BDAU SE PRIVACY NOTICE

This privacy notice applies to all studies conducted solely within the Imperial College Big Data and Analytical Unit (BDAU) Secure Environment (SE) on pseudonymised data provided by external data providers for the purposes of healthcare research. It does not apply to data processed outside this environment. In cases where data which potentially identifies a natural living person having previously been covered by this privacy notice is transferred outside the BDAU SE a new privacy notice will be generated and distributed as required.

The BDAU is a part of the Centre for Health Policy (CHP) as part of the Institute for Global Health Innovation (IGHI) which is part of Imperial College London. Imperial College London is the sponsor for this study and use of personal data, including pseudonymised record level data. Data associated with this study will be processed solely in the BDAU SE with computer and data assets residing solely in the United Kingdom. However, for certain studies with the appropriate approvals in place, processing may also be undertaken in countries within the European Economic Area (EEA) or worldwide. The processing location for any study covered by this privacy notice can be provided on request.

Data will be held within the BDAU SE for only as long as necessary to complete the processing of the data. Typically, this is limited to 12 – 36 months depending on the project. The BDAU can provide the data retention start and end dates for any dataset covered by this privacy notice on request. Furthermore, data can be destroyed at the request of the data provider according to the terms and conditions of the data processing or data sharing agreement with that entity. Further information on Imperial College London's default retention periods may be found at https://www.imperial.ac.uk/media/imperial-college/administration-and-support-services/records-and-archives/public/RetentionSchedule.pdf. Long-term retention will apply only to data anonymised according to ICO guidance which falls outside the remit of General Data Protection Regulation (GDPR).

This privacy notice only covers the use of pseudonymised data in which every reasonable effort has been made to de-identify any natural persons and prevent re-identification of such individuals by the processors of the data. For data which is identifiable a separate privacy notice will be required and this notice will not apply. Personnel involved in processing of data will make no attempt at any time to re-identify individuals from de-identified data. Any suspected or actual re-identification will immediately be reported back to the data provider as a breach within the guidelines of breach reporting as per GDPR.

The BDAU SE is an ISO 27001:2013 certified research environment which provides appropriate safeguards both in terms of technological security but also in terms in process and procedure relating to the use of your information. Access to data is allowed only to persons with appropriate legal obligations to maintain the protection of that data and those persons are trained on how to appropriately handle data. Furthermore, data is reduced to the minimum required dataset for the purposes of processing as per GDPR guidance. Datasets created as a result of processing are fully anonymised according to ICO guidance which then permits their onward use for secondary purposes such as publications and other academic outputs.

Data processing in the BDAU SE complies with all guidance provided by Imperial College London. A link to Imperial College London's data protection webpage may be found at https://www.imperial.ac.uk/admin-services/secretariat/information-governance/data-protection/ but this is the notice most applicable to the information provided by participants and therefore takes precedence for all purposes described hereunder.

PROCESSING OF DATA

Data is processed in the BDAU SE for the purposes of healthcare research. This includes de-identified patient level analysis of personal information related to health outcomes. List of current studies conducted within the BDAU SE (BDAU SE Research Registry) can be downloaded from the BDAU webpage at https://www.imperial.ac.uk/media/imperial-college/institute-of-global-health-innovation/centre-for-health-policy/BDAU-SE-Research-Registry.xlsx. This list is updated regularly. Specific purposes of processing can be obtained for any study on request as these are published in several public registers depending on study. Examples include the NHS England Data Uses Registers (https://digital.nhs.uk/services/data-access-request-service-dars/data-uses-register) or the Clinical Practice Research Datalink (CPRD) Protocol Repository (https://www.cprd.com/approved-studies-using-cprd-data). If you desire specific purposes for processing for a particular study, please contact us as per the details in the Contact Us section.

YOUR RIGHTS

Due to data being de-identified, we are not able to uphold certain obligations which would apply to identifiable data. This includes any process which would require re-identification of participants such as data subject access requests and the right to opt-out of data sharing. In cases where such requests are made we will make all reasonable attempts to redirect you to the responsible authority for the data. We will also make all reasonable attempts to protect your data from re-identification and any suspected or actual re-identification will be reported as a breach as required by GDPR.

LEGAL BASIS

As a university, we process pseudonymised 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 pseudonymised data which is considered personal data. This means that data provided to us and covered by this privacy notice will be used only for purposes which are in the public interest and will be collected under GDPR Article 6 (1a) or Article 6 (1e) and disseminated under GDPR Article 9 (2) (j).

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.

CONTACT US

The BDAU can be reached by emailing bdau@imperial.ac.uk for any further clarifications.

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.