

Information Note for Participants from the UK Biobank Cohort

Project title: « *Analysis of the Role of the Exposome and Genetic Predispositions in Complex Diseases and Multimorbidity in the UK Biobank* » - UK-ExpoGen

Principal Investigator: Thérèse Truong, Inserm U1018

- **Identity and Contact Information of the Data Controller:**
We inform you that the processing of your data is under the responsibility of the French National Institute of Health and Medical Research (Inserm), the data controller for your personal data, located at 101 rue de Tolbiac, 75 013 Paris – www.inserm.fr
- **Contact Information of the Data Protection Officer:**
The Data Protection Officer of Inserm can be contacted via email at dpo@inserm.fr or by postal mail at 101 rue de Tolbiac, 75 013 Paris.
- **Purposes of the Processing for Which Personal Data is Intended:**
The etiology of complex diseases such as cancer, diabetes, cardiovascular, and neurological diseases is multifactorial and poorly understood.
We aim to study the role of the exposome (i.e., lifestyle-related behaviors, environmental and social factors) and genetic factors in the onset and prognosis of these complex diseases as well as multiple, potentially interconnected diseases (i.e., comorbidities or multimorbidities).
Our project is based on data from the UK Biobank. We will use various statistical methods for the analysis of longitudinal data to assess risk and prognostic factors for disease, as well as multi-state methods to study multimorbidity. We will also investigate potential pleiotropic effects (genetic factors associated with multiple phenotypes) that may explain multimorbidity due to common biological mechanisms. To assess whether the associations between risk factors and disease are causal, we will apply causal modeling techniques, particularly methods based on Mendelian randomization.
Our project will contribute to a better understanding of the etiology and prognosis of complex diseases by evaluating the combined effect of the exposome and genetic factors, and will generate knowledge to improve prevention strategies.

- **Legal Basis for Processing and Use of Sensitive Data:**

The processing of personal data essential for the execution of this study is conducted in the fulfillment of a public interest mission entrusted to Inserm, necessitating the handling of your health-related personal data for the purposes of scientific research.

- **Categories of Data Involved in the Processing:**

The following data will be made available to the investigator and/or the coordinating research team: identification data (age and/or month and year of birth); occupational history; tobacco and alcohol consumption; lifestyle habits and behaviors (physical activity, dietary behaviors); ethnicity; health data (medical history, medication use, weight, height, waist circumference, hip circumference); genetic data.

- **Recipients or Categories of Recipients of Personal Data:**

As part of this research, your data will be made available to the principal investigator of the project, data managers, and statisticians. This transfer is necessary for conducting the statistical analyses carried out by Inserm Unit U1018.

- **Retention Period for Active and Archival Storage of Personal Data:**

Your data will be retained within the secure information systems of the data controller until September 2026, in accordance with the material transfer agreement concluded with UK Biobank. Thereafter, the data will be permanently deleted.

- **Data Subject Rights and Procedures for Exercising Them:**

The processing of data for this project is conducted in compliance with the General Data Protection Regulation (Regulation (EU) 2016/679) and the amended French Data Protection Act No. 78-17 of January 6, 1978. Comprehensive information regarding your rights and the modalities for exercising them is available on the UK Biobank website: <https://www.ukbiobank.ac.uk/explore-your-participation/basis-of-your-participation>.

In the event of any difficulty in exercising these rights, you may contact Inserm's Data Protection Officer either by email at dpo@inserm.fr or by postal mail at 101 rue de Tolbiac, 75013 Paris, France.