### Research Participants

1. **What personal information we collect**

If your personal information is used by NEIGHBOURLYLAB because you are a participant in one of our research projects, you should also refer to the Privacy Notice for the project you are involved. This will be provided to you by us or the project delivery team(s) or independent research evaluator organisation(s) at the time they are collecting your personal information.

Research participants are typically made up of children, families, teachers, carers, social workers and other people within a professional capacity involved in a programme of work upon which we are conducting a project or piece of research.

The information below is to provide you with non-specific list of possible personal information we may request from you within any project or piece of research we conduct. We may collect and process the following types of personal information which will be highly dependent on the work we are doing:

* Personal identifiers: for example, name, email address, telephone number, post code, unique pupil number (UPN), where you work, job title, local council
* Characteristics: for example, age, gender, ethnicity, academic achievement, instances of harm, location, first language, disability, school attendance information, special educational needs (SEN), eligibility for free school meals
* Responses to interviews and surveys
* Information held in Child Protection Plans (CPP), Child Looked After (CLA) records, Child in Need (CiN) records, case reports, social care, and social worker reports/documentation
* Further information that may assist in our activities for the archiving of information ready for future use
* Sensitive information including hospital or GP records, criminal records and further special categories of personal information as characterised in the UK GDPR (race, ethnic origin, political opinions, religious or philosophical beliefs, trade union membership, genetic data, biometric data, health data, information concerning your sex life or sexual orientation)
* Personal information related to the Equality Act 2010 inclusive of data known as ‘[Protected Characteristics](https://www.legislation.gov.uk/ukpga/2010/15/section/4)’ (age, disability, gender reassignment, marriage or civil partnership (in employment only), pregnancy and maternity, race, religion or belief, sex, sexual orientation)
* Personal information related to our internal equality and diversity monitoring policy (geographical location, organisation, socio-economic class, caring responsibilities, educational background)

The list above may not be relevant to you, and you should always refer to the project specific Privacy Notice. If you think you have not received a relevant Privacy Notice for the project or piece of research in which you are participating, please make contact with our Data Protection Officer: dpo@whatworks-csc.org.uk

Each piece of research we conduct will have a Trial Protocol (TP) document written which outlines all the parameters of the research being undertaken. The language in the TP is aimed at an academic audience and each TP contains a section about data protection processes. To provide more clarity on our data protection practices within research we conduct and commission we have also prepared a “NEIGHBOURLYLAB Research Data Protection Statement” to go alongside information found within the TP. If you are interested in reading this statement it can be found [here](https://whatworks-csc.org.uk/wwcsc-research-data-protection-statement/).

1. **Why we collect your information and what we use it for**

We collect your personal information for two distinct reasons when you are a research participant. You should always refer to the Privacy Notice provided to you which will be specific to the research you’re involved in.

The first reason for collecting your personal information will be to analyse it in the context of the research. This means the personal information collected from you is needed so we can conduct research on your personal information. Our work seeks better outcomes for children, young people and families by bringing the best available evidence to practitioners and other decision makers across the children’s social care sector.

It is highly unlikely we will analyse one participant’s personal information in isolation. Most research we conduct is the bringing together of multiple people’s information to make discoveries to inform results to be published in a research report. Your personal information is never published unless we have gained permission from you to do so. Research outcomes are mainly statistical, and derived into statements and reproducible facts without any individual personal information associated to them.

The second reason for collecting your personal information is so we are able to gather the information needed for the research project from you. To achieve this we will use your personal information: (not all uses listed below will be relevant to you and you should refer to the purposes for use as listed in the project Privacy Notice):

* To conduct an interview, workshop or focus group with you as a participant, which may or may not be recorded
* To contact you to participate in an interview, and/or a workshop, and/or a focus group session as part of a project or piece of research
* To gain your permission for participation in the research
* To match your data with your data held in the government data sources, including the , the [**National Pupil Database (NPD)**](https://www.gov.uk/government/collections/national-pupil-database), the [**Individualised Learner Record (ILR)**](https://www.gov.uk/government/collections/individualised-learner-record-ilr) and the [**Higher Education Statistics Agency (HESA)**](https://www.hesa.ac.uk/).
* To allow us to match your data with your data held in government data sources for the enrichment of data held in our secure data archive in the Office for National Statistics Secure Research Service. For example, this means we will create the ability for research data we have collected to be re-used for future research, against centralised (government secure) datasets for new research discoveries and research reports that will inform sector policy and procedures.
* To transcribe the audio captured from any recorded interviews, workshops or focus groups we have with you as a participant
* To identify your data, which would be deleted where possible, should you no longer agree to have your data processed for the purpose of conducting the evaluation
* To associate your answers with yourself where we would like to make confidential contact with you based upon the answers you have provided which we have identified as useful in our development of the research area
* To make confidential contact with you where you have indicated interest in being contacted about the research area or to participate in any research projects associated with this area of research (you are able to opt out at any time and are under no obligation to participate in any subsequent research projects)

We will also use your personal information to respond to and identify your personal information when you submit a data subject rights request.

