



# HEALTH, EDUCATION, AND SOCIAL SERVICES ROUTINE | LINKED DATA: *perspectives of a trials unit*

Fiona Lugg-Widger

Rebecca Cannings-John

Research Associate – Routine Data

Research Fellow– Statistics

# Routine | Linked data projects

## Centre for Trials Research

### Building Blocks trial



Evaluation of FNP in England  
**Family Nurse Partnership**

### Building Blocks: 2-6



Longer term consequences of the  
FNP programme using routine data



### POOL

Establishing the safety of  
waterbirth for mothers and babies

Cancer trials  
utilising ONS  
death data:

**FRAGMATIC**

**FOLFERA**

**AML-15**

**AML-16**

**SCOPE 1**

**SCALOP**

## Division of Population Medicine Collaborations



### LUCI Study

Long term follow-up of children  
with UTI using routine data



### HealthWise Wales

Doeth am Iechyd  
Cymru  
HealthWise  
Wales

Welsh national cohort using  
prospectively collected data  
linked with NHS records



The Novo Nordisk  
UK Research Foundation

Investigating the pathway of type 1 diabetes  
in childhood presenting in Primary Care

# Our experience | expertise:



*Local Health Board data – Radiology, Maternity*

*Health data in **England** (Inpatient, Outpatient & Emergency care)*



Office for  
National Statistics

**UK** mortality data

**Dept. for Health:** Abortion statistics team

Clinical Practice Research Datalink (**CPRD**) – GP data in the **UK**



Secure Anonymised Information Linkage

**SAIL**



– Health & Education data in **Wales**

**National Pupil Database** - Education and Social Care data in **England**



**EK | EuroKing & NNRD** National Neonatal Research Dataset – **UK** Maternity & neonatal data



**eDRIS** electronic Data Research and Innovation Service – Health data in **Scotland**

**EAS** – Education and Social Care data in **Scotland**



@fionalugg  
@becacj  
@CTRCardiffUni

College of Biomedical and Life Sciences

# Secure Anonymised Information Linkage



<https://saildatabank.com/>

Brecon cohort

MS Register

UK Cystic Fibrosis Registry

National Pupil Database

Maternity dataset coming soon

External datasets study specific

Annual District Birth Extract

Annual District Death Extract

Critical Care Dataset

Diagnostic & Therapy Services Waiting Times

Emergency Department

National Community Child Health Database

Outpatient

Outpatient Referral

Patient Episode Database for Wales

Postponed Admitted Procedures

Primary Care GP (Audit+)

Referral to Treatment Times

UK Health Dimensions

Welsh Demographic Service





**Research Question 1:** Does childhood UTI lead to renal scarring and other long term-complications in **routinely sampled** children?

Create cohort  
of children <5  
yo in Wales



Exposure: UTI  
or not



Outcomes

Datastore Public  
Health Wales

Radiology data  
Health Boards

Diagnostic & Therapy Services Waiting Times

Emergency Department

National Community Child Health Database

Outpatient

Outpatient Referral

Patient Episode Database for Wales

Postponed Admitted Procedures

Primary Care GP (Audit+)

