**[*DRAFTING NOTES ARE INCLUDED IN SQUARE BRACKETS IN BOLD ITALICS*]**

**[*This privacy notice is drafted to comply with data protection legislation (including GDPR) and mandated HRA transparency wording that must be provided to participants*]**

**[*The highlighted fields will need to be completed on a case by case basis. Depending on the nature of the study (i.e. whether personal data or anonymised data is being used) there is a choice of paragraphs at Sections B and C.*]**

**[*Personal data is any information relating to (1) an identified participant (e.g. you have their name) or (2) a participant who is identifiable (i.e. you hold data that could identify the individual by means reasonably likely to be used taking into factors such as cost, time, available technology – for example, if you had a NHS number then the participant is identifiable. A correctly implemented code system should not result in the participant being identifiable and, in such cases, health data would not qualify as personal data). However, even where the data is anonymised, the HRA states that participants should still be provided with clarity over how their data will be processed*]**

**[IMPERIAL COLLEGE LETTERHEAD]**

**PARTICIPANT PRIVACY INFORMATION**

**Research Study Title:** [insert title]

[insert ID if applicable e.g. IRAS ID or other relevant ID]

Imperial College Londonis the sponsor for this study based in [the United Kingdom]. We will be using information from [you and/or your medical records] in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Imperial College London will keep identifiable information about you for:

* [insert number of years] after the study has finished in relation to data subject consent forms.
* [insert number of years] after the study has completed in relation to primary research data.

Further information on Imperial College London’s retention periods may be found at https://www.imperial.ac.uk/media/imperial-college/administration-and-support-services/records-and-archives/public/RetentionSchedule.pdf.

**[*The retention periods specified above follow the MRC guidelines and are as specified in the College’s retention policy. Studies which propose a retention period for research data for longer than 20 years should include valid justification, although the MRC acknowledge that 25 years may be appropriate for clinical studies*]**

A link to Imperial College London’s data protection webpage may be found at https://www.imperial.ac.uk/admin-services/legal-services-office/data-protection/ but this is the notice most applicable to the information provided by participants and therefore takes precedence for all purposes described hereunder.

**YOUR RIGHTS**

Your usual statutory rights to access, change or move your information are limited, because of exceptions applicable to some types of research, and also because we need to manage your information in specific, lawful 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.

**LEGAL BASIS**

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

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.

**INTERNATIONAL TRANSFERS**

There may be a requirement to transfer information to countries outside the European Economic Area (for example, to a research partner). Where this information contains your personal data, Imperial College London will ensure that it is transferred in accordance with data protection legislation. If the data is transferred to a country which is not subject to a European Commission (**EC**) adequacy decision in respect of its data protection standards, Imperial College London will enter into a data sharing agreement with the recipient organisation that incorporates EC approved standard contractual clauses that safeguard how your personal data is processed.

**CONTACT US**

If you wish to raise a complaint on how we have handled your personal data or if you want to find out more about how we use your information, please contact Imperial College London’s Data Protection Officer via email at dpo@imperial.ac.uk, via telephone on 020 7594 3502 and via post at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ.

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). The ICO does recommend that you seek to resolve matters with the data controller (us) first before involving the regulator.

***[Choose as applicable Section A or Section B (HRA-mandated wording):]***

**[A] [*Use where participants are providing personal data directly (i.e. personal data is obtained for the primary purpose of research either verbally or in writing from participants e.g. questionnaires or interviews, or documented by care staff e.g. diagnosis, or obtained from care interventions e.g. lab results)*]**

[NHS/other site] will collect information from [you and/or your medical records] for this research study in accordance with our instructions.

**[*USE EITHER Paragraph A1 or Paragraph A2*:]**

**[A1] [*If a code system is used and the key is kept confidential and not disclosed to Imperial College London, except where Imperial College London is also the site providing the data (i.e. anonymised data is being used)***]

[NHS/other site] will keep your name, [NHS number] and contact details [*add other identifiers collected by NHS/other site if applicable*] confidential and will not pass this information to Imperial College London. [NHS/other site] will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from Imperial College London and regulatory organisations may look at your medical and research records to check the accuracy of the research study. Imperial College London will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name, [NHS number] [, *include any other identifiers added above*] or contact details.

[NHS/ other site] will keep identifiable information about you from this study for [20] years after the study has finished.

***[The NHS/other site’s retention period should be checked and amended as appropriate]***

**[OR:]**

**[A2] [*If the College will receive personal data, or where the sponsor is also the site. Note that participant contact information provided to the College should only be provided to staff who need it and should not be passed to researchers who are conducting analysis*]**

[NHS/other site] will use your name, [NHS number] and contact details [*add other identifiers collected by NHS/other site if applicable*] to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Individuals from Imperial College London and regulatory organisations may look at your medical and research records to check the accuracy of the research study. [NHS/other site] will pass these details to Imperial College London along with the information collected from [you and/or your medical records]. The only people in Imperial College London who will have access to information that identifies you will be people who need to contact you to [*insert reason if applicable*] [or] audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name, [NHS number] [, *include any other identifiers added above*] or contact details.

[NHS/ other site] will keep identifiable information about you from this study for [20] years after the study has finished.

**[*The NHS/other site’s retention period should be checked and the period above amended as appropriate*]**

**[B] [*Where participants are providing information indirectly e.g. being obtained from previously collected medical records or database*]**

**[*USE EITHER Paragraph B1 or Paragraph B2*:]**

**[B1] [*If a code system is used and the key is kept confidential and not disclosed to the College (i.e. anonymised data is being used)*]**

Imperial College London will collect information about you for [research/this research study] from [source]. [Source] will not provide any identifying information about you to Imperial College London. We will use this information to [i*nsert the purpose of the research/research study*].

**[*OR:*]**

**[B2] [*If the College will receive personal data*]**

Imperial College London will collect information about you for [research/ this research study] from [source]. This information will include [your name, NHS number, contact details, *add any other types of personal data collected not including health data*] and health information, which is regarded as a special category of information. We will use this information to [*insert the purpose of the research/research study*].

**[C] *If applicable use this HRA-mandated wording where data is intended to or likely to be used for future research*]**

When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research (https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/).

***[USE EITHER Paragraph C1 or C2]***

**[C1] [*Use where no personal data is held in the research study data set and it won’t be combined with other data sets in a way that could identify the participant (i.e. it will remain anonymised data)*]**

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.

***[OR:]***

**[C2] [*Use where personal data is held (i.e. the participant is identified or identifiable) in the research study data set – ‘identifiable’ means the individual can be identified by means reasonably likely to be used taking into factors such as cost, time, available technology)*]**

Your information could be used for research in any aspect of health or care, and could be combined with information about you from other sources held by researchers, the NHS or government.

Where this information could identify you, the information will be held securely with strict arrangements about who can access the information. The information will only be used for the purpose of health and care research, or to contact you about future opportunities to participate in research. It will not be used to make decisions about future services available to you, such as insurance.

Where there is a risk that you can be identified your data will only be used in research that has been independently reviewed by an ethics committee.