**Research registration form**

All research projects using Personal Data must be registered with the UCL Data Protection Office before the data is collected. Completing this form is part of that process.

For research projects that require a review by a Health Research Authority (HRA), Research Ethics Committee (REC), or if your study involves the processing of special category personal data (sensitive), and you are an undergraduate, or postgraduate student.

Where UCL is a Controller it must comply with the Data Protection Legislation. For students who are processing Personal Data as part of their UCL programme of studies, UCL will be the Controller.

This form should be completed if Personal Data is collected and used as part of the research project. Research registration will not be required when staff or students are only processing Anonymous Data.

Definitions of terms used in this form, such as Personal Data, are given below.

All sections **must** be completed before submitting this form. Please ensure all required supporting documentation is also uploaded. Failing to comply will result in a delay to your research registration.

If you are external to UCL, please complete the following form below instead of completing the online Microsoft form and submit it electronically to data-protection@ucl.ac.uk together with the supporting documentation.

If you are having issues accessing or using this form, please notify us at data-protection@ucl.ac.uk.

We may have some questions about the information you provide, but you will normally be provided with a registration number within 10 working days of submitting the form. However, the period leading up to meeting of Ethics Committees is always very busy, and you should allow more time for your application to be processed.

If you are having issues accessing or using this form, please notify us at data-protection@ucl.ac.uk

**Definitions**

**Personal Data**: any information relating to an identified or identifiable living individual.

**Pseudonymised personal data** means:

*‘...****personal data****[that] can no longer be attributed to a specific data subject without the use of additional information, provided that such additional information is kept separately and is subject to technical and organisational measures to ensure that the****personal data****are not attributed to an identified or identifiable natural person'*
[GDPR, Article 4]

**Anonymised data**: data which does not relate to an identified or identifiable natural person or personal data that has been rendered anonymous in such a manner that the data subject is not or no longer identifiable.

**Special categories of personal data**: personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation.

**Controller**: a person which, alone or jointly with others, determines the purposes and means of the Processing of Personal Data.

**Data Protection Legislation**: all applicable laws and regulations relating to the Processing of Personal Data as the same may be in force from time to time.

**Joint Controller**: a Controller which, jointly with one or more other Controllers, determines the purposes and means of Processing.

**Processing**: any operation or set of operations which is performed on Personal Data or on sets of Personal Data.

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| 1. **STUDY DETAILS**
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1. Title of the study:

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| *Health, education and social engagement of young people with visual impairment* |

1. Proposed start date:

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| *02/10/2022* |

1. Proposed end date (if known):

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| *03/10/2023* |

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| 1. **CHIEF INVESTIGATOR (CI); PRINCIPAL INVESTIGATOR (PI)**
 |

**Please note:** *students cannot be the CI/PI for Ethics purposes.*
*If the CI/PI is not a UCL employee you should provide details below of a responsible UCL employee below.*

1. Full Name:

|  |
| --- |
| *Xxxxxxxxxxx Xxxxxxxxx* |

1. Position held:

|  |
| --- |
| *Professor of Child Health* |

1. Faculty:

|  |
| --- |
| *UCL Faculty of Population Health Sciences* |

1. Department:

|  |
| --- |
| *UCL GOS Institute of Child Health (GOS ICH)* |

1. Email:

|  |
| --- |
| *xxxxxxxxx@ucl.ac.uk* |

1. Confirm Email:

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| --- |
| *xxxxxxxxx@ucl.ac.uk* |

1. Telephone:

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| --- |
| *+44 (0)20x xxx xxxx* |

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| 1. **DATA COLLECTOR(S)**
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Data Collector(s) Details*(if Applicant is not the CI/PI e.g. student details).*If the CI/PI is also the Data Collector, applicants are advised to insert **N/A** below.

1. Full Name:

|  |
| --- |
| *Xxxxxxxxx Xxxxxxxxxxx* |

1. Position held:

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| *Masters student* |

1. Faculty:

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| --- |
| *UCL Faculty of Population Health Sciences* |

1. Department:

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1. Email:

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| --- |
| *xxxxxxxxx@ucl.ac.uk* |

1. Confirm Email:

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| *xxxxxxxxx@ucl.ac.uk* |

1. Telephone:

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| 1. **DETAILS OF THE PROJECT**
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1. Please provide a brief summary of the project, including an explanation of the aims, design, methodology and plans for analysis that you propose to use.

