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

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NIHR Statistics Group – Routine Data meeting
23rd April 2018
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

**Division of Population Medicine Collaborations**

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

- **HealthWise Wales**
  Welsh national cohort using prospectively collected data linked with NHS records

- **Cancer trials utilising ONS death data:**
  - FRAGMATIC
  - FOLFERA
  - AML-15
  - AML-16
  - SCOPE 1
  - SCALOP

- **POOL**
  Establishing the safety of waterbirth for mothers and babies

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Our experience | expertise:

Local Health Board data – Radiology, Maternity

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

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

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

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Secure Anonymised Information Linkage

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

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https://saildatabank.com/
Research Question 1: Does childhood UTI lead to renal scarring and other long term-complications in **routinely sampled** children?
Research Question 2: Are outcomes different for children with a childhood UTI identified through **routine sampling** compared to **systematic sampling**?
LUCI Study
Long term follow-up of children with UTI using routine data

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

Cardiff University (CU) → NHS Digital → NHS Wales Informatics Service (NWIS) → Secure Anonymised Information Linkage (SAIL) Databank

Data Received:
- Study ID
- Hospital Episode Statistics (HES) Datasets
- ALF Study ID
- HES Datasets
- De-Identified data:
  - Week of birth
  - Gender code
  - Area of residence
- ALF (Study ID)
- SAIL Databank

Data Linkage:
- ALF
- Study ID
- Clinical data:
  - DUTY
  - EURICA
- Clinical data:
  - DUTY
  - EURICA

Data available:
- ALF E
  - HES datasets
  - De-identified data
  - Requested clinical records from SAIL Databank
  - DUTY Clinical Data
  - EURICA Clinical Data

Access only for Data Providing Organisation
Access only for authorised SAIL staff
Views to approved data users
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

Building Blocks: 2-6

Longer term consequences of the FNP programme using routine data
Building Blocks: 2-6
Longer term consequences of the FNP programme using routine data
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
- Health 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)
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.

Study started 1\textsuperscript{st} April 2018

Estimated Sample Size:
30,000 women
16,200 babies
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Thank You!

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