

Data Protection Consent Guidance

GDPR impact on research activities

GDPR = General Data Protection Regulation 2016. New data protection legislation replacing the Data Protection Act 1998 from 25th May 2018. Intends to strengthen and unify data protection for all individuals within the European Union (EU).

GDPR will affect the way researchers collect, analyse and transfer research data, which includes processing personal data/sensitive personal data (special categories of data).

Useful definitions:

Data Controller: determines the purposes and means of processing personal data. E.g., Coventry University will be the data controller, not the researcher personally.

Processing - an operation (or set of operations) which is performed on personal data (or on sets of personal data), such as: collection, recording, organisation, structuring, storage, adaption, alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, restriction, destruction or erasure.

Personal data - any information relating to an identified or identifiable natural person ('data subject') who can be directly or indirectly identified in particular by reference to an identifier. This definition provides for a wide range of personal identifiers to constitute personal data, including name, identification number, location data or online identifier.

Special categories of data: personal data, which the GDPR says, is more sensitive, and so needs more protection. Racial or ethnic origin, political opinions, religious or philosophical beliefs, trade union membership, genetic data, biometric data for the purpose of uniquely identifying a natural person, health, sex life and sexual orientation.

Consent forms/Participant Information Sheet (PIS) Data Protection Compliance:

Where you use a consent form and PIS in accordance with Ethics requirements, and consent/explicit consent is also your legal basis for processing the personal data or special categories of data in accordance with the GDPR, please ensure across these documents the following are included in order to be GDPR compliant:

- State the data controller's name Coventry University or CU College, etc.
- State what type of data you will collect and use
- State the purpose(s) for processing and the processing types i.e. why you want the data and what you're going to do with it, including listing any recipients of that data
- If there is more than one purpose, consent should be given for all purposes, otherwise it is not freely given. *Exception for scientific research – data subjects can give their consent to certain areas of scientific research when in keeping with ethical standards for scientific research*
- Consent should be freely given - the data subject should have real choice to participate in the research project not feel compelled to or risk negative consequences for refusing consent
- Keep your consent requests separate from other terms and conditions
- Use clear and plain language that is easy to understand and be concise
- In order to obtain "informed consent" from a child you must explain in language that is clear and plain for children, how you intend to process the data you collect

- You cannot rely on implied or opt-out consent i.e. ask people to positively opt-in. DO NOT USE PRE-TICKED OPT-IN BOXES!
- You must tell the individual how long you will store or otherwise process their data. You can use months, years, etc. or a formula, but the general rule is the retention period must not be longer than the purpose.
- Right to withdraw consent at any time – make it easy for people to withdraw consent. Tell them they have the right to withdraw and how to do it. If they withdraw, any processing prior to the request shall not affect the lawfulness of the processing that is based on consent before its withdrawal. If you plan to anonymise the data and therefore can't give effect to the data subject's withdrawal rights, explain in the PIS the timeframe which they can withdraw the data, i.e. when the data can still identify them, and when you plan to anonymise and therefore can no longer give effect to their withdrawal rights. Please avoid using individual email addresses because in the event of absence you may be unable to action the request.
- Do not penalise individuals who withdraw consent
- Consent must be verifiable – who, when, how and what you told individuals. The burden of proof for valid consent is on the data controller – YOU have to show the data subject consented. Keep a copy, whether hard or electronic (not both) in a local University repository with appropriate security controls
- Name your organisation & any third party organisation who is also a data controller relying on the consent. **You must contact the IPU before you share data with a third party organisation.**
- If the consent relates to transfers outside of the EEA, tell the data subject about the possible risks of data transfers to third countries in the absence of an adequacy decision and appropriate safeguards. You will need explicit consent for this (please see below for further information on explicit consent). **You must contact the IPU before you store or otherwise process data outside of the EEA.**
- If you are collecting consent by electronic means, the request must be clear and concise. Layered and granular information can be an appropriate way to deal with the two-fold obligation of being precise and complete on the one hand and understandable on the other hand
- Keep consent under review to check that the relationship, the processing and the purposes have not changed and refresh it anything changes

If you rely on explicit consent as the legal basis for processing special categories of data, as well as the above, you need a very clear and specific statement of consent, rather than by any other positive action, e.g. just an opt-in tick box is not enough.

If offering online services to children please contact the IGU enquiry.igu@coventry.ac.uk early on in your project for further advice as you must have age-verification measures (and parental-consent measures for younger children) in place