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| *The aims of the study are to explore young people’s experiences of understanding of health, education and social engagement, by exploring their evaluations on these subjects, and what their needs might be to help them with their future life experiences.**We hope this study shall provide empirical analysis in an under researched area, and by doing so, contributing towards a future digital tool for our target population.* |

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| 1. **PRIVACY IMPACT SCREENING QUESTIONS**
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If the answer to any of these questions is ‘yes’, then a [DPIA](https://www.ucl.ac.uk/data-protection/guidance-staff-students-and-researchers/practical-data-protection-guidance-notices/data-protection) is required.

1. Will the project require individuals to provide information about themselves?

[What is personal data](https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/key-definitions/what-is-personal-data/)?

[x]  Yes [ ]  No

1. Will information about individuals be shared with organisations or people who have not previously had routine access to the information?

☐ Yes ☒ No

1. Will the project use information about individuals for a purpose it is not currently used for, or in a way it is not currently used?

☐ Yes ☒ No

1. Does the project involve you using new technology that might be perceived as being privacy intrusive? For example, the use of biometrics or facial recognition.

☐ Yes ☒ No

1. Will the project result in you making decisions or treating individuals in ways which can have a significant impact on them?

☐ Yes ☒ No

1. Is the information about individuals likely to raise privacy concerns or expectations, e.g. health records or information that people would consider to be particularly private?

[Special category data](https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/special-category-data/)

☒ Yes ☐ No

1. Will the project require contact with individuals in ways they may find intrusive, e.g. unexpected telephone calls?

☐ Yes ☒ No

1. Will the project use personal data, including personal data obtained from live or operational systems for access or transfer outside the UK (e.g. use of Cloud, Hybrid or offshore support purposes)?

☐ Yes ☒ No

1. Will the project involve processing [special category personal data](https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/special-category-data/)?

☒ Yes ☐ No

1. Will the project involve the processing of under 18’s personal data?

[Children and the UK GDPR](https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/children-and-the-uk-gdpr/)

☒ Yes ☐ No

1. Will your research involve the use of secondary data (e.g. books, personal sources, journals, newspapers, websites, government records etc.)?

☐ Yes ☒ No

1. If your research involves re-analysis of secondary data, please indicate the original purpose for which the data was collected, and comment on whether the original participants were supplied with relevant information at data collection for additional use later on.

If this section does not apply, applicants are advised to insert **N/A** below.

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| 1. **PARTICIPANTS**
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Will the study enrol potentially vulnerable groups (e.g. children, older persons or adults with learning difficulties for those who fall under the remit of the Mental Capacity Act 2005) participants? Vulnerability may be defined in different ways and researchers will need to assess the level of potential vulnerability within the context of the research.

1. Children under 18.

[Children and the UK GDPR](https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/children-and-the-uk-gdpr/)

[x]  Yes [ ]  No

1. People lacking capacity (e.g. unable to understand information provided about a particular decision. Retain that information long enough to make a decision. Consider and assess the information to make a decision. Communicate a decision by talking through sign language or any other means.

[ ]  Yes [x]  No

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| 1. **DETAILS OF PARTICIPANTS**
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Please provide details of the participants for this project, including how they will be selected and recruited.

1. How many participants will be involved in the research?

[ ]  1 – 20

[ ]  21 – 100

[x]  101 – 1000

[ ]  1001 – 5000

[ ]  Greater than 5000

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| 1. **DATA COLLECTION**
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1. What type of information will be collected?
*If a mixture of types will be collected, select all that are applicable.*

[ ]  **Anonymised data** – no personal identifiers with no link between the individual and the data.

[ ]  **Pseudonymised personal data** – e.g. key-coded data which includes some (often partial) personal identifiers (e.g. initials and DOB) thus potential for indirect identification of participants from the information in combination with other information.

[x]  **Fully identifiable personal data** – e.g. data with any of the following; names, addresses, hospital number, and NHS number.

1. If personal identifiers (including within pseudonymised data) will be collected, please list all e.g. *initials, DOB, names, addresses, NHS number.*

[What is personal data?](https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/key-definitions/what-is-personal-data/)

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| *The following personal identifiers will be collected from the participants:**- Date of birth**- Postcode* *- Ethnicity* *- Sex**- Physical or mental health**- Name* |

1. Is it intended to include participants who are prisoners or young offenders in the custody of HM Prison Service or supervised by the probation service?

