Data Protection Guidance – obtaining and managing consent for research

Please note that this guidance is for obtaining consent for data protection purposes only. You may still be required to obtain consent for research ethics purposes and will have other guidance in that regard.

Background

It is often erroneously assumed that you must have an individual's consent to process their personal data. This is particularly the case with research where you are required to obtain the participant's consent to take part in the research, and over time the two may have become conflated.

Data protection legislation does not specifically require consent; in fact, most of the time consent will not be appropriate. The consent you are required to obtain as part of your ethics process will be purely for that purpose, and using the same consent for data protection purposes may render it invalid.

Lawful basis

Under the UK General Data Protection Regulation (UK GDPR) 2016 you must have a lawful basis to process an individual's personal data. These lawful bases are:

- 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 you should consider the 'public task' lawful basis (research is a task in the public interest).

The problem with consent as a lawful basis

1. Consent can be withdrawn at any time and for any reason, without any exemption for the purpose of research. This could cause problems for your work as it may mean that you have to delete the data earlier than anticipated; this rule applies even if the ethical right to withdraw participation has expired. A good rule of thumb would be that if you would not be able to fully action a withdrawal of consent (for example because deleting data would undermine the research and anonymisation is not possible) you should not use consent as your lawful basis.

2. Consent must be freely given – this may mean that in certain circumstances consent is not valid, for example where we have a particular relationship with the data subject (e.g. employer/employee).

In essence, consent is probably not appropriate where there is another lawful basis as there will be a conflict over competing interests and it is good practice to rely on it only as a last resort, if no other lawful basis exists, but only then if appropriate.

Where consent is to be used as the lawful basis, the following guidance will assist in ensuring compliance with the UK GDPR requirements of consent management.

If you are in doubt about which lawful basis to rely upon, the Information Governance Unit is available for advice and guidance: enquiry.igu@coventry.ac.uk.

Consent form

The best way to obtain an individual's consent is to issue them with a consent form. It can be a physical paper form, or an electronic version. The individual can sign the form or tick a box to confirm their consent. Either way, the information required within the form will be the same.

Unambiguous

The consent form must be unambiguous and easy to understand: its wording should be clear, concise and specific, and use plain, straightforward language. It should adopt a simple style appropriate for your audience, which is particularly pertinent where you are asking children to consent. In this case, parental input may be appropriate. You should avoid technical jargon and confusing terminology, and use consistent language.

Data protection consent should be separate from, and unconnected to, other consents and other terms and conditions: you should not use the same consent for data protection purposes as for ethics purpose. It is appropriate to use the same document for different consents, however the data protection consent should be on a completely separate page, ideally at the end of the document, and clearly identified as being for data protection purposes.

Clear and affirmative action

The data subject must have taken some clear affirmative action in order to confirm their consent, for example, ticking a box or signing their name. Pre-ticked boxes would not 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, you should obtain one consent for use of the data as part of the research project, and a separate consent to:

a) share that data with partners if such sharing is not directly connected to, and not required for, the research;

b) collect the individual's email address so they can receive a copy of the final research for their interest;

c) use the same data on another area of research.

This idea of separating consent can equally apply to separating the lawful basis, for example you may rely on the 'public task' lawful basis in order to undertake the research, but require consent to collect the individual's email address so they can see the results. Giving them access to the results is unlikely to fall within the public task remit, so we need to identify another lawful basis.

Content of consent forms

The following should be included in every consent form:

- Where possible and easy to identify, the particular data to be collected.
- The name of the organisation, e.g. Coventry University and the name of any third party controllers/processors who will rely on the consent, i.e. those we share the data with.
- The purpose of processing the data, i.e. what we will do with it. It is recognised that with a lot of research you cannot be precise with this information, however as much information as possible should be given (see below for further information).
- Confirmation of withdrawal rights: how and when. You should explain that these rights only apply for as long as the data remains personal data, so if it is anonymised at the end of the research, there is no right to withdraw consent since the data will no longer be personal data. You should provide a contact, preferably an email address, to send withdrawal requests to.

Other information can be included where necessary, however this is likely to be included a Privacy Notice, for example:

- Whether data will be shared outside the UK and EEA, and how the data will be protected in that regard.
- Confirmation of what will happen to the data after the project has concluded, e.g. it will be destroyed, archived or anonymised.

Recording of consent

All data protection consent should be recorded to evidence who consented, when and to what. These records should be kept separate from the main research data.

Consent forms for research purposes – 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 research, it may not always be possible to be specific about this use so instead a statement about the general area of research would suffice.

A further word on the 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 at any time and for any reason. 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 research purposes. Participant consent can be withdrawn up to a certain stage, but there is no similar provision with respect to data protection consent.

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.

Use of previously collected personal data

If you would like to use previously collected data for a new purpose, for example use the information collected on one study for the purpose of another unconnected study, you can only do so if that data is anonymised or if each individual consents to the new use. The scope of the original consent may extend to the new processing notwithstanding that the study is new, and you should seek advice from IGU in that regard.