**Examples of GDPR wording to go in participant information sheet**

Simon Kolstoe, December 2024

Please note this document is not providing legal advice. You need to consider how DPA2018/UK GDPR principles relates to your specific research and adapt this text accordingly.

Whenever you process (collect, use, store, destroy) personal or special category data in your research, you need to have a lawful basis for that processing. Of the legal bases listed in the GDPR, there are two that are most relevant for research:

1) “*When the processing is carried out in the public interest*” is recommended by the Information Commissioners Office (ICO) and also organisations such as the Health Research Authority (HRA). **Note that this does not remove the requirement for seeking consent for participants to actually take part in the research which almost *always* is still needed (in addition to the lawful basis for handling data - which this document addresses).**

2)“*With the individual’s consent*”. While this has historically been the recommended legal basis it is no longer recommended by the ICO or HRA, This is based on experience from clinical trials where medical/safety data is needed to be kept for indemnity or other purposes, and thus it might be unsafe (both medically and legally) for participants to withdraw their data. Note again, that the consent we are talking about here **relates to data use and retention**, not to withdrawing from the research itself. It is important to note that the law distinguishes consent for data use from consent for other research activities.

The following text can be used in participant information sheets as a way of providing the information to potential participants that the GDPR requires:

***1) RECOMMENDED: When “performance of a task carried out in the public interest” is the legal basis:***

***How will we use information about you?***

The [enter name of department /school /project team etc] of the University of Portsmouth wishes to process your personal data (that is, collect, use, store and destroy data that identifies you) as part of the [enter name of the project / survey / reason for requiring the data]. If you have any queries about this [project / survey / other reason for processing] please contact [enter contact details of someone in the dept / school or project team etc] or if you have any general queries about how your data will be processed, please contact the University’s Data Protection Officer, Samantha Hill, using any of the following contact details:

Samantha Hill, 023 9284 3642 or data-protection@port.ac.uk, Mercantile House, Hampshire Terrace, Portsmouth, PO1 2EG

The [enter name of department /school /project team etc] legal basis for processing your personal data is that the processing is necessary for the performance of a task carried out in the public interest – that is, scientific or historical research purposes. If you withdraw from this research study we may still rely on this lawful basis to continue using your data if your withdrawal would be of significant detriment to the research study aims. We will always have in place appropriate safeguards (secure computer systems, encryption etc.) to protect your personal data.

Your personal data will be held securely on [University servers / held on paper in cabinets] for [how long do we keep the data in a way that can identify anyone?], and securely destroyed after that date. [If we might keep the information anonymously after this date it is best to explain that here and why we might do this]. Include here either i) [Your data will not be shared outside the UK] or ii) [We may share data about you outside the UK for research related purposes such as \*sharing information with our research partners, sharing results with our research funders … (\* delete, amend or add to, as required) We will make sure your data is protected.

Anyone who accesses your data outside the UK will only do so in ways that respect our levels of data protection. We will make sure your data is safe outside the UK by doing the following [DELETE AS APPLICABLE]:

* (some of) only sharing your data with countries which have an adequacy decision in place. This means that we know their laws offer a similar level of protection to data protection laws in the UK
* we use specific contracts approved for use in the UK which give personal data the same level of protection it has in the UK. For further details [visit the Information Commissioner’s Office (ICO) website](https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/international-transfers/)
* requiring other organisations to have appropriate security measures to protect your data which are consistent with the data security and confidentiality obligations we have. This includes having appropriate measures to protect your data against accidental loss and unauthorised access, use, changes or sharing
* we have procedures in place to deal with any suspected personal data breach.  We will tell you and applicable regulators when there has been a breach of your personal data when we legally have to. For further details about UK breach reporting rules [visit the Information Commissioner's Office (ICO) website](https://ico.org.uk/for-organisations/report-a-breach)
* [OTHER]

***What are your choices about how your information is used?***

 You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

OPTION: If follow up data will be collected after withdrawal: If you choose to stop taking part in the study, we would like to continue collecting information from [central NHS records / your hospital / your GP/ etc.]. If you do not want this to happen, tell us and we will stop.

You have the right to ask us to remove, change or delete data we hold about you for the purposes of the study. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this. For more information on your rights in general, please see the information on the following link: https://www.port.ac.uk/about-us/structure-and-governance/legal/data-protection-and-gdpr/requesting-your-data

OPTION: If data will be used for future research: If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study. [Insert details of any specific bank / repository and ensure that there is a consent item for this]

You also have the right to lodge a complaint about the use of your personal data to initially the University (email data-protection@port.ac.uk) and then, if you are unhappy with our response, to the Information Commissioner’s Office (ICO) – for more information please see <https://ico.org.uk/your-data-matters/raising-concerns/>.

***2) When “consent” is the legal basis (N.B. No longer recommended):***

The [enter name of department /school /project team etc] of the University of Portsmouth wishes to process your personal data (that is, collect, use, store and destroy data that identifies you) as part of the [enter name of the project / survey / reason for requiring the data]. If you have any queries about this [project / survey / other reason for processing] please contact [enter contact details of someone in the dept / school or project team etc] or if you have any general queries about how your data will be processed, please contact the University’s Data Protection Officer, Samantha Hill, using any of the following contact details:

Samantha Hill, 023 9284 3642 or data-protection@port.ac.uk, Mercantile House, Hampshire Terrace, Portsmouth, PO1 2EG

We ask for your consent to process the data we ask for in the [project / survey / other reason for processing], so that we can conduct the research as described in the participant information sheet. We will only share your personalised data with [enter here anyone with whom we might share the data outside of the University if relevant].

Your personal data will be held securely on [University servers / held on paper in cabinets] (we [will/will not] store your data outside the EU) for [how long do we keep the data in a way that can identify anyone?], and securely destroyed after that date. [If we might keep the information anonymously after this date it is best to explain that here and why we might do this].

You have the right to ask us to remove, change or delete data we hold about you for the purposes of the study. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this. For more information on your rights in general, please see the information on the following link: https://www.port.ac.uk/about-us/structure-and-governance/legal/data-protection-and-gdpr/requesting-your-data

You also have the right to lodge a complaint about the use of your personal data to initially the University (email data-protection@port.ac.uk) and then, if you are unhappy with our response, to the Information Commissioner’s Office (ICO) – for more information please see <https://ico.org.uk/your-data-matters/raising-concerns/>.

***3) Additional requirement in consent form***

In addition to the relevant text (above) being present in your participant information sheets, please include the following in your consent form alongside a yes/no option or tick box, and the usual signature and date line at the bottom of the consent form:

* I understand that data collected during this study will be processed in accordance with data protection law as explained in the Participant Information Sheet [version number]