

# Guidance on Sharing Data with Third Parties in a Research Context

**Last updated: 19 January 2021**

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## Introduction

UCL is a world-leading research university, with over 6,000 research staff. Competitively won research grants and contracts account for more than one third of UCL's income and we have developed research partnerships within and beyond the education sector.

UCL will often need to share data with third parties as part of research projects, and this note:

- provides guidance on the key issues UCL departments need to consider where they are part a research project that involves the sharing of data;
- looks in particular at the issues raised where a project involves the sharing of personal data; and
- sets out a standard approach which should be followed by all UCL departments when sharing data (including personal data) in the context of a research project.

This guidance note should be read in conjunction with existing UCL guidance on research and data, including this note on [sharing data after the life of a research project](#).

## Identifying data sharing as part of a research project

Data sharing can take place in a number of ways as part of a research project.

It includes, in particular: the sharing by UCL of data collected or generated directly by UCL; the use by UCL of data that has been collected or generated by third parties such as the NHS, other universities or commercial organisations; and the sharing by UCL of data collected or generated by third parties.

It is important to take the time early on to consider if the research project is likely to involve any sharing of data so that you can consider and address the issues raised as a result of any data sharing before the research project starts.

## Only share data where necessary

UCL should only share data with third parties as part of a research project where it is *necessary* to do so to achieve the objectives of the research project.

If the objectives of your research project can be achieved without sharing data then data should *not* be shared and the rest of this guidance note will not be relevant to the project.

If you have determined that it is necessary to share data to meet the objectives of your research contract then please read the rest of this note for guidance on how that data should be shared.

## The importance of data sharing contracts

Before sharing data with third parties in relation to a research project, you must enter into a contract with those third parties that sets out the terms on which data is to be shared. The contract can either be a stand-alone data sharing contract or form part of a larger, all-encompassing research project contract.

The data sharing terms that will need to be included in the contract will depend upon a number of factors, including where the data has originated from, the types of data to be shared and the reasons for sharing the data.

For template data sharing terms or further advice on terms to include as part of data sharing arrangements, please contact the data protection team at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk).

## General issues to consider when sharing data with third parties

### Consider where the data has originated from

You need to consider where the data you wish to use or share has originated from before you use or share that data. The source from which UCL obtained the data will inform you about the type of restrictions that UCL is likely to be under when using or sharing the data.

For example, where data is obtained by UCL from a third party and you wish to share the data with another party, you must consider the terms upon which the data was given to UCL, including any restrictions imposed on UCL's ability to share the data. If UCL is not permitted to share the data then doing so would put UCL in breach of its obligations to the original third party. Even where UCL is permitted to share the data, there are likely to be contractual restrictions/conditions imposed on UCL dictating how that data should be shared, which must be flowed down to the party with whom UCL shares the data.

### Consider the format in which data should be provided

You should consider the format in which the data will be provided. For example, should the data be shared in a specific format to make it easy to use for all parties and should the shared data be encrypted and subject to specific security measures to help ensure the continued security of the data?

### Consider the type of data to be shared

There are different types of data and, when using and sharing data, not all types are equal. In particular, there may be laws that apply, over and above the general rules, to specific types of data.

The most obvious example of this is personal data – a subset of all of the data held and used by UCL. There are laws that apply specifically to the use and sharing of personal data that UCL must comply with when personal data is being shared as part of a research project.

The rest of this note provides more detailed guidance on the sharing of personal data as part of research projects.

## Determining whether personal data will be shared

### What is personal data?

Before starting a research project, you must determine: whether any personal data will be shared by UCL with another party, or vice versa, as part of the project; and what categories of personal data are to be shared.

Personal data is information that relates to an identified or identifiable living individual. There are different categories of personal data, such as 'special category' personal data and criminal convictions

data, where the rules around using and sharing that data are stricter, which is why it is important to know not only if you are sharing personal data, but also what categories of personal data you are sharing. Further guidance on what constitutes personal data, including 'special category' personal data and criminal convictions data, is available on the [Personal Data Overview](#) webpage.

### Is it necessary to share personal data as part of your research project?

Given the strict laws governing the sharing of personal data, you should only use and share personal data as part of a research project where it is necessary to do so to meet the objectives of the research project.

If the objectives of the project can be met without sharing personal data then you should *not* share personal data with third parties.

In many instances it may be possible to achieve this by amending the data set you intend using for your research project so that it does not include personal data. One of the ways of doing this is through sharing only *anonymous* data or data that has been *pseudonymised* by UCL before it is shared.

Where you are not sharing personal data as part of a research project, we recommend that this fact is expressly stated in the data sharing contract and a term added to the contract that prohibits the third party from attempting to (re-)identify individuals using the UCL data set.

### Anonymisation and pseudonymisation

Anonymous data is data which does not relate to an identified or identifiable natural person. Truly anonymous data is *not* classed as personal data and falls outside the scope of data protection legislation.

It is possible to render personal data anonymous using well-known anonymisation techniques such as data masking (where personal data elements are removed to create a dataset where personal identifiers are not present) and aggregation (where data is displayed as total rather than individual values). However, if an organisation has the ability to (re-)identify the individual (for example, by combining the stripped data with other information it holds) then the data will not be anonymous in the hands of that organisation and the data will still constitute personal data.

