

## SAPPHIRE PRIVACY NOTICE

This privacy notice applies to the **Safe Access for Personal Patient Health Information and Records Environment (SAPPHIRE)** platform and data contained and used within this platform. SAPPHIRE is a data access platform which uses existing pseudonymised (data in which patient identities have been masked using a new identifier) healthcare data to a) generate synthetic datasets to enable safe theory testing and b) enable safe theory validation to produce fully anonymised outputs. At no time will anyone from SAPPHIRE or PKB have access to identifiable data and researchers will only have access to fully anonymised data which is not re-identifiable. The pseudonymised data is used in SAPPHIRE systems and can be used to remove data at a later point for patients who may remove consent. Researchers will only have access to fully anonymised data in which any identifiers have been removed.

SAPPHIRE is a grant-funded research project being conducted in partnership with **Patients Know Best (PKB)** and **MDCIone (MDC)**. The aim of this project is research into how data can be better utilised to improve healthcare. If purposes for processing of data change, a new privacy notice will be generated and sent to any registered participants using the PKB system. Imperial College London is the sponsor for this study and use of personal data, including pseudonymised record level data associated with this study, will be processed solely in the United Kingdom.

Data will be held within SAPPHIRE for only as long as necessary to complete the processing of the data. Data anonymised according to the Information Standard Board standard (ISB1523) which falls outside the remit of General Data Protection Regulation (GDPR) will not be subject to a retention limit.

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. Personnel involved in processing of data outside of PKB systems will make no attempt at any time to re-identify individuals from pseudonymised data. Removal of data for patients who have withdrawn consent will be based on the new identity provided by PKB. 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.

SAPPHIRE is an ISO certified environment (27001:2013, 27017:2015 and 27018:2015) 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 process 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 ISB1523 which then permits their onward use for any purpose.

Data processing in SAPPHIRE 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 SAPPHIRE for the purposes of healthcare research. Researchers will only have access to fully anonymised data and will not have access to pseudonymised data. A register of specific research project titles and descriptions will be maintained and available to participants through SAPPHIRE or PKB at any time.

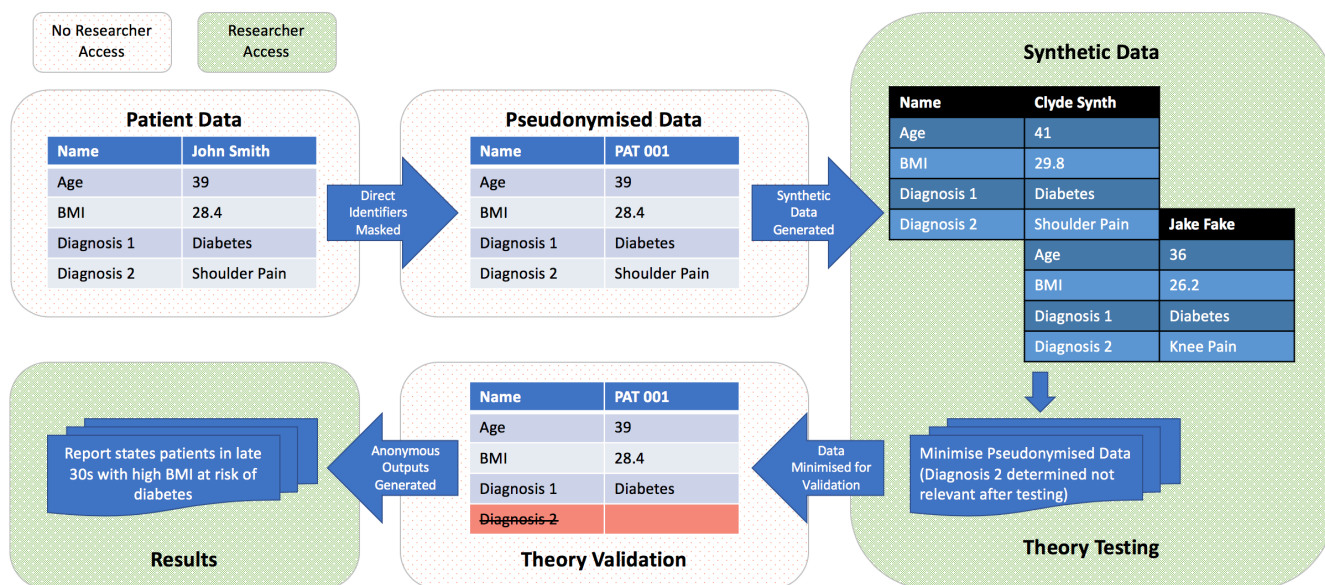
Processing of data will include two phases (diagram below shows overall process):

#### *Phase 1: Safe Theory Testing*

The aim of this phase of SAPPHIRE is to use proven technology (MDC) to produce fully anonymous synthetic data based on pseudonymised data from PKB. To achieve this, data will be pseudonymised before it is transferred to the database in MDC, which will then be protected by the MDC interface and used to produce synthetic data. As there are no real people in this synthetic data, your information is not at risk.

#### *Phase 2: Safe Theory Validation*

The aim of this component of SAPPHIRE is to allow theory validation on theories tested during phase 1 on pseudonymised data. The data is never exposed to the researchers running the query so data is not at risk. Only fully anonymised outputs are produced and provided to the researchers.



Data output will always be anonymised in line with ISB1523 ensuring that data shared with researchers does not put patient identity at risk. Outputs of findings will be shared with patients using the PKB portal to allow feedback.

## YOUR RIGHTS

Participants can withdraw from participation in the SAPPHIRE programme at any time and their data, where not already fully anonymised, will be removed from SAPPHIRE systems using the pseudonymised identity provided by PKB. You also have a right to know what data is being held on you at any time, which you can obtain by contacting us at [sapphire@imperial.ac.uk](mailto:sapphire@imperial.ac.uk).

## LEGAL BASIS

As a grant-funded research project, we process personal and sensitive personal data to conduct research to improve health, care and services. As a public institution, we have to ensure that it is in the public interest when we use data which is considered personal data or sensitive 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. This project will be processed under GDPR Article 6 (1a), GDPR Article 6 (1e) and GDPR Article 9 (2) (j).

The purposes for each individual research project will also be available within the SAPPHIRE portal so participants can understand what types of questions are being asked and for what purpose.

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 SAPPHIRE team can be reached by emailing [sapphire@imperial.ac.uk](mailto:sapphire@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](mailto: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 (Imperial) first before involving the regulator.