree to your data being deposited to the UK Data Archive later.

9. Limits to confidentiality

Please note that assurances on confidentiality will be strictly adhered to. The only exception to this would be *if* you select to disclose your identity in the survey (without being asked to) and you disclosed harm or risk of harm: if both these were to happen, the researcher has a duty of care to report to the relevant authorities possible harm/danger to the participant or others. In such cases, confidentiality would be limited.

10. What will happen to the results of the research project?

We will share the results of the study with education policy makers through our partner (Council for Disabled Children): we will do this in a policy workshop that the Council for Disabled Children will organise. A policy brief will be made widely available following the end of the project (2022) and will be accessible through the researchers' webpages at UCL, and the webpage of the Council for Disabled Children. We will also present the results of the study in conferences in the UK and abroad. Any publication or dissemination arising from this project will not identify individuals who participated in the study.

Storage and future use: Data from the study will be stored at UCL beyond the end of the study for a period of 10 years in line with UCL's data retention policy. Data might be used for additional or subsequent research of a similar nature by the UCL research team. If shared outside of UCL it will only be shared with UK collaborators and data sharing agreements will be drawn between Universities to control the conditions for data sharing, including access, storage and use. If required, by the research funder (q.12), data may also be deposited in the UK Data Archive (as an anonymised survey database), following additional checks to ensure confidentiality is protected. The [UK Data Archive](#) is a national centre for digital data archiving in the United Kingdom. Once the anonymised database is deposited with the UK Data Archive, the terms of data access and storage are controlled by them, and the anonymised dataset may be accessed by users nationally and internationally following an application to the UK Data Service.

11. 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 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:

Child ethnicity

Health: child neurodevelopmental conditions, physical health, mental health

The lawful basis that would be used to process your *personal data* will be the 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.

Data will be held for at least 10 years in line with UCL's data retention policy for this type of research. Data will be anonymised to minimise the processing of personal data and special category 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.

During the course of the study no data will be transferred outside the EEA (European Economic Area).

12. Who is organising and funding the research?

The research is being funded by the Economic and Social Research Council (Grant Ref ES/W001993/1).

13. Contact for further information

If you would like further information, please contact Ms Nancy Kouroupa: athanasia.kouroupa.12@ucl.ac.uk

Telephone: 07843 149256

Please retain a copy of this information sheet for your records if you decide to participate in the research.

Thank you for reading this information sheet and for considering taking part in this research study.