Referral to Treatment Times

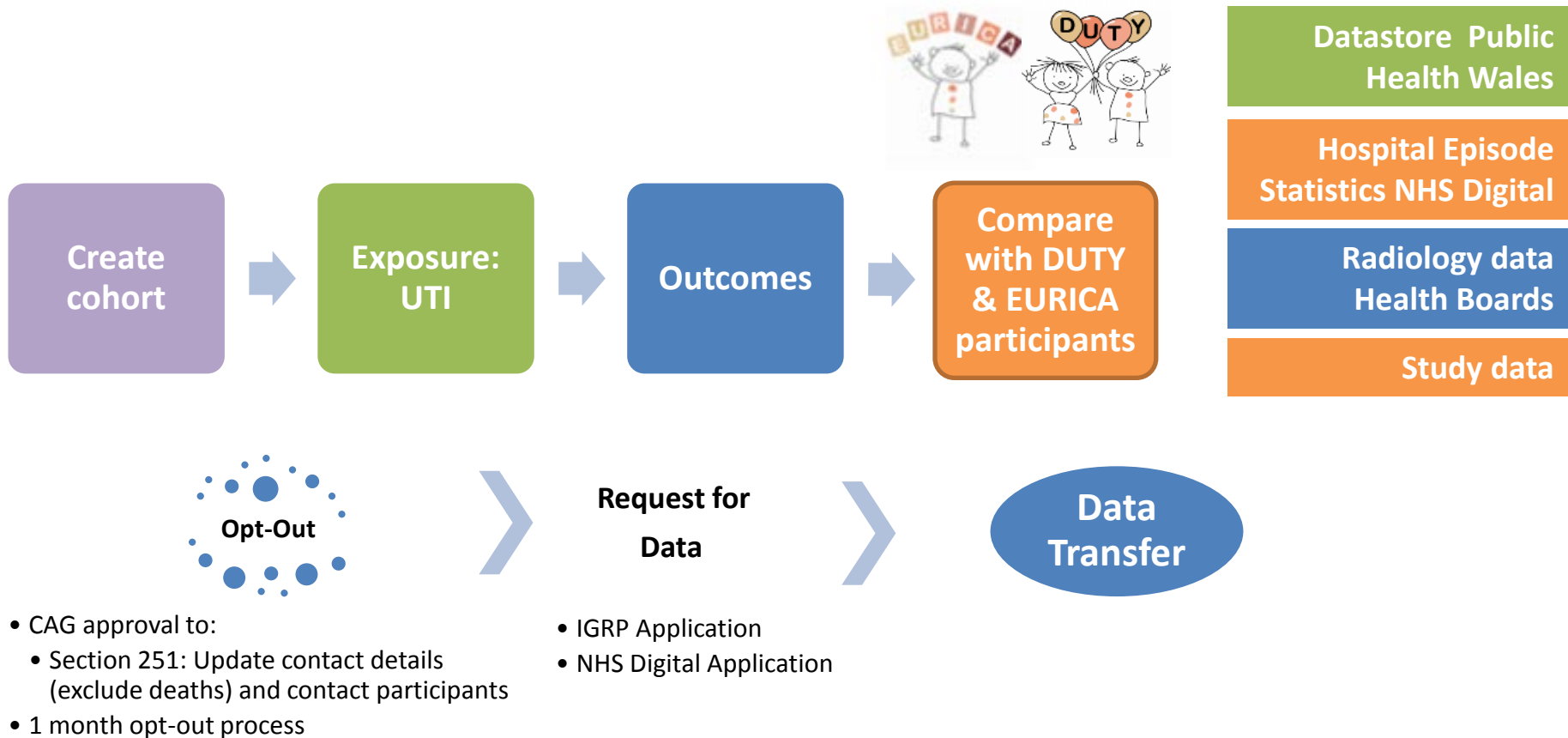
UK Health Dimensions

Welsh Demographic Service

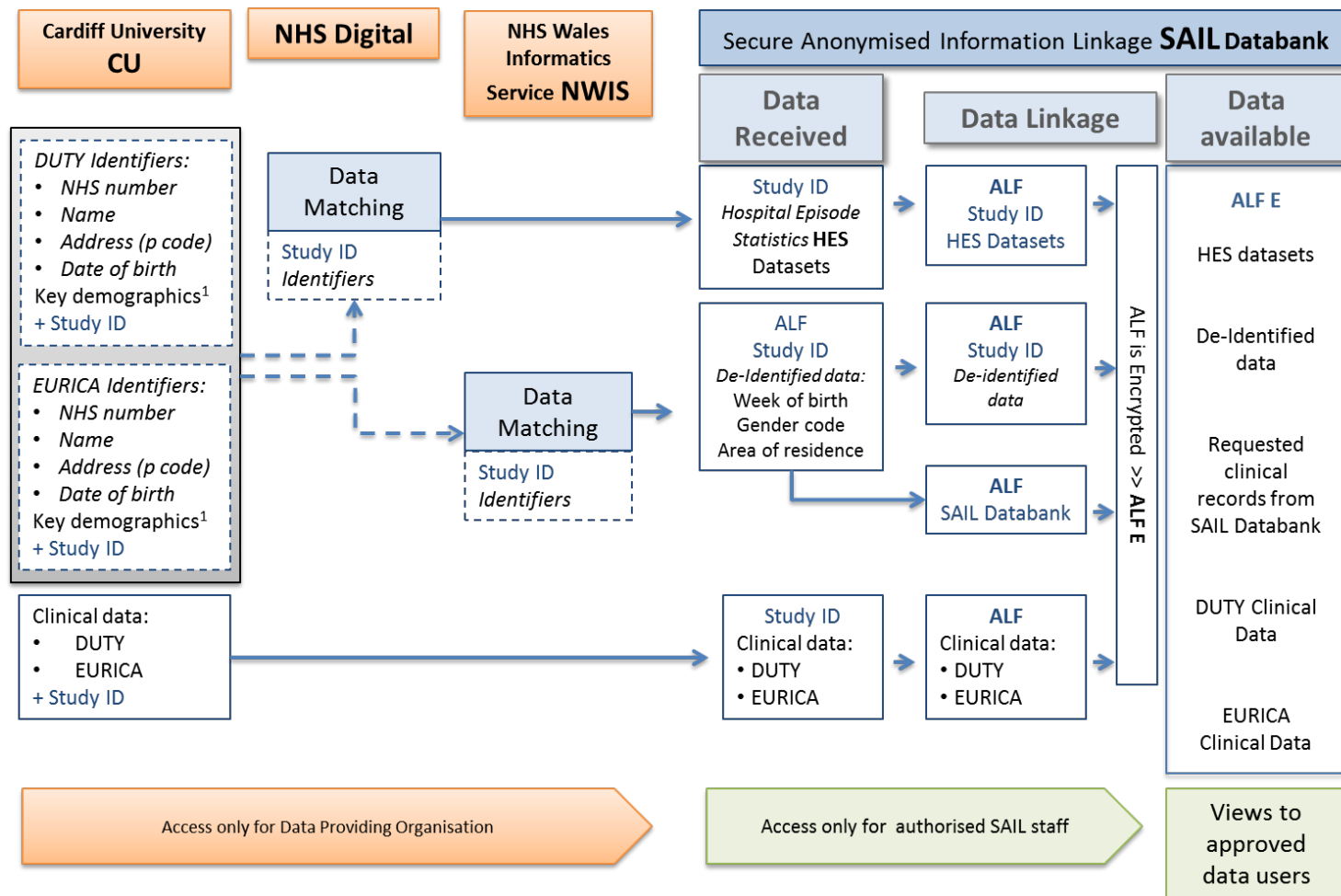
Wales Electronic Cohort of Children [WECC]



## Research Question 2: Are outcomes different for children with a childhood UTI identified through **routine sampling** compared to **systematic sampling** ?



## Model of pseudonymised data linkage: LUCI Research Database (31.01.17)





## Study aim

To determine the effectiveness of the FNP programme in reducing objectively measured **medium-term maltreatment outcomes** when compared to usually provided health and social care alone using **routine data**.