[ ]  Yes [x]  No

1. Have you completed a [Data Protection Impact Assessment](https://www.ucl.ac.uk/data-protection/guidance-staff-students-and-researchers/practical-data-protection-guidance-notices/data-protection) (DPIA)?

[x]  Yes [ ]  No [ ]  Pending

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| 1. **DATA STORAGE**
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1. What type of information will be stored?

*If a mixture of types will be collected, select the most identifiable option.*

[What is personal data?](https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/key-definitions/what-is-personal-data/)

[ ]  Anonymised data

[ ]  Pseudonymised personal data

[x]  Fully identifiable personal data

1. Where will the data be stored by UCL?
For data storage outside of UCL, see **section** **M**.

[x]  UCL Data Safe Haven

[ ]  UCL system, e.g. ‘S’ or ‘N’ drive

[ ]  Hard drive of a portable device

[ ]  Cloud (inside EU/EEA)

[ ]  Cloud (outside EU/EEA)

[x]  Manual files (e.g. paper) at UCL

[ ]  Other, please specify in Q40

1. If the data will be stored outside UCL, please provide details below. (This should include any stipulations of the security of the data, such as an encrypted storage facility, geographical location of physical servers; please also outline who will be accessing it for analysis).

If this section does not apply, applicants are advised to insert **N/A** below.

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| 1. **PARTNERS AND DATA PROCESSORS**
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Please list all study collaborators / third parties, who will be sending / receiving personal data for study purposes or their own purposes. These can include contract research organisations, funders, other universities involved in the research or in publishing findings from the study.

[Key definitions](https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/key-definitions/what-is-personal-data/)

If there are more than one study collaborator involved with the research, please provide details of them all.

If this section does not apply, applicants are advised to insert **N/A** below.

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1. Name of third party:

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| *Transcription Services 123* |

1. Status of party:

☐ Controller

☒ Processor

☐ N/A

1. Location of third party collaborator:

[x]  Inside EU/EEA

[ ]  Outside EU/EEA

[ ]  N/A

1. Activity/ purpose (e.g. storage, processing, analysis):

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| *Processing and analysis* |

1. Method of data transfer (e.g. UCL Data Safe Haven, AES-256 encryption with password):

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| *256 encryption* |

1. Data storage (e.g. private company computers/ system, NHS computers/ system, home or other personal computers, cloud):

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| --- |
| *Third party has GDPR-compliant UK based servers* |

1. Length of data retention (e.g. duration of trial and archive for x years):

|  |
| --- |
| *Storage of data upon receipt and, on completion, then automatic removal of all data received after 90 – 120 days (or sooner on request).* |

1. Is there a contract in place. If **Yes,** please attach.

[x]  Yes [ ]  No [ ]  Pending

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| 1. **INTERNATIONAL TRANSFER**
 |

1. Please indicate if personal data be transferred outside the EU as part of this study:

[ ]  Yes [x]  No

1. If personal data is transferred outside the EU, confirm you have followed the [guidance on transfers](https://www.ucl.ac.uk/legal-services/sites/legal-services/files/ucl_guidance_note_-_transfers_outside_the_eea.pdf):

[ ]  Yes [x]  No

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| 1. **SPONSOR**
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Please provide details of the sponsor for this research below. This can be an individual, company, institution, funding council, or another organisation which takes responsibility for the initiation, management and/or financing of the research.

If this section does not apply, applicants are advised to insert **N/A** below.

1. Proposed sponsorship arrangement:

|  |
| --- |
| *N/A* |

1. Details of sponsor:

|  |
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| *N/A* |

1. Is there a contract in place with the sponsor? If **Yes**, please attach.

[ ]  Yes [ ]  No

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| 1. **SUPPORTING DOCUMENTATION AND CHECKLIST**
 |

1. **Please provide**a summary of the study including:
* A description of the study and any information flows.
* Details of any personal data being collected, e.g. ‘basic identifiers’ or Special Category Data.
* The methods of data collection and analysis.
* A diagram setting out the information flows, if available.
* Details of any partners involved in the study, e.g. other universities or organisations.
* Details of any processors being used, e.g. data storage providers or transcription services.

