

Developing a new cohort of children born to women who used opioids in pregnancy using administrative data: insights into cohort creation and linking of administrative datasets

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Why is this research important?

- Around 500 children a year in Scotland are born to women who use opioids in pregnancy
- However, we have surprisingly little evidence about this group. Overall there is a lack of evidence about:
 - Longer term effects of different drugs on children
 - Treatment of children born with Neonatal Abstinence Syndrome
 - Care pathways for this group
 - Long-term outcomes across a range of domains



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Hidden Harm Report



‘A programme of research should be developed in the UK to examine the impact of parental problem drug use on children at all life stages from conception to adolescence. It should include assessing the circumstances of and consequences for both those living with problem drug users and those living elsewhere, and the evaluation of interventions aimed at improving their health and well-being in both the short and the long term.’



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Why are we lacking in evidence?

- Identifying these children can be tricky
- Traditional methods (involving talking directly to families over multiple years) are challenging:
 - Children may move between carers
 - Often have unstable housing
 - Frequently live in families with chaotic lifestyles → hard to keep in touch
 - Demonstrated in Sim et al.
- Evidence we do have often from small, clinical samples with only short term follow-up



What do we know about these children?



- Children exposed to opioids in pregnancy experience a range of early adverse outcomes, e.g. low birth weight, preterm delivery, reduced head circumference, and poorer visual development;
- Evidence of increased risk language difficulties, cognitive functioning and behavioural problems in early years;
- In addition, living with parents who use drugs associated with family and social problems, including inconsistent parenting, parental conflict and stress, and a higher risk of the child experiencing abuse or neglect.



Pilot study: Aims

1. To establish the feasibility of identifying and linking data related to children born to opioid dependent mothers
2. To describe the postpartum outcomes of children born to mothers who use opioids and publish these findings in a high quality peer-reviewed journal
3. To use these results as the basis of a larger grant application to extend the cohort follow-up period.

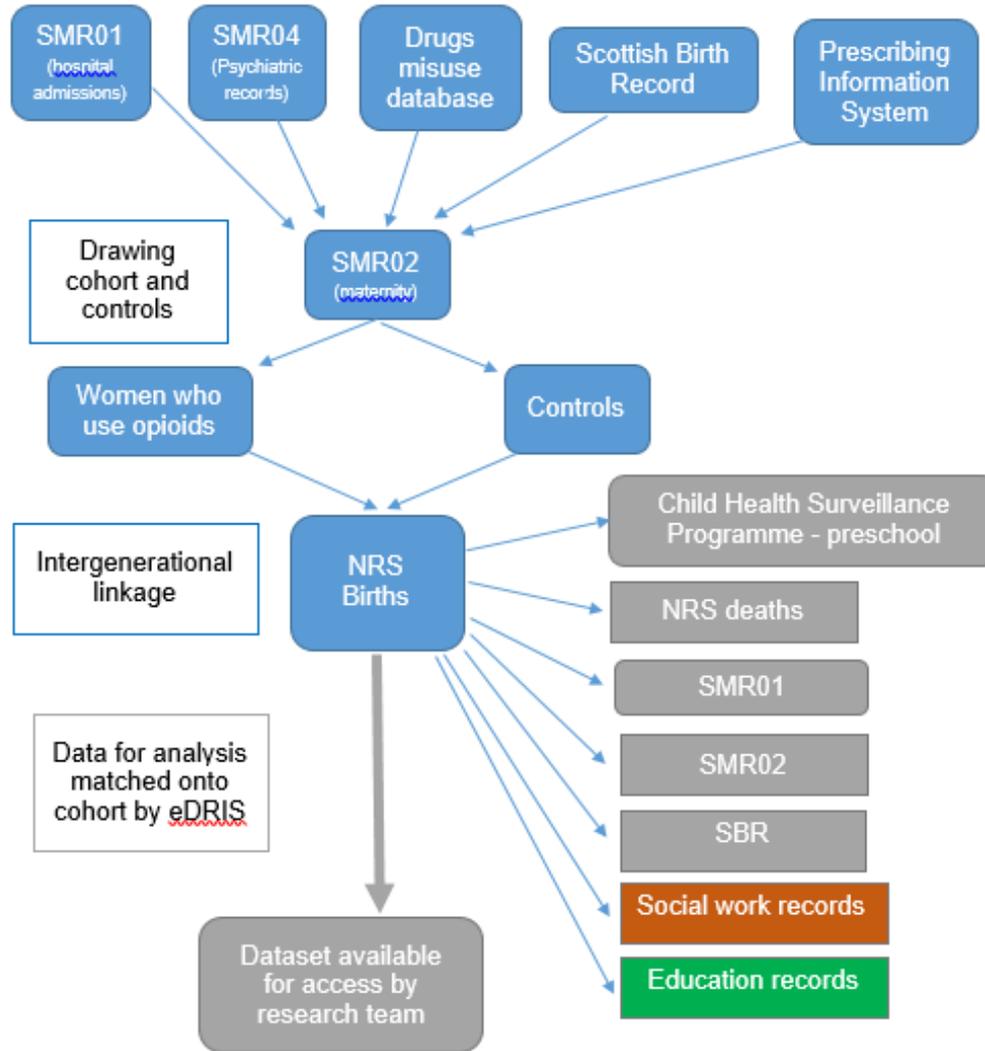


How are we doing this?

- Explore this area using data collected routinely through:
 - **Health records** (e.g. hospital admissions data, birth records, data collected by midwives and health visitors);
 - **Education records** (data about which children are in Local Authority schools, their demographic details, Additional Support Needs and items like exclusions);
 - **Social Work records** (e.g. Looked After Status and reasons for this, whether a care plan is in place etc.).