**Study Design:** Data linkage study with an additional 4 year follow up

**Participants:** n=1,563 mothers/children exiting BB1 trial

**Outcomes:**

- Objective and associated measures of maltreatment
- Intermediate FNP programme outcomes
- Child health, developmental & educational outcomes

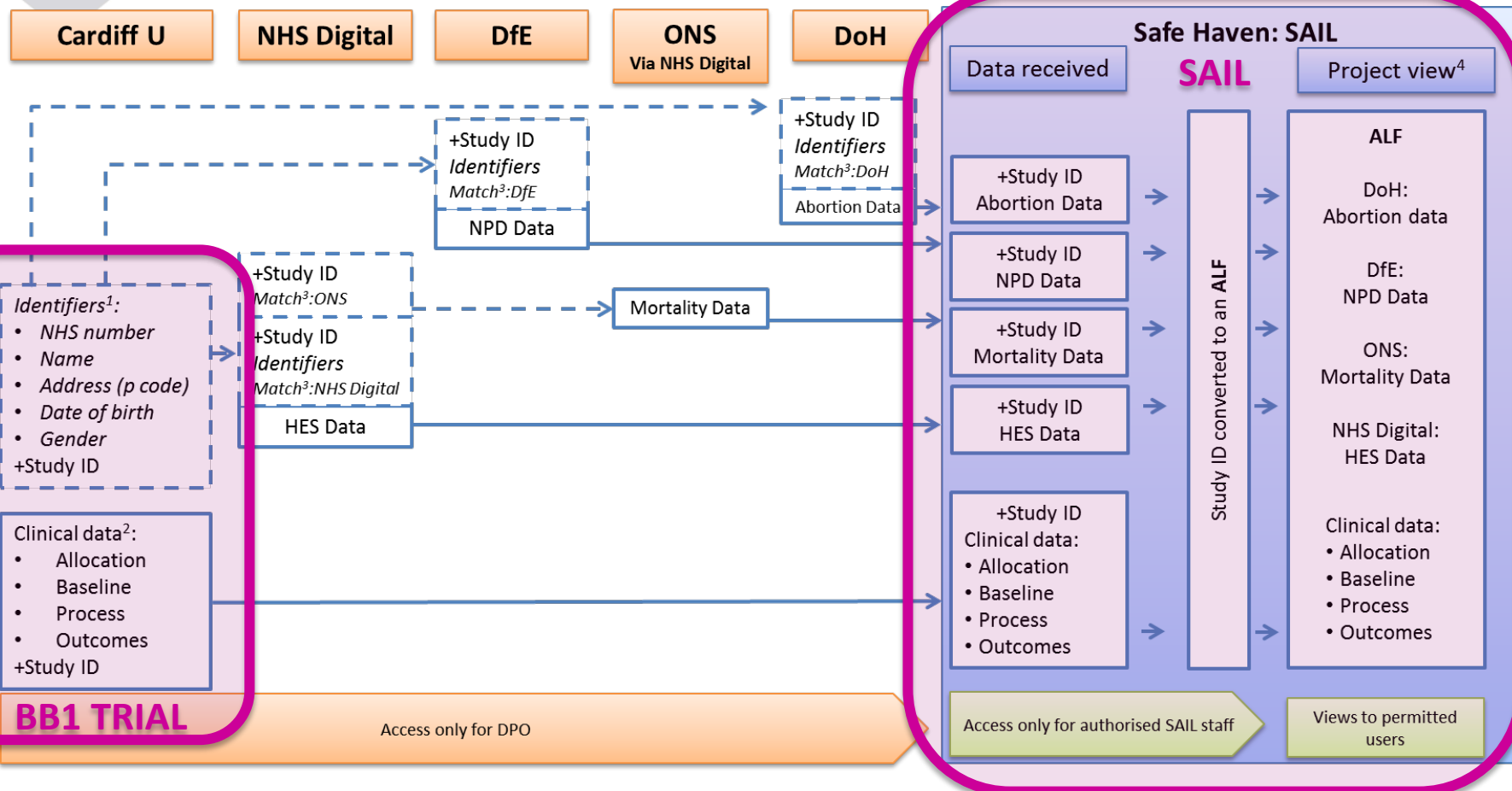
Lugg-Widger FV, Cannings-John R et al. 2017. Assessing the medium-term impact of a home-visiting programme on child maltreatment in England: protocol for a routine data linkage study. *BMJ Open*, 7(7) e015728.





