

Guidance

Not processing in ways that are likely to cause substantial damage or distress to individuals;

Not supporting measures or decisions with respect to individuals; and

Having the assurance that research ethics committee approval is in place where needed.

UCL's view is that the ethics application, data protection registration process and review itself will help ensure that the research is in the public interest.

In circumstances where it is not possible to rely on Article 9(2)(j) GDPR, it may be possible to establish that another condition under Article 9(2) GDPR applies. Examples of alternative conditions include the following:

Article 9(2)(a) - the research participant has given explicit consent to the processing of the personal data for one or more specified purposes. (Note that consent as a lawful basis should only be used if no other condition applies, as

As is the case with 'special category personal data', it may be possible to rely on an alternative basis for processing, although this is not UCL's recommended approach.

Researchers should justify why they wish to rely on any condition other than Article 9(2)(j) GDPR.

E. Consent and ethical issues

In order to obtain ethical approval for a project and to comply with accepted ethical standards for research, researchers will generally still need to obtain the informed consent of individual participants for their involvement in the research. GDPR recital 33 notes that research must act in a manner that is 'in keeping with recognized ethical standards for scientific research', and the UCL REC and other ethical review boards will usually expect informed consent.

In effect in order to use personal data for research you need two bases; the legal basis (GDPR) and the ethical basis (informed consent). For example, a person may be asked to consent to participate in research (ethical basis) and told that, if they agree to participate, data about them will be processed for a task in the public interest (legal basis). Here, the legal basis for data processing will be 'public task' rather than consent.

While consent to participate in a project that is obtained for ethics purposes must be fully informed and freely given, in addition to meeting other requirements, researchers do **not** therefore need to obtain consent that meets the high standards set out in the GDPR, which is:

any freely given, specific, informed and unambiguous indication of the data subject's wishes by which he or she, by a statement or by a clear affirmative action, signifies agreement to the processing of personal data relating to him or her

F. Fairness and transparency

The GDPR requires UCL to use personal information in a fair and transparent manner. Treating research participants fairly and transparently is also important from an ethics perspective, and to ensure that any disclosure of confidential information meets the requirements of the common law duty of confidentiality.

Researchers must be as transparent as possible about the uses to which data will be put and any risks involved. This usually requires that the research participant is provided with appropriate information about how and why their data will be processed through the provision of an Information Sheet. Participants can then give their 'fully informed' consent to take part in the research.

The Information Sheet must include the legal basis relied upon for the processing (as stated above, this will generally be the 'public task' basis). For clarity, researchers who process 'special category personal data' as part of their project must state both the Article 6 and the Article 9 GDPR conditions they are relying on in both their ethics application and in the information they supply to participants. For criminal convictions/offences personal data, the basis under established under both Article 6 and Article 10 GDPR and must be documented in the ethics application and in the information supplied to research participants

Information provided to participants must be:

Concise, transparent, intelligible;

Provided in easily accessible form, using clear, plain and simple lay language;

Prepared with consideration of the audience e.g. information addressed specifically to a child; and

Provided by an appropriate means (e.g. in writing, orally, electronically).

We hope that you find this guidance helpful. If you require any further information on the issues raised in this document, please use the following contact details:

For **data protection enquiries**, please contact the data protection team at data-protection@ucl.ac.uk; or

For **ethics enquiries**, please contact the ethics team at ethics@ucl.ac.uk.