

Data Protection Guidance – obtaining and managing consent for research

Please note that this guidance is for obtaining consent for data protection purposes only.

Under the UK General Data Protection Regulation (UK GDPR) 2016 and the Data Protection Act 2018, you must have a lawful basis to process an individual's personal data. These lawful bases are set out by the UK GDPR and are as follows:

- Consent
- Contract
- Legal obligation
- Vital interests
- Public task
- Legitimate interests

The temptation will be to rely on 'consent' as a lawful basis as it appears to be the most straightforward and least problematic. However, this is not necessarily the case and as a default it is recommended that you consider the 'public task' lawful basis (research is a task in the public interest).

However, there will be times where this is not appropriate and consent is necessary as the lawful basis. Where this is the case, the following guidance will assist in ensuring compliance with the UK GDPR requirements of consent management.

Consent form

The best way to obtain an individual's consent is to issue them with a consent form. This form should set out the data to be collected, and indicate how it will be used and who it will be shared with. There should be a box for the individual to sign to confirm their agreement or another way to indicate their consent in the event they cannot sign the document, or for example, the form is in electronic format.

There are several rules which must be followed when collecting consent, otherwise it may be deemed invalid.

Unambiguous

The consent must be unambiguous, so should be clear and concise using plain language and not connected to any other terms and conditions.

Clear and affirmative action

For consent to be valid, the data subject must have taken some clear affirmative action in order to specify their consent. For example, ticking a box or signing their name. Pre-ticked boxes would be constitute valid consent, and neither would statements such as 'returning this document constitutes your consent' or 'if you do not return this form within 7 days, it will be deemed that you consent'.

Granular consent

Where appropriate, the individual should be given the option to consent on a granular level, i.e. different consents for each processing option. It is not envisaged that this will often be appropriate for research purposes, however for more complex processing it might be. For example, one consent option might be for use of the data as part of the research project, however there must be a separate consent option in order to share that data with partners if such sharing is not directly connected to the research. In addition, the same data might be relevant to two areas of the research, and consent should be sought for each of them.

Content of consent forms

As outlined, consent requests must be prominent, concise, easy to understand, and separate from other terms and conditions. For research purposes, this means that, ideally, a data protection consent should be separate from other consents, e.g. for ethics purposes and other forms and documents.

The following should be included:

- Name of the organisation, i.e. Coventry University
- Name of any third party controllers who will rely on the consent, namely those we share the data with
- Whether data will be shared outside of the UK (except the EEA) and how their data protection rights will be protected in that regard
- The purpose of processing the data and what we will do with it
- Confirmation of what will happen to the data after the project has concluded, e.g. it will be destroyed or archived (after having put safeguards into place to protect it, e.g. pseudonymisation), or anonymised. This is important as the individual has a right to know whether their data will remain live at the end of the research.
- Confirmation of withdrawal rights. Included in this should information about what happens to the data at the end of the research, for example if it is destroyed or anonymised, there will be no right to withdraw consent since the data will no longer be personal data so UK GDPR will not apply.

As part of the information provided to the data subject so that they can be fully apprised of what will happen to their data, it is important to advise on what will happen.

The consent must always be 'opt in' so pre-ticked boxes would not be compliant.

Please note that all data protection consent should be recorded to evidence who consented, when and to what.

Consent for scientific research – specificity of use of data

In general, the individual must be given precise information about how their data will be used so their consent can be as informed as possible. However, for the purpose of scientific research, it may not always be possible to be specific about the use of data so instead a statement about the general area of research would suffice. Granular consent options should safeguard against any confusion.

Right to withdraw consent

It is important to remember that where consent is used as a lawful basis, the data subject has a right to withdraw that consent. The consent form must stipulate this, and provide an easy method for them to communicate their withdrawal.

Please note that there are rarely exemptions to withdrawing consent and specifically there is no exemption for scientific research purposes. Consent for ethics purposes can be withdrawn up to a certain stage, however there is no similar provision with respect to data protection consent. Accordingly, if consent withdrawal is likely to cause a problem for your research, consent is not the right lawful basis.

Where an individual withdraws their consent, you do not have to delete or otherwise remove their data – anonymisation is sufficient. This may be a way to avoid interference with your research data.

It is important to include in the consent form and information sheet, information about what will happen to the personal data at the end of the research. You may destroy it, archive it (after having first put safeguards into place, such as pseudonymisation), or anonymise it.