

Born in Scotland in the 2020s NewsLetter



Summer 2023

Welcome...

... to the Summer 2023 issue of the Born in Scotland Newsletter!



It's been a busy few months for the Born in Scotland team! Find out about the latest news and events on **page 2 & 3**. We recently started to collect biological samples from some Born in Scotland participants at the time of birth - see our article on **page 4** for more details.

We also continue to explore previous cohort studies, which hopefully helps to clarify what Born in Scotland hopes to achieve! In this issue we're looking at the '1970 British Cohort Study' on **page 6**.

Don't forget to check out **page 7** for our summer family fun ideas and there's the **chance to win a £10 voucher** on **page 8**!

Thanks for reading, and please do get in touch if you have any comments or feedback.

- The Born in Scotland Team

2023 Highlights

- We now have almost 600 participants!
- Born in Scotland was represented at a University of Edinburgh event held at Dynamic Earth 'Our Planet, Our Health, Our Future' examining how climate and our environment impacts health.
- Following on from our initial biosample collection of booking & 28 week blood samples, we are now collecting delivery samples. This will include placenta, membranes, umbilical cord and cord blood. Read more on **page 4**.
- Follow us on social media:

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 EdinburghPregnancyResearchTeam

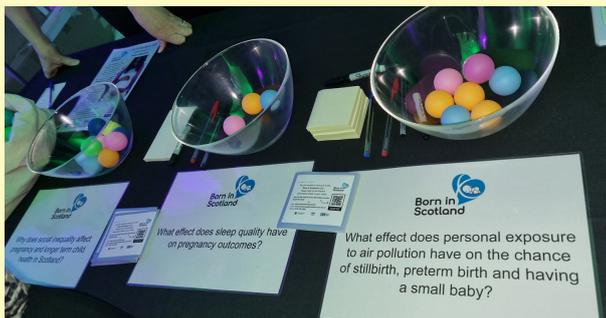


Born in Scotland Update

The latest news from the Born in Scotland Team

We've been delighted to have Born in Scotland (BiS) represented at a few events so far in 2023!

- **Our Planet, Our Health, Our Future** was an event at Dynamic Earth during the Edinburgh Science Festival in April. Our very own **Dr Rosie Townsend** (BiS Co-Investigator) gave a talk, **Our environment and pregnancy health, the foundation of the health of the community**, which highlighted the innovative nature of BiS being a digital birth cohort, designed to understand maternal and child health after pregnancy experiences. We also had a stall at the event where we asked attendees what research questions are important to them. The question with the most votes was **"Why does social inequality affect pregnancy and longer term child health in Scotland?"**



BiS Stall at *Our Planet, Our Health, Our Future*

- **Red4Research** is a day to highlight and celebrate research, created by NIHR (National Institute for Health and Care Research). **BiS** shared a stall with other research teams based at the Edinburgh Royal Infirmary and our poster was also available to view. We asked people to name our BiS Bunny!



- The annual **Centre for Cardiovascular Science (CVS) Symposium** was in June. **Born in Scotland** presented a poster. It was a great opportunity to share the latest updates with our CVS colleagues!
- We have now started collecting birth delivery samples from some BiS participants. See **page 4** for more details!



Introducing
Bunny
McBunFace

Born in Scotland Data Trust Update

Born in Scotland Data Trust has also had a busy few months:

- BiS Data Trust recently released an infographic which explains what the **Born in Scotland Data Trust** is:

DataTrusts

How we share information about ourselves is a big part of our life - from social media to the smart watches people wear every day, we share our data more widely than ever.

With lots of new ways to collect and combine data, there is an opportunity for health researchers to use it to improve public health and patient care.

However, with these new opportunities comes new questions about how data is used and by whom - have you considered how you prefer your data to be used?

As a researcher, it can be difficult to know the boundaries of what research participants find acceptable and how to use data in line with their interests and preferences.



If you choose to take part in health research, it can be hard to keep up with all the study developments and the different ways in which your data might be used.

Academics and health researchers from the **Universities of Warwick and Edinburgh**, and the **Association for Young People's Health** are exploring a different way of managing data in health research through something called a Data Trust. This is where a group of independent trustees are dedicated to representing your interests, to help shape how your data is used.

In a data trust, **trustees** have a legal duty to act in your best interests and to ensure that data is being used for the purposes you agreed it could be used for.

Trustees could also be experts who can make decisions about new or unanticipated ways of using your data on your behalf.



We know from other research that trustees could offer a way to manage data on behalf of people. But we don't know **HOW** this might work in health research and what **legal frameworks** are needed.



We are exploring how a data trust could work with participants in a **birth cohort study**. This is a study that follows a group of people and their babies born at the same time, throughout their lives to find out answers to questions like, for example, why are some babies born too early, or ill.