1. **Collecting your personal information**

As a Research Participant we will collect your data in a variety of ways and at a variety of times throughout any given project.

Not all methods of collection listed below will be relevant to you and you should rely on the project specific Privacy Notice to keep you informed. Below is a list of all possible ways we, or a Project Team may collect your personal information.

We refer to “primary data collection” when data is collected directly from you, and we refer to “secondary data collection” when the data is not collected directly from you.

* From yourself within online/telephone interviews (primary data collection)
* From yourself within online workshop or focus group interviews (primary data collection)
* From yourself via an online survey we have sent you or you have voluntarily answered (primary data collection)
* From yourself when you communicate directly with us (primary data collection)
* From your place of work to make initial contact with you (secondary data collection)
* From publicly available websites and sources including social media (secondary data collection)
* From a reference passed to NEIGHBOURLYLAB or the Project Team by an individual or organisation within NEIGHBOURLYLAB’s or the Project Team’s network of previously established contacts database (secondary data collection)
* From a database held by NEIGHBOURLYLAB or the Project Team where your data has been held with your permission for a secondary use within a NEIGHBOURLYLAB (including a Project Team) project (secondary data collection)

We also receive personal information indirectly (secondary data collection), from other sources in the following scenarios:

* We may receive information from local authorities, schools, virtual schools, education providers, charities, and other organisations that are funded by us or collaborating with us on research projects.
* We may receive information from parents, relatives, guardians, carers, care providers, social workers, allied professionals, care reports, case reports/records and administrative data that is shared with us.
* We may also directly match research participant information with government data sources, including but not limited to the [**National Pupil Database (NPD)**](https://www.gov.uk/government/collections/national-pupil-database) and the [**Individualised Learner Record (ILR)**](https://www.gov.uk/government/collections/individualised-learner-record-ilr).
1. **Our lawful basis for using your data**

We process the personal data of research participants in a variety of ways. As a research participant we will only use your personal data when the law allows us to.

We will always inform you of our lawful basis for processing within either the Research Participant Data Privacy Notice and/or the Participant Information Sheet and/or a Consent Form you are presented with at the point of collection of your personal data.

Most commonly, the lawful basis for using your personal information may be one or more of the following within a project:

* Legitimate Interest for societal benefit within a research project
* Public Task when we work in the public interest
* Legal Obligation when we must comply with the laws of the country in which we are working in or where you have provided information where we have a statutory requirement to inform relevant authorities

For the collection of your sensitive personal information, also known as GDPR [special categories](https://gdpr-info.eu/art-9-gdpr/) of personal information, in general we rely on GDPR Article 9.2(j) for research purposes with a basis in law. This is also relevant to any personal information known as “[protected characteristics](https://www.equalityhumanrights.com/en/equality-act/protected-characteristics)” under the UK Equality Act 2010. Confirmation of this will be found in the project specific Data Privacy Notice.

**A note on Consent**: Research projects will often ask you for your consent to participate in a project. Unless it is clearly stated in the relevant Privacy Notice provided to you, in general, this will **not** be data protection consent as the lawful basis we use to process your personal information.

A lot of research we do is dependent on gathering “informed consent” for your participation as part of ethical considerations required by either a research ethics committee who have reviewed the project proposal or to follow best practice in accordance with the [Helsinki Declaration](https://www.verywellhealth.com/declaration-of-helsinki-4846525).

Should you withdraw your consent for participation when the data is being analysed, we would not be able to immediately remove your data until the analysis is complete. Where possible we would endeavour to remove all association to your personal information from the point of withdrawal and inform you where this may not be possible depending on the stage of analysis and project as a whole.

1. **Security, Storage and Sharing of your data**

We take the security of your information very seriously and have put physical, technical, operational, and administrative strategies, controls and measures in place to help protect your personal information from unauthorised access, use or disclosure as required by law and in accordance with accepted good industry practice. We will always keep these under review to make sure that the measures we have implemented remain appropriate.

We use Google Workspace & Google Cloud Platform for the secure storage of personal information processed by us. Through the use of Google services, the organisation is able to provide a high level of security around the storage of highly sensitive personal data which is captured within a high variety of our activities. You can find further security and compliance information in the Google [Compliance Resource Centre](https://cloud.google.com/security/compliance), [Privacy Resource Centre](https://cloud.google.com/privacy) and the [Google Cloud & the GDPR](https://cloud.google.com/privacy/gdpr) pages.