Pseudonymisation is the practice of extracting and replacing personal data elements within a data set with a coded reference, known as a *key*, where there is a means of using that key to re-identify the individual. Pseudonymising personal data can reduce the risks to the data subjects from the processing of their personal data and help UCL meet its data protection obligations. However, pseudonymised data will still constitute personal data in the hands of the organisation that holds both the pseudonymised data and the separate key.

UCL's standard approach is that:

- pseudonymised data in the hands of an organisation that has access to the key – or any other means of identifying those individuals – is personal data; and
- pseudonymised data in the hands of an organisation that does not have access to the key – or any other means of identifying those individuals – is anonymous data and will not therefore be classed as personal data. Where pseudonymised data is shared with a third party, the key is not usually provided to the third party as part of the data sharing arrangement.

This means that where UCL shares data that, in the hands of UCL, is either: (i) truly anonymous data, or (ii) pseudonymised data for which UCL holds the key, that data is unlikely to constitute personal data in the hands of the third parties with which UCL has shared the data.

**However, please note that where UCL shares pseudonymised data with a third party acting as a data processor for UCL (where it cannot process data for its own purposes) – that data should still be considered pseudonymised personal data within the scope of GDPR. This is because a processor is considered an ‘extension’ of the controller as UCL will retain the ability to identify the individual from the pseudonym.**

## Genetic materials

Where a research project involves sending or receiving genetic materials, determining whether personal data will be shared may be more complex, although it is likely in most cases that personal data will be being shared.

Under current data protection laws, genetic data is classed as 'special category' personal data and is defined as "*personal data relating to the inherited or acquired genetic characteristics of a natural person which give unique information about the physiology or the health of that natural person and which result, in particular, from an analysis of a biological sample from the natural person in question*". It includes chromosomal, DNA or RNA analysis, or any other type of analysis that enables you to obtain equivalent information.

In its guidance, [What is special category data?](#), on genetic data, the ICO has made the following points clear:

- a genetic sample itself is not personal data until you analyse it to produce some data;
- genetic analysis which includes enough genetic markers to be unique to an individual is special category personal data, even if you have removed other names or identifiers;
- any genetic test results which are linked to a specific biological sample are usually personal data, because the sample is by its nature specific to an individual and provides the link back to their specific genetic identity; and
- there are cases where genetic information is not identifiable personal data. For example, where you have anonymised or aggregated partial genetic sequences or genetic test results (e.g. for

statistical or research purposes), and they can no longer be linked back to a specific genetic identity, sample or profile; a patient record; or to any other identifier.

## Determining each party's status as a controller or a processor (or neither)

### Where personal data will be shared

If personal data will be shared, it is important to determine whether the parties are acting as controllers or processors so that the appropriate terms may be included in the data sharing contract.

A *controller* determines how and why personal data will be processed whilst a *processor* acts only on the instructions of the controller in terms of how they use any personal data.

#### *When will UCL act as a controller?*

UCL will be a controller where it decides how and why personal data is processed. For example, if UCL wishes to investigate a particular healthcare issue and designs a study involving the collection and processing of individuals' medical information, UCL will be a controller in respect of that personal data.

Please note that multiple controllers may be involved in the same research project. For example, UCL may act as the lead institution and work with several universities and commercial organisations on a research project. If each university and commercial organisation uses personal data for both the project and their own purposes, each one will be a controller in its own right.

#### *When may UCL engage processors?*

If UCL engages a third party to conduct a survey or to store personal data collected as part of a research project and that third party is not permitted to use the data for its own purposes, then that third party will be a processor.

#### *What are the implications for the parties' respective statuses if another organisation is required by the contract to send personal data back to UCL?*

If UCL collaborates on a research project with third parties, it is possible that certain conditions may be imposed on the use of personal data by those third parties. For example, there may be a requirement to send results containing personal data back to UCL. This will *not* necessarily mean that the third parties are processors. If the third parties are using personal data for both the project and for their own purposes, they will be controllers for the purposes of current data protection laws, even though they are obliged to share their project results with UCL.

### Where no personal data will be shared

As discussed above, there may be circumstances where personal data held by UCL will not be personal data when shared with a third party – for example, where UCL provides the third party with only a

pseudonymised data set without the necessary tools to be able to (re-)identify the individuals to which the data set relates. In such circumstances, whilst UCL will be a controller of the personal data, the third party will be neither a controller nor a processor since the data in its hands will not constitute personal data.

However, if a third party is engaged with the intention that it processes data for UCL (and cannot process data for its own purposes), it will be a processor even where it does not hold the key to re-identify the data subjects. As explained previously, this is because a processor acts as an extension of the controller who retains the ability to identify the data subjects.

## Putting in place appropriate controller to controller or controller to processor contract terms where personal data will be shared

In addition to general data sharing contractual obligations, it is very important to put in place appropriate data protection terms when sharing personal data with third parties in order to comply with current data protection laws. This includes adding – where applicable – provisions which deal with the transfer of personal data outside the EEA.

UCL has template clauses which should be used in the context of controller to controller and controller to processor transfers of personal data, and when transferring personal data outside the EEA.

For assistance in putting together appropriate controller to controller or controller to processor contract terms for your research project, please contact the data protection team at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk).

## Further information

If you have any questions on this guidance, you would like any further information on this issues raised, or you would like guidance on the data sharing terms you should put in place for a specific research project please contact the data protection team at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk).