### 

**Secure Anonymised Information Linkage (SAIL)**

**Information Governance Review Panel (IGRP) Application Form**

**SAIL IGRP Application Form**

The following form has been designed to collect the information needed for the information governance approval process for work involving the SAIL databank. The information you provide will facilitate consideration of your enquiry. Guidance notes on completing this form can be found at: <http://www.saildatabank.com/media/25300/Guidance_Notes_for_SAIL_IGRP_Application.docx>

***SAIL Feasibility Agreement***

*All projects require a SAIL Feasibility Agreement to be completed and signed before proceeding to IGRP. This agreement will have been developed as part of the initial project scoping process with a SAIL analyst. Do not continue with this form until you have had your project scoping discussion.*

*Please provide the agreement number: 0895*

**1a. Provide contact details of project lead:**

Name: Dr Arron Lacey

Job title: Research Officer & Data Scientist

Organisation: HDR-UK Wales and Northern Ireland, Swansea University Medical School (SUMS)

Address: Swansea University, Singleton Park, Swansea. SA2 8PP

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Fax:

Email: [a.s.lacey@swansea.ac.uk](mailto:a.s.lacey@swansea.ac.uk)

**1b. Provide contact details of the lead contact from any other organisation who will be accessing the data:**

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Name** | **Job title** | **Organisation** |
| 1 | Dr Owen Pickrell | Clinical Lecturer | AMBUHB / SUMS |
| 2 | Ashley Akbari | Senior Research Officer & Data Scientist | SUMS |

**2. Provide full title of the project:**

Educational attainment of children with epilepsy in Wales.

**3. Provide details on who is commissioning the project:**

This a collaboration between the Swansea Neuroscience Research Group and HDR UK Wales and Northern Ireland.

**4. Provide the aim of the project, including anticipated outcomes:**

*Please include a copy of the protocol/plan for the proposed work with SAIL, including the contact details of any co-applicants when you return your completed form.*

We aim to investigate educational attainment using the Welsh Government education data from schools around Wales, for children with epilepsy, and compare their Key Stage 1-4 results during school to a matched control group (sex, school year, social deprivation, birth weight and gestational age) for all other children receiving education in Wales between the same key stages. Children with epilepsy are prescribed different anti-epileptic drug prescriptions and these would form the basis of multiple sub-groups to analyse. This is an important piece of work because children with chronic conditions such as epilepsy often face additional challenges in school and determining gap (if any) between their peers in Welsh schools can help signify the level of additional need they require.

**5. Provide a lay summary of the project:**

Epilepsy is a condition associated with a range of other problems. Around 40% of children with epilepsy also have an additional neurological problem and 1 in 4 people with epilepsy have a learning disability. Behavioural issues, at home and in school, are common in children with epilepsy. Children with epilepsy are a stigmatized group, and are more likely to be bullied. A study of children with severe epilepsy saw their seizures as a barrier to a normal life. Drugs used to treat epilepsy may also have side effects. Given this, it is possible that children with epilepsy may not do so well at school when compared to children without epilepsy. In this study we aim to compare the school performance of children with epilepsy to that of children without epilepsy. We will also look at drugs used to treat epilepsy to see if they influence school performance.

**6. Provide an outline of the public engagement strategy for the study, or a brief explanation why there is not public engagement:**

The results of this study would likely be published in an academic journal, and given that the results would come from routinely collected data rather than a prospective observational study, there will not be any public engagement strategy required.

**7. Provide information on the relevant permissions you have obtained or that are being sought:**

*Obtained Being sought Not required*

***Research ethics***[  ] [  ] [  ]

*Please state the name of the committee that is being applied to/ has given approval, as applicable:*

*Research ethics committee:*

*If you have ticked ‘not required’ please specify the reasons:*

The project will use onlyanonymised data, and therefore research ethics review is not required.

Other:

*Obtained Being sought Not required*

***Independent peer review***[  ] [  ] [  ]

*Please state the name of the peer reviewing organisation that is being applied to/ has given approval, as applicable:*

*Peer reviewing organisation:*

*If you have ticked ‘not required’ please specify the reasons:*

This project uses only anonymised already made available for research via the SAIL Databank.

***Permission from data-holding*** *Obtained Being sought Not required* ***organisation to use their datasets***[  ] [  ] [  ]

*Please state the name of the data provider that is being applied to/ has given approval, as applicable:*

*Data organisation:*

*If you have ticked ‘not required’ please specify the reasons.*

The project uses only SAIL unrestricted core datasets and/or data held by the project.

Other:

**Please note that it is the responsibility of the project lead to ensure that the relevant permissions are obtained.**

**8a. Provide a prospective start date for the work involving SAIL (dd/mm/yy):**

01/04/2019

**8b. Provide anticipated end date of the project: (**End date OR time duration after approval):

01/12/2021

**9a. Provide details of data you require access to for the proposed work with SAIL?**

Please list:

The SAIL datasets you require information from:

EDUW/EDUC (Wales Education data)

NCCH (National Community Child Health dataset)

WDSD (Welsh Demographic Service Dataset)

WLGP (Welsh Longitudinal General Practice dataset)

The information needed from each dataset:

EDUW/EDUC (Wales Education data) will be used to identify Key stage 1-4 CSI, Maths, Science English Welsh results, as well as school year, learning difficulties (LEN) and days of absence.

NCCH (National Community Child Health dataset) will be used to identify maternal age, gestational age and birth weight.

WDSD (Welsh Demographic Service Dataset) will be used to identify where children move around Wales and potential to different schools in combination with the education data, as well as LSOA changes to investigate social deprivation changes between birth and school years.

WLGP (Welsh Longitudinal General Practice dataset) will be used to identify diagnostic and medication events and dates including epilepsy status and anti-epileptic drugs, and co-morbidities of interest.

Please indicate the time period for which data is requested:

January 1st 2003 and December 31st 2018, as well as prior historical records for anyone within the cohort period to confirm for prior medications, diagnoses and outcomes of interest.

Please indicate the geographic area for which data is requested:

All people receiving education and health services in Wales between the time periods stated above.

Please indicate demographic criteria for the data requested (age, gender, etc.):

All ages and genders for children, including maternal variables requested on the children of interest including maternal age as a covariate in our analysis.

**9b. Will you be providing any other dataset(s) to be incorporated into the SAIL databank?**

Yes [  ] No [  ]

If yes:

Provide the name of the dataset(s):

Provide details of the contents of the dataset(s):

**9c. Provide an outline of your analysis plan including the anticipated outputs:**

The analysis plan is as follows:

1. Obtain Key Stage 1-4 data between 2003 and 2016 for all-children receiving education in Wales (EDUW/EDUC).
2. Identify which children have been diagnosed with epilepsy from primary care General Practice (GP) records (WLGP) before their year of study in each Key Stage. This will be done by using an existing algorithm developed and validated on SAIL data 10.1016/j.seizure.2017.10.008.
3. For each child with epilepsy, and for each Key Stage, define a matched control cohort where control variables would aim to include sex, school year, social deprivation, birth weight and gestational age (NCCH & WDSD), ideally with a minimum of a 1:3 match.
4. Stratify the epilepsy cohort by what anti-epileptic drug prescription(s) they are taking.
5. Compare attainment between the epilepsy cohort (and subgroups) to the matched control using the Core Subject Indicator (CSI), maths, science and language (English or Welsh), where each child is classed as either achieving a pass (Level 2 or above) or not. A proportions test such as chi-square or logistic regression will be used to indicate statistical significance of the comparisons.

The expected outcomes would test the hypothesis that children with epilepsy do worse than their peers in school, with certain sub-groups with different drug prescriptions also potentially doing worse.

**9d. Are the results/methods developed likely to have other potential applications?**

Yes [  ] No [  ]

If yes, please specify:

**10a. Please indicate your plans for publishing the results of your project, e.g. target journal or intended recipients of report:**

We intend to present at national and international specialist conferences and publish in major, peer-reviewed neurology/epilepsy journals.

**10b. What are the potentially sensitive issues that need to be taken into account when publicising the findings of the project?**

Please outline the issues and your proposed solutions:

We will follow data safe handling and use procedures as well as ensure all data follows standardised anonymization and privacy protecting processes to ensure the data coming into SAIL is protected. The project will also look at strategic optimization of resources and could potentially be misinterpreted by healthcare providers. As such, all results and outputs will make sure to ensure results can be interpreted correctly.

We will follow all standard data masking protocols to make sure no small numbers (<5) are allowed to be communicated via our results, as well as making sure no potentially identifiable subgroups or cohorts are communicated via our results. Hence, we do not anticipate that small numbers disclosure issues will arise. We will follow all SAIL policies on such issues when reviewing outputs for data out and publication in project findings.

**What to do next**

Please return your completed form and supporting documents by email to Cynthia McNerney, Information Governance Coordinator [c.l.mcnerney@swansea.ac.uk](mailto:c.l.mcnerney@swansea.ac.uk) Thank you.