## Building Blocks: 2-6

Longer term consequences of the  
FNP programme using routine data

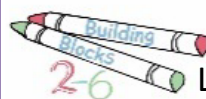


**Sensitive person identifiable information**

- +Study ID converted to **ALF**
- ALF: Anonymised Linking Field**

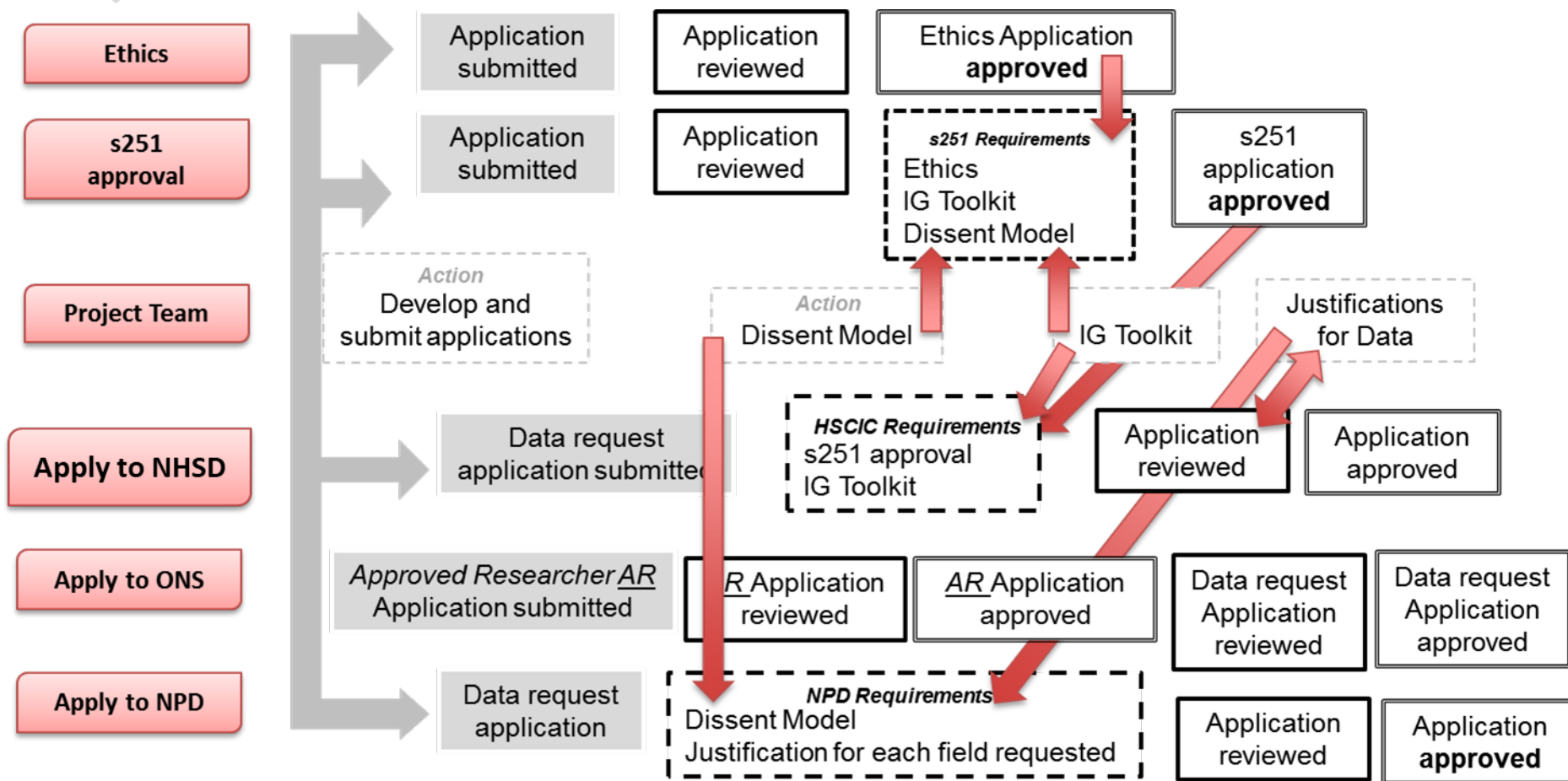
DPO: Data Providing Organisation  
Identifiers: i.e. specifically for linkage  
SAIL: Secure Anonymised Information Linkage

