

## ***Patient notification materials of research project***

*Fair processing text has been developed specifically for this project based on the plain English summary. Given the data for research is anonymised there is no scope for re-identifying and removing people from the study. The scope for withdrawing is either through opting out of the audit datasets as covered above or contacting our research project in advance of the data providers providing data to NWIS and SAIL.*

## **Diabetes and Educational Outcomes Fair Processing Notice**

### **Introduction to this Fair Processing Document**

This fair processing document aims to inform research participants of how their information will be used fairly and ethically. This document will be made available to participants immediately once agreement has been reached with the data providers on release of the data. This information will be posted on the data providers website. The fair processing for this project relates to the flow of identifying information (NHS number, name, postcode, date of birth, gender) from the data provider to NHS Wales Informatics Service (NWIS) who act as a trusted third party to use this information to create 'anonymised linkage fields' to link pseudonymised data in the Secure Anonymised Information Linkage Centre at Swansea University. We include broader information on the research project for context, though anonymised data is used for the statistical analysis.

### **Motivation for the project and data linkage**

The type of diabetes most prevalent in children is estimated to account for £1 billion in direct costs and £0.9 billion in indirect costs for the UK each year. A child with T1D must self-inject insulin to keep blood sugar within acceptable limits, the amount needed varying with what they have eaten and planned physical activities. Our research asks whether children with diabetes experience adverse outcomes with respect to their education and to what extent these outcomes may be influenced by the quality of their diabetes management. This is an important question not just because of the direct medical effects of diabetes on the brain caused by low ('hypos') or high sugar levels, but also because management of T1D can be a time consuming and isolating process.

### **Aims of the project and data linkage**

The overall aim of the research is to better understand the associations between diabetes (diagnosis and management) vs educational outcomes, recognising that the causality between will operate in both directions. We are interested in how other factors influence these relationships, these include characteristics of the child (e.g. gender, age of diagnosis), their families (e.g. single parent families), and the health services they use (e.g. type of diabetes clinic).

### **Objectives of the project and data linkage**

Through an ethically acceptable anonymised process of linking databases, we will link the diabetes related health measures from diabetes audits to educational records of

individuals collected by schools and universities to see (i) whether educational trajectories are different for children with diabetes (ii) how trajectories of diabetes management (HbA1c measures) are associated with educational outcomes.

### **The identity of the researcher and their relationship with the University/department**

The principal investigator is Dr Robert French, Research Fellow in the School of Medicine at Cardiff University.

### **The identity of other people who may have access to the data**

The identifiable dataset will only be flowed between the data provider and NHS Wales Informatics Service, before being pseudonymised, with any identifiable information subsequently being destroyed. Neither the researcher nor the Secure Anonymised Information Linkage Centre at Swansea University ever has access to the identifiable information.

### **Opting out of the study**

Opting out of this study must happen prior to the data flows, after which the data will be anonymised. Participants can opt out of any combination of the three datasets. This can be done by contacting the researcher: Dr Robert French, Cardiff University, (0)2920 743703, [frenchr3@cardiff.ac.uk](mailto:frenchr3@cardiff.ac.uk).