Our birth cohort study includes pregnant women and pregnant people, families, and carers, who consent to their data, and child's data, being used for research into the future.

Our goal is to find new ways to empower people to have a voice in how data is used for public benefit.



For more information about the research and to get involved, visit:



<https://bit.ly/datatrust1>

Let's build our data future together.....



- You can find it on our website along with a short animated video: www.ed.ac.uk/edinburgh-pregnancy-research/current-studies/born-in-scotland-data-trust
- **'Data Trusts: Lessons Learned and Future Directions' Symposium**, in May, was a multi-disciplinary symposium to share lessons learned from the Data Trust Initiative pilot projects, and was attended by BiS Data Trust.

Coming Up....

- We're aiming to open up recruitment for Born in Scotland in the Borders.
- We are planning more BiS Data Trust focus groups. These focus groups will ask participants whether the Data Trust model may be better for governance of personal data such as that gathered from wearable technology (eg watches that record heart rate).

Biological Sample Collections

The different biological samples we're collecting for Born in Scotland

Born in Scotland Antenatal Samples

As you may remember from our first **Born in Scotland** (BiS) Newsletter (Winter 2023), BiS is hoping to create a 'virtual cohort' - linking routine pregnancy data with routine childhood data so we can start to see patterns of how our time in the womb impacts long-term health and wellbeing. As it is currently a pilot study, we are testing various aspects of the study to see what works, where we need to make amendments and which aspects will scale up best.

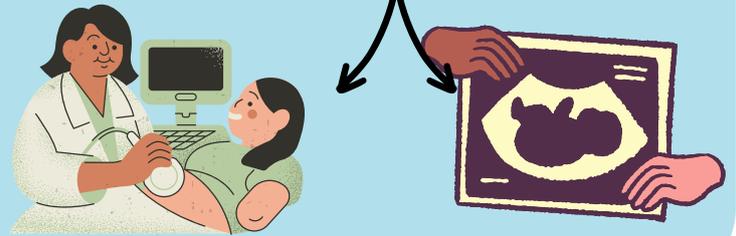
BiS has been designed to be as low impact on participants as possible. Participants complete the consent form, and there are no extra tests, surveys or appointments unless they have given consent to be approached for sub-studies.

We currently collect left over blood from the routine blood tests taken in pregnancy. In this pilot phase we need to know if routine blood

Born in Scotland Antenatal Samples

In **Born in Scotland** we're collecting routine pregnancy information including leftover blood from blood tests

and information from any ultrasound scans done during pregnancy



Pictures taken from Canva stock images

tests which are not taken under research conditions will still produce viable and reliable information, or do these samples degrade and are therefore unable to be used for research? To be able to answer this question, we have been looking at cotinine levels and DNA in leftover blood samples. Cotinine is a chemical which the body produces when exposed to nicotine, typically from cigarette smoking. DNA (deoxyribonucleic acid) are molecules in your body that contain all your genetic information, it's like your body's instruction manual for life. By looking at cotinine levels and DNA, we are establishing firstly if these leftover blood samples remain high enough quality for use in research; and secondly we are creating valuable data to contribute to global research into various factors which lead to pregnancy complications such as small for gestational age babies or stillbirths. This will help us find ways to prevent these pregnancy complications and improve perinatal (the time



Picture taken from Unsplash stock images

Biological Sample Collections Continued

during pregnancy, birth and the postnatal period) outcomes.

Born in Scotland Birth Samples

We have also started collecting delivery samples. When signing the BiS consent form, BiS participants have the option of agreeing to be contacted for further BiS research (which may include extra tests or appointments). For the collection of birth samples we approach BiS participants who are happy to be contacted about other research, and who are choosing a Caesarean birth. There is an additional consent process through the Edinburgh Reproductive Tissue BioBank (ERTBB). The samples are collected after all clinical checks have been completed and would otherwise be discarded.

We are collecting samples from the placenta, membranes, umbilical cord and cord blood. Again, this is in part to establish whether this is possible within the BiS study, and if it can



Pictures taken from Unsplash stock images

be scaled up, while highlighting any issues we may need to address beyond this pilot phase. As with the antenatal samples, we are also collecting data that may help to answer why some pregnancies develop complications. Any birth samples collected as part of BiS are kept within the Edinburgh Pregnancy Research Team (EPRT) ERTBB, which is a 'bank' of biological samples from the perinatal period.

As we discover new biomarkers for diseases of pregnancy, samples collected for BiS and ERTBB can help in vital research and may help in developing improved pregnancy care - whether that is helping to identify diagnostic criteria, physical or biological markers.

Early Findings

The antenatal blood samples collected so far look promising - despite not being collected or immediately preserved under research conditions, the initial results indicate the blood samples will produce high quality data for research purposes which the BiS team is delighted with!

Born in Scotland Birth Samples