1 De-identification and Standardisation (DIAS) applied (e.g. date of birth to week of birth)  
2 Hosted on SAIL secure platform  
3 Information Centres confirm matching of BB/NHS/ONS/DfE identifiers



## Building Blocks: 2-6

Longer term consequences of the  
FNP programme using routine data



# electronic Data Research and Innovation Service (eDRIS)

## Safe haven linking various Scottish datasets

<http://www.isdscotland.org/Products-and-Services/eDRIS/>



1. A named Research Co-ordinator from start to finish
2. Help with study design
3. Expert advice on coding, terminology, meta data and study feasibility
4. Assistance with obtaining the required permissions for access to data through the Public Benefit and Privacy Panel (PBPP)
5. Agreed deliverables and timelines
6. Liaisons with data suppliers to secure data
7. Access to data within the NSS National Safe Haven
8. Analyses, interpretation and intelligence about data (where reqd.)



### Scottish Morbidity Record

- Outpatient
- General & acute inpatient | day cases
- Maternity inpatient | day cases
- Mental inpatient | day cases health



### Accident and Emergency

### Child Health Systems Programme – School

- Primary 1 (4-5 years)

### Child Health Systems Programme –pre-school

- Heath visitor 10 days | 6-8 weeks | 27-30 months

### Community prescribing and dispensing National Record for Scotland (NRS): deaths



### Education Analytical Services (EAS)

#### Children and Young People:

- Looked after children
- Child protection register

#### Education

- School/Pupil Census
- Attendance, Absence and Exclusions
- School leavers
- Skills Development Scotland: destinations
- Scottish Credit and Qualifications Framework
- Achievement of Curriculum for Excellence levels collections (EAS)

Study started 1<sup>st</sup> April 2018

New data items added to Euroking®

Clinical data recorded by midwives and stored  
in Euroking® at each site

EACH SITE

Data extraction syntax run remotely to  
sites by Euroking® to create two datasets:

Clinical data &  
LINKING FIELD\*

Baby NHS Number  
& LINKING FIELD\*

EUROKING

EuroKing  
Maternity information system

The primary study aim is to establish whether  
for 'low-risk' women who use a pool during  
labour, waterbirth, compared to leaving a pool  
prior to birth, is as safe for mothers and babies.

Maternity (maternal and neonatal) data  
transferred to Cardiff  
University identified  
by LINKING FIELD\*  
only

Section 251 approval  
Data sharing agreement  
Baby NHS and LINKING  
FIELD sent to NNRD

Data linked to NNRD, NHS  
number removed and  
matched neonatal data  
transferred to CU identified  
by LINKING FIELD\* only

NNRD

NDAU

Neonatal Data Analysis Unit

Cardiff University receive pseudonymised data  
Maternity and NNRD data matched by LINKING FIELD

CARDIFF  
UNIVERSITY

Data available for analysis at Cardiff University

Estimated Sample Size:

30,000 women

16,200 babies



Centre for  
Trials Research  
Canolfan  
Ymchwil Treialon

**NHS**  
National Institute for  
Health Research



@fionalugg  
@becacj  
@CTRCardiffUni

## HEALTH, EDUCATION, AND SOCIAL SERVICES ROUTINE | LINKED DATA: *perspectives of a trials unit*

# *Thank You!*

**Fiona Lugg-Widger**

**Rebecca Cannings-John**

**Research Associate – Routine Data**

**Research Fellow– Statistics**