Your personal data may also be stored with specific third-party services for the minimum period necessary to perform activities with your personal information. Each third-party is subject to contractual and security reviews to ensure adequate and comparative levels of security, we’d expect for ourselves, is provided for the data they process on our behalf.

The types of third-party providers we use include:

* Transcription services
* Mass email services
* Communications providers
* Survey platform services
* Client Relationship Management services
* Website services and platform providers
* IT services organisations

Where appropriate, we may share your personal information with our professional advisers including our lawyers and auditors, project partners, industry experts, peers (of a group you are involved in as a Sector Stakeholder), and local and central government departments where it is strictly necessary. It is also possible that we may be required to share your data to comply with applicable laws or with valid legal processes, such as in response to a court order.

Whenever we transfer your personal data out of the UK, we ensure a similar degree of protection is afforded by implementing at least one of the following safeguards:

* Transfer your personal data to countries that have been deemed to provide an adequate level of protection for personal data by the UK (the UK also recognises the European Commission list of adequate countries. For further details, see [European Commission: Adequacy](https://ec.europa.eu/info/law/law-topic/data-protection/international-dimension-data-protection/adequacy-decisions_en) of the protection of Personal Data in non-EU countries)
* Specific contracts/agreements approved by the UK which give personal data the same protection it has in the UK. For further details, see [UK International Data Transfer Agreements](https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/international-data-transfer-agreement-and-guidance/). We will also assess in-country standards as part of this process.

We may share the information we gather with other organisations in the following scenarios (where this has been outlined in the privacy notice):

* Evaluators and Delivery Partner organisations and other organisations that are funded by us or collaborating with us on projects or pieces of research.
* Independent contractors or suppliers we hire to work on specific projects or pieces of research we conduct or commission.
* The Department of Education (DfE), the NPD and ILR for the purpose of matching as outlined above.

Always refer to the research project Privacy Notice to confirm how your data will be stored, shared, and kept secure.

**8.****How long we keep your data**

We will only keep personal information for as long as it is needed to fulfil the purpose for which it was collected.

The length of time which we plan to keep any information for will be outlined on the privacy notice for each individual project. Wherever possible, personal data will be anonymised or pseudonymised, as long as this does not impair the aims of the project.

When data is no longer needed, unless there is another legal reason for us to retain your personal information, we will securely destroy any paper or digital records (as specified in the privacy notice for any particular project).

Archived data within the ONS SRS shall remain in a pseudonymised OR anonymised form within the archive for an indefinite period of time. The retention of the data in the archive is calculated in accordance with an ONS policy alignment which states the following:

“ONS will delete data if it has been unused for a period of two years and there is no demonstrable research need for it to be retained. If that data had previously been used for research, it will be retained in an archive for five years after it was last accessed to allow for analysis to be repeated.”

We will also review the storage of all data in the archive every 2 years to assess whether there is a continued benefit to storing the data and its potential use in future research. At which time we may either delete the data identified as no longer having benefit for future research or will send a request to the ONS for an extension to the length of time it is retained in the SRS with reasonable explanation on the reason for this extended retention outside the parameters of the ONS policy outlined above.

Article 5(1)(e) of the GDPR permits storage of personal data for longer periods for the purposes of historical research, archiving in the public interest, and statistical purposes. The ICO’s guidance on storage limitation (https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/principles/storage-limitation/#archiving) also indicates that personal data can be held indefinitely for research and archiving purposes, and this is also consistent with the National Archives Guide to Archiving Personal Data (https://www.nationalarchives.gov.uk/documents/information-management/guide-to-archiving-personal-data.pdf).

In his preliminary opinion on data protection and scientific research, published on 6 January 2020, the European Data Protection Supervisor (EDPS) acknowledged that there are few guidelines on the application of data protection rules to scientific research. We have referred to the EDPS’s preliminary opinion when developing our approach to data storage, but we note that further work is taking place within the European Data Protection Board (EDPB) and national authorities on questions of data retention for archiving and research purposes. NEIGHBOURLYLAB will continue to monitor developments in this area and review our approach to data storage and retention to ensure it continues to reflect the law and best practice in this area.

1. **Last update to this Privacy Notice**

This Privacy Notice was last updated in April 2022.

1. **Project & Research Privacy Notices**

NEIGHBOURLYLAB maintains access to all research projects and research privacy notices to maintain transparency and accountability for each research project. Please see the relevant project which can be found by typing the name of the project into the Website search box above. Alternatively, you can send us a message at dpo@whatworks-csc.org.uk