

Privacy Notice for Research Participants -University level

This Privacy Notice outlines how the University of Kent collects, uses and manages the personal information of individuals in accordance with data protection law.

The University of Kent is registered as a 'Data Controller' under registration number Z6847902. [View the full entry on the register](#)

Please read the **Participant Information** which accompanies this Privacy Notice provided by the research team conducting the research. It provides specific details about the project and the further additional information we are required to provide to you.

How we use your personal information

As a university we use personally-identifiable information to conduct research, including to improve health, care and services. As a publicly-funded organisation, when we use personally-identifiable information from people who have agreed to take part in research, we do so in the public interest.

This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. The ICO has provided [guidance](#) on typical processing activities in research. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate.

If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

The [University Charter](#) sets out that *'the objects of the University are to advance education and disseminate knowledge by teaching, scholarship and research for the public benefit'* (paragraph 3). This underlies the University's use of the personal data provided by research participants for research and evaluation in the public interest under the United Kingdom General Data Protection Regulation (UK GDPR) and (where applicable) the EU GDPR lawful basis: 'task carried out in the public interest'.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the [UK Policy Framework for Health and Social Care Research](#) for our research projects involving health and care.

For specific information about the following, please refer to the **Participant Information** which is given to you when you agree to participate in a particular research study:

- types or categories of personal data processed
- the source of the personal data (if not provided directly by you)
- the purposes of the processing
- any other lawful basis relied for specific processing activity that is outside our primary 'public task' basis and the 'research purposes' exemption for special category data
- the recipients or categories of recipients of the personal data
- the details of overseas transfers of personal data (including the transfer mechanism used to legalise the transfer if applicable)
- the period for which the personal data will be retained
- details of the existence of any automated decision making, including profiling. In this context automated decision making refers to use of personal data in machine learning or other technologies that will result in a decision about the individual, e.g. a diagnosis. Electronic randomisation technologies are not included.¹

We are usually the Data Controller for research studies meaning that we will decide how your personal information is used and why. If any other organisation will make decisions about your information this will be made clear in the **Participation Information Sheet** provided to you.

Our lawful basis for processing your data

We rely on the following lawful basis as allowed by the UK GDPR for processing your personal data as this is necessary for:

- the performance of a task carried out in the public interest or in the exercise of official authority -Article 6(1)(e)

Where we also use your special category data (which is information about your race, ethnic origin, political opinions, religious or philosophical beliefs, your trade union membership, your genetic or biometric data (used to uniquely identify you), your health data or data concerning your sex life or your sexual orientation) we must identify a further basis for processing that data.

¹ As referenced in HRA guidance: <https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-guidance/what-law-says/transparency/>

Our further basis is that the processing is necessary for:

- archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) as supplemented by section 19 of the Data Protection 2018 Act based on domestic law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject – Article 9(2)(j)

This basis requires that appropriate safeguards for your rights and freedoms must be in place (such as appropriate staff training) and organisational and technical security measures (such as policies, firewalls or pseudonymisation). Wherever possible your personal information will be de-identified (anonymised), pseudonymised (directly identifiable information such as your name is removed and replaced with a unique code or key) or deleted as soon as possible. You will be informed about storage in the **Participant Information** provided.

This lawful basis also means the research must not be likely to cause substantial damage or distress to you. Where special category data is processed on this basis it must be in the public interest. Research ethics committee approval processes will help to address these considerations.

The research must also not be carried out for the purposes of decisions about an individual person or their care, unless the processing is for medical research approved by a research ethics committee.

Special category and criminal offence data (if processed) is carried out under the research condition in Schedule 1 of the Data Protection Act 2018 and is therefore subject to similar public interest and data minimisation requirements being put in place.

We have a Special Category and Criminal Offence Data Appropriate Policy document in place throughout the time that we use your data and for 6 months after we cease to use it.

What about consent?

It is important to note that the fact that the research will seek your consent to participate in a research study does not mean that consent is the most appropriate lawful basis for processing personal data under UK GDPR. The two types of consent are distinct. Even if there is an ethical or legal obligation to get consent from participants, this should not be confused with UK GDPR consent.

Who your information will be shared with

We use products or services from third party organisations (known as data processors) who carry out services on the University's behalf under contract (for example, data stored within MS Teams is processed by Microsoft on behalf of the

University). We will ensure that only the minimum amount of relevant personal data necessary for the purpose of using these services is transferred. We will ensure that contractual agreements exist to ensure compliance with data protection regulations and that data is used solely under our instruction. In these circumstances personal data shall be deleted after the contract has terminated.

The University uses Microsoft 365 as its main IT system and therefore Microsoft is a data processor. Personal data processed in our Microsoft 365 tenancy is hosted within the UK.

For more information please see:

<https://www.microsoft.com/licensing/docs/view/Microsoft-Products-and-Services-Data-Protection-Addendum-DPA>

Occasionally the University may, if appropriate, legitimate and necessary, rely on relevant exemptions to UK GDPR provisions as are allowed under the [Data Protection Act 2018](#) (in relation to the exemptions for research and statistics).