Figure 1 Data flow chart



Establishing the cohorts

Children born to women who used opioid substitution therapy in pregnancy

Recorded on SDMD, Prescription data, psychiatric and hospital admissions, maternity records, birth records.

Control group 1: Children born to women who used opioids for chronic pain relief

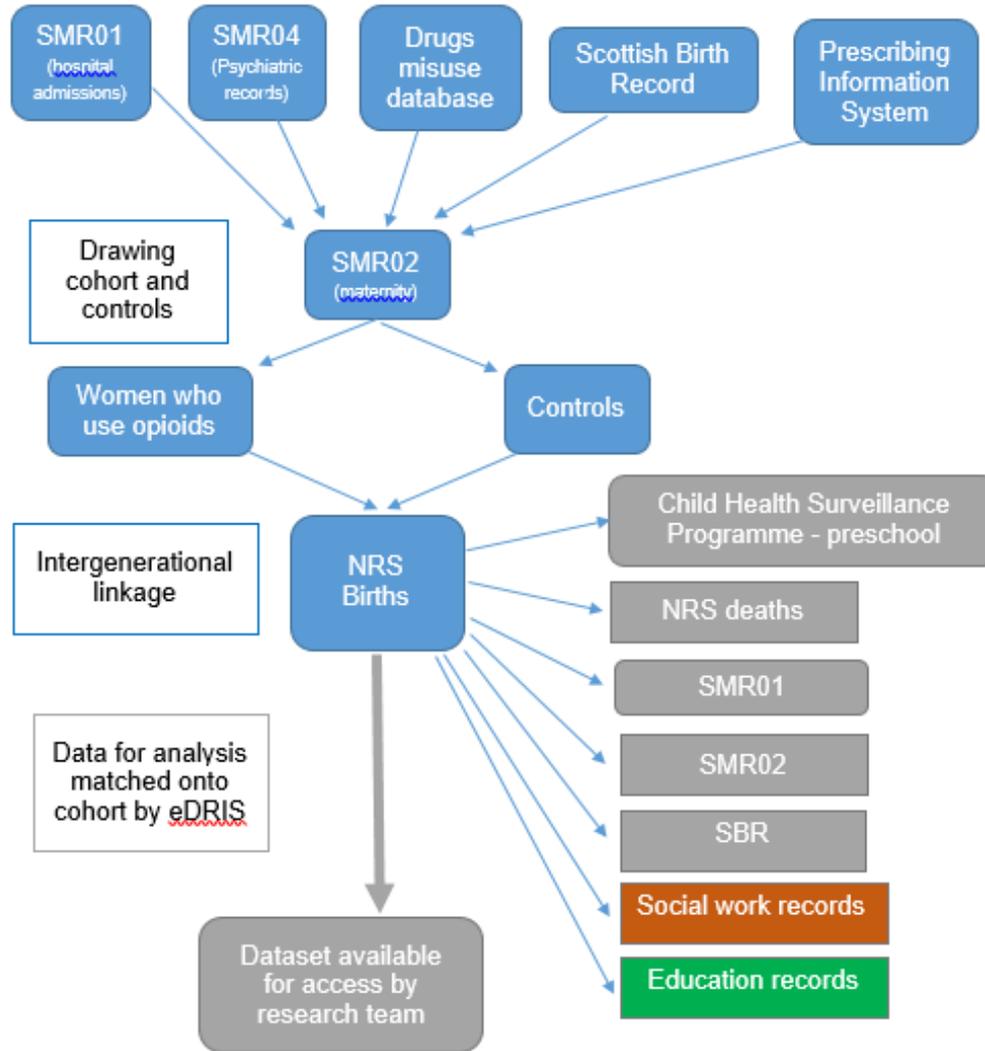
Recorded on Prescription data

Control Group 2: Children with similar demographics but no exposure to opioids

Matched by sex of child, Health Board, age of mother, SIMD (using data from maternity records)



Figure 1 Data flow chart



Outcomes for pilot study

Birth

- Apgar score
- Resuscitation required
- Birth weight/length
- Gestation
- Head circumference
- Congenital abnormalities

Neonatal

- Length of stay in hospital
- Irregular discharge
- Neonatal death

Health visitor

- Concerns raised by carer
- 2nd hand smoke exposure
- Breastfeeding
- Health Plan Indicator (HPI)
- Sleeping position
- Development concerns raised
- Weight/length



The process for accessing data

1. eDRIS provide initial costs for proposal
2. Outline what is hoped to be achieved to funder within proposal
3. Ethics
4. Data Privacy Impact Assessment
5. Assigned eDRIS Research Coordinator
6. Discussions with ISD teams and exploration of online data sources
7. Complete Public Benefit and Privacy Panel application
8. PBPP meet and approve or suggest changes to project
9. Assigned analyst at eDRIS – works with Research Coordinator to obtain data
10. Confirm cost of study
11. Sign contract with eDRIS in order to receive data
12. Data in safe haven for access by research team

2 YEARS



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Challenges



- Data...data...data
 - Financing data linkage costs
 - Navigating the eDRIS system
 - Knowing what data is available, what you need, in what format
- Time
 - For data access
 - For recruitment
 - For applying for more funding!



Next steps

- Hopefully (!) get data in New Year
- Results out Summer 2020
- Applying for further funding to enhance dataset:
 - Additional health data
 - Add education and social work data
 - Increase follow-up time
- Watch this space....!



Any questions?



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