

Patient notification materials for the diabetes and education research project

Fair processing text has been developed specifically for this project based on the plain English summary. Once the data has been 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 in their fair processing documentation or contacting our research project in advance of the data provider extracting the data.

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, legally and ethically. This document will be made available to participants immediately once agreement has been reached with the Health Research Authority (HRA) on the legal basis for the data flows (9th Feb 2018). This information will be posted on the data provider's 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 (Royal College of Paediatric and Child Health) 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 (SAIL) at Swansea University. In this document we also include broader information on the research project for context, though only 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 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) and 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 from the data custodians (Royal College of Paediatric and Child Health) scheduled for 13th April 2018, after which the data will be anonymised. Participants can opt out of any combination of the three datasets for which identifiers will be flowed for linkage (i) the National Paediatric Diabetes Audit (ii) The National Diabetes Audit (iii) Higher Education Statistics Agency Dataset. This can be done by contacting the administrative lead for the project: Mrs Lynne Hope University Hospital Wales 02920 742182 hopelm@cardiff.ac.uk or the academic lead for the project: Dr Robert French, University Hospital Wales 02920 743703, frenchr3@cardiff.ac.uk.