**Background Information**

Bart’s Cancer Institute has desgined a research project on pancreatic cancer. The project aims to evaluate known risk factors of pancreatic cancer, and identify novel ones, in the multi-ethnic population of East London. The research will contribute to identifying a high-risk population of potential pancreatic cancer patients for targeted screening. This could speed up diagnosis and further down the line, facilitate the development of targeted treatments for pancreatic cancer. The success of the project will open the door for conducting the study on a national scale.

Electronic health records are a powerful yet under-utilised resource in medical research. The project plans to use medical histories of relevant patient groups, collected from their electronic health records. Their medical histories will be stored for research purposes in an anonymised form, so that individuals cannot be identified.

A key aspect of this project is accessing the patients’ healthcare information without their explicit consent to achieve the research objectives. This is because the majority of the patients intended to be included in the study have deceased, and taking their consent will not be possible. Additionally, it would be almost impossible to track all the living patients and obtain their consent. Due to the potential impact of the research and the potential benefit to patients**,** the research has already been approved by the NHS Research Ethics Committee. However, the project also requires a second layer of approval from the NHS Confidentiality Advisory Group (CAG). We therefore want to gather patient and public opinion on this research and its use of electronic health records. The survey results will be combined to provide a representation of patient and public opinion for consideration by the CAG.

**You do not need to have a medical or scientific background. We just ask that you are enthusiastic about medical research AND have a personal experience of healthcare services either as a patient or carer (e.g. family members) with an experience of disease involving the pancreas, liver, gallbladder or bile duct.**

It is advised that you read the research summary first (included at the end of this document) before completing the survey. If you have queries about the opportunity and want to know more about this proposed research project, please contact the research team directly, led by Dr Dayem Ullah ([d.ullah@qmul.ac.uk](mailto:d.ullah@qmul.ac.uk); 020 7882 3831; 07796652947).

Age: \_\_\_\_\_\_\_\_\_\_\_ years

Gender:

Please briefly indicate if you are suffering or have suffered from any diseases of the pancreas, liver, gallbladder, hernia or bile duct.

Have you read the research summary provided? **Yes/No**

1. How do you feel about the **use of electronic health records without patient consent** in this research aiming to improve pancreatic cancer management? Do the potential public benefits justify the approach?

Please feel free to use more space as necessary.

1. What are your general concerns about the use of electronic health records in medical research? How do you think those concerns can be addressed?

Please feel free to use more space as necessary.

***Please email your completed form to*** *d.ullah@qmul.ac.uk****.***

**Research Summary**

**Use of Electronic Health Records in Pancreatic Cancer Research**

***What are Electronic Health Records?***

A huge amount of health information is routinely generated and stored in computers by the hospitals and GPs during the normal care of patients. These are known as electronic health records and include information about patients’ symptoms, tests, diagnosis, treatments, etc. This rich resource could help us learn how to tailor treatments for individual patients and create provisions for better healthcare. However, only a fraction of the wealth of information contained in electronic health records is currently utilised for diagnosis, treatment and other clinical decisions. The research proposed here intends to unlock the potential of electronic health records to enable improved management of pancreatic cancer.

***What is Pancreatic Cancer?***

Pancreatic cancer is a devastating disease. By the time of diagnosis, pancreatic cancer is usually well-advanced in the majority of patients which means they are unable to have surgery. If diagnosed at an early stage, surgery is possible to remove the pancreatic tumour. This, in combination with specialised treatment such as chemotherapy, is shown to improve survival and quality of life. In the past decade, the number of new patients diagnosed with pancreatic cancer has gradually increased in the UK and is likely to continue rising. Yet, only around 10% of cases are diagnosed at an early-stage. Identifying the population at risk as well as early detection of the disease may help to improve patient management and extend survival.

Only 3%

of the patients

survive beyond

5 years

10% Operable

**Rising**

incidence

in the UK

***What We Want to Do***

Previous studies have identified a number of factors, including age over 55, diabetes, pancreatitis, smoking, alcohol and obesity, which may increase the risk of pancreatic cancer. Most of this research focused on studying the Caucasian population in Europe or in the USA. As such, the risk factors for pancreatic cancer in an ethnically diverse community, such as that in London or the UK in general, have not been sufficiently explored.

**To address this gap, we have designed a research project focusing on the multi-ethnic population in East London.** The project aims to evaluate known risk factors and identify novel ones in target population. The research will contribute to identifying a high-risk population for targeted screening, speeding up the diagnosis and further down the line, facilitating the development of targeted treatments. The success of this pilot project will also open the door for conducting the study on a national scale.

***Study Method***

To achieve the research aims of this project, it is critical to compare the medical history of two particular groups of patients.

* **Cases**: Patients with pancreatic cancer
* **Controls**: Patients with
  + non-cancerous diseases of pancreas
  + any diseases of liver, gallbladder or bile duct.

The medical histories will be collected from patients’ electronic health records and stored in an approved secured facility. **The stored information will be completely anonymised so that no individual can be identified.** These measures will ensure the confidentiality of the patient information.

* Patients will not be contacted for information.
* Patients will not be required to provide any specimen such as blood or urine.
* Patients’ routine care will not be affected, whether they remain a part of the study or not.

***Regulatory Compliance***

We estimate to access and review healthcare data of 11000 Cases and Controls in the East London patient population, identified between 2007 and 2021. The poor survival rate of pancreatic cancer patients meansthemajority of the patients in the study are deceased, therefore taking their consent will not be possible. Also, in practice, it will be almost impossible to track all the living patients and obtain their consent. Therefore, a key aspect of this project is **accessing the patients’ healthcare information without their explicit consent to achieve the research objectives.** Considering the potential impact of the project and benefit to patients**,** the NHS Research Ethics Committee has already approved the project. However, accessing healthcare data without patients’ explicit consent requires special approval from the NHS Confidentiality Advisory Group (CAG) who would like to view patient and public opinion on the research.

***Contact***

If you have queries about any aspect of this proposed research project, please feel free to contact the research team directly, led by Dr Dayem Ullah ([d.ullah@qmul.ac.uk](mailto:d.ullah@qmul.ac.uk); 020 7882 3831; 07796652947).