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| *This study will record participants talking about their own experiences of health, education and social engagement. These experiences may include some sensitive topics, such as participants’ health problems, difficulties in education, or behaviour in social environments. Participants will between the ages of 16 - 18. A full description of the study is provided in the participant information sheet.* *We propose 2 workshops to be held during term time, for our target populations. All participants will provide informed consent, and where applicable, parents will be provided with a full information sheet with an appropriate ‘opt int’ section should they wish for their child to be involved with the research. These workshops will use activities designed to explore young people’s perspectives on health, education and social experiences, identify where they may need information and support, and to think about what sort of digital tool they might find helpful in relation to a broader agenda of health, education and social issues in the future.**Once the data has been collected, identifiable data will only be transferred between members of the research team using Microsoft OneDrive (Cloud-based storage and collaboration space which can be used to create, edit and share content between colleagues) with an access controlled folder.* *No data will be shared outside the research team, or with with another organisation or researcher based in another country within, or outside European Economic Area.**In order to reduce the likelihood of third parties accessing any identifiable information attributed to this study, participants will be assigned a random ID and it will be kept separately from any identifiable information relating to the participants, and will be held on a password-protected file only accessed by the research team.**- details of any personal data being collected, eg ‘basic identifiers’ or Special Category Data**The following personal identifiers will be collected from the participants:**- Date of birth**- Postcode* *- Sex**- Name**The following special category data will be collected and used for analysis:**- Ethnicity**- Physical or mental health**- the methods of data collection and analysis**During data collection, we will gather personal information (postcode, ethnicity, sex, physical or mental health and names) from participants. Identifiable data will only be used at the initial stages of this study. To reduce the likelihood of third parties (parties not involved in the research project) accessing this identifiable information, participants will be assigned a random ID and their ID will be kept separately from any identifiable information on a password-protected file. The personal information will only be accessed by the members of the research team at any time.**Upon the completing of each survey, all documentation will be scanned to PDF and stored securely on SharePoint in a folder that only I have access to. Paper consent forms will be shredded. All files will be uploaded for processing to the same folder on a password protected, encrypted hard-drive accessible only to me. After the data collection period has finished, files will be anonymised, and anonymous files will be shared with other team members via a GDPR-compliant storage platform (Dropbox Business and/or the UCL Data Safe Haven service).**- a diagram setting out the information flows, if available**Not currently available**- details of any partners involved in the study, eg other universities or organisations**This study will constitute part of my doctoral thesis, and is intended for publication in a relevant peer-reviewed journal and at* *national and international conferences. I am not planning on sharing any identifiable information with any partners, either during, or after the completing of this study. Participants will be referred to only by numerical identification. Data will not be presented at any point with real names. However, anonymous data will be made accessible by the research team upon request.* *- details of any processors being used, eg data storage providers or transcription services**We are intending to share personal data with a UCL approved external transcription service for which the University is the data controller. Both parties have already entered into a personal data processing agreement, which has gone through the normal channels of procurement, and legal services to ensure that the contract is appropriate.* |

1. Data Protection Impact Assessment (DPIA). If **Yes**, please attach.

[x]  Yes [ ]  No [ ]  N/A

1. Participant information sheet(s) (PIS) and Privacy Notice if separate. If **Yes**, please attach.

[x]  Yes [ ]  N/A

1. Informed consent form(s). If **Yes,** please attach.

[x]  Yes [ ]  N/A

1. Other documentation being used to invite/inform participants about the research. If **Yes,** please attach.

[ ]  Yes [ ]  N/A

1. Data Sharing/Processor agreements. If **Yes**, please attach.

[ ]  Yes [x]  N/A

1. Local Data Protection Coordinator notified. **Please confirm.**
**Please note:** *not all departments have a local data protection coordinator. This role is different from the data protection officer (which is a centralised function) and you should check with your department whether this requirement applies to you.*

[x]  Yes [ ]  N/A

1. Appropriate [safeguards guidance](https://www.ucl.ac.uk/legal-services/sites/legal-services/files/guidance_for_researchers_on_appropriate_safeguards_under_gdpr_2016_and_dpa_2018.pdf) read and implemented. **Please confirm.**

[x]  Yes [ ]  N/A

1. If this application is linked to a previously approved research registration, please provide the number issued.

If this question does not apply, applicants are advised to insert **N/A** below.

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| *N/A* |