Very rarely it is necessary for your personal information to be shared:

- with competent authorities (such as the police, NCA) or action fraud for law enforcement purposes (for on substantial public interest reasons – Article 9(2)(g) – for preventing or detecting unlawful acts, safeguarding or fraud purposes.
- with our professional advisors where it is necessary for the establishment, exercise or defence of legal claims – Article 9(2)(f).

Transfer of your information outside of the UK

When it is necessary for us to transfer your personal information across national boundaries to a third party data processor, such as one of our service providers, we will ensure this safeguards your personal information by requiring such transfers are made in compliance with all relevant data protection laws.

Personal data is either stored via our on-premise file storage or in our Microsoft 365 tenancy (managed by Microsoft), hosted within the UK.

How long your personal data will be kept

We will keep your personal data in an identifiable form for no longer than is necessary for the purposes and as detailed in the **Participant Information** provided to you separately.

Generally, personal data may be stored for longer where it is:

1. Solely processed for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes;
2. Pseudonymised or anonymised as far as possible to ensure appropriate data minimisation; and

3. Appropriate technical security and organisational measures (such as training and organisational policies) are in place to ensure that we safeguard your rights and freedoms.

Security

We will ensure that security measures are in place to prevent the accidental loss, unauthorised use or access to your data. Access is given to staff on a 'need to know' basis. Our staff are required to keep your data safe and complete data protection training.

Under the data protection legislation, there is a requirement to implement safeguards for personal data for research². This means we will give consideration to the arrangements for security and storage of personal data and ensure that data are pseudonymised or anonymised wherever possible and that data is only collected when needed (known as 'data minimisation'). If we can undertake some of our research activities without using identifiable personal data, we will make arrangements to do so.

We have procedures in place to deal with any data security incidents and will notify you and the ICO in the event of a data breach where we are required to do so.

Your rights

If you wish to exercise your rights or raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

Please be aware of the following rights which can be accessed free of charge by contacting dataprotection@kent.ac.uk:

- to object to direct marketing
- to complain to the ICO

In some circumstances you also have the following rights, however in a research context these may be limited:

- know how we are using your personal information and why (right to information)
- access the personal data held by us (subject access request)
- ask for correction of any mistakes (rectification)
- restrict us from using your information.

(The above rights may be exempted to the extent that the application of the rights would prevent or seriously impair the research purposes and where the personal

² [Section 19](#) of the Data Protection Act 2018 and [Article 89](#) UK GDPR

data is pseudonymised/other de-identification techniques are used and the research results are not available in a form which identifies you.)

- object to how we are using your information (an exception for research is built into the right)
- ask us to delete information about you ('the Right to be forgotten' does not apply to public task processing; or to processing carried out for archiving purposes in the public interest, scientific or historical research or statistical purposes if the erasure seriously impairs the research objectives or makes them impossible)
- have your information transferred electronically (not applicable to research carried out under public task or on a legitimate interests basis)
- object to automated decisions which significantly affect you.

For further guidance regarding your rights please see the [ICO website](#).

Where you have given consent or explicit consent for a specific use of your personal data

If the **Participant Information** provided by your research team indicates that they are relying on consent as an additional lawful basis for a separate processing activity (for example for a limited purpose such as sending you emails about future projects), you can withdraw your consent at any time. You can do this by contacting the researcher named in the **Participant Information** provided which is specific to the research project you are participating in. This does not affect the lawfulness of the processing based on consent before its withdrawal.

Your right to complain to the Information Commissioner

You have the right to lodge a complaint with the [Information Commissioner's Office](#). Their helpline telephone number is: 0303 123 1113.

Contacts

If you have any questions or concerns about the way the University has used your data, or wish to exercise any of your rights, please consult our [website](#).

The University's Data Protection Officer can be contacted at:
dataprotection@kent.ac.uk

Document review

This privacy notice will be reviewed at least annually.

Version	Author	Description of Change	Date	Next Review date
1				
2	DPO	Addition of paragraph 'For specific...profiling/ Updating DPO email address	09.22	09.23
3	Acting DPO	Moved existing text to standard PN template. Added link to University Charter and the UK Policy Framework for Health and Social Care Research and ICO's guidance on research activity. Added reference to the UK GDPR/EU GDPR. Added fourth bullet regarding additional lawful bases. 2 nd & 3 rd sentences added to last bullet and footnote added. Paragraph about role as a data controller and 'What about consent?' added. Wording added from HRA guidance Additional wording on research related safeguards under 'security' adapted from: https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/data-protection-and-information-governance/gdpr-guidance/what-law-says/safeguards/ Template rights section amended to reflect rights relating to public task and research purposes. Qualified addition to standard 'consent' paragraph added. Deletion of 'Wording adapted from the Heath Research Authority GDPR guidance' https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/dataprotection-and-information-governance/gdpr-guidance/templates/template-wording-for-generic-information-document as link broken	06.23	06.24