**PRIVACY INFORMATION**

**Research Study Title: The Wynn Database – Metabolic risk factors and mortality**

**IRAS ID 252548**

The Wynn Database holds information on metabolic risk factors for cardiovascular disease, diabetes and cancer recorded between 1965 and 2000 by Professor Victor Wynn’s group, working initially at the Department of Metabolic Medicine, St Mary’s Hospital Medical School and then at the Wynn Institute of the National Heart and Lung Institute. The Wynn database has been preserved and is currently managed by Dr Ian Godsland. Work on the data is in collaboration with Professor Desmond Johnston and Professor Nick Oliver.

The Wynn Database comprises 29,245 records of metabolic information for 13,848 individuals. Adiposity, blood pressure, and serum lipid and plasma glucose and insulin concentrations measured during a range of investigative procedures are recorded, as well as more specialised measurements in limited numbers.

Data has been acquired in a variety of contexts including:

* healthy volunteers
* different ethnic groups
* anabolic steroid therapy
* anti-androgen therapy
* oral contraceptive users
* HRT users
* coronary heart disease patients
* heart failure patients
* lipid clinic patients
* obesity clinic patients
* endocrine clinic patients

Currently, applications are being developed to enable mortality status and cause of death to be incorporated into the Database. The Wynn Database is a unique research resource with which important questions regarding metabolic risk factors can be explored. With mortality status and cause of death information, our team will be able to investigate in depth the long-term implications of risk factor variation.

To date, work with data being incorporated into the Wynn Database has focused on the occupational cohort studied between 1971 and 2000 - the Heart Disease and Diabetes Research Indicators in a Screened Cohort (HDDRISC) study. With completion of the full Wynn Database, including mortality information, a number of further analyses will be possible, five of which are summarised below.

Imperial College London is based in the United Kingdom 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. The data will be pseudonymised. Once pseudonymised, non-identifiable data will be kept indefinitely by Imperial College London. Imperial College London will not have access to the list of codes allowing identification after a maximum period of 10 years – this will be sent to (via encrypted nhs.net mail) and stored securely with NHS digital. Once the identifiable information file has been sent to NHS digital allowing them access to the identification codes, the identifiable information within the ICL secure enclave will be destroyed in order to establish pseudonymised working. This will be done within a period of 2 years, to allow appropriate time for NHS digital to perform linkage of the records with NHS numbers. Once the identifiable information within secure enclave has been destroyed along with all paper records relating to the Wynn Database that could be used to identify individuals represented, Imperial College London and any future investigators or applicants to use the Wynn Database will be unable to link either member number or database number to personal identity.

You can find out more about how we use your information **Professor Nick Oliver (**[**nick.oliver@imperial.ac.uk**](mailto:nick.oliver@imperial.ac.uk)**, 020 7594 2460).**

**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. As data will be pseudonymised, we will be unable to identify you from the data set should you wish to have your data removed. Therefore, we will keep the information about you that we have obtained.

**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.

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.

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 UK and 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 to be transferred to a country which is not subject to a European Commission (EC) adequacy decision or by decision by other relevant regulatory agencies in respect of the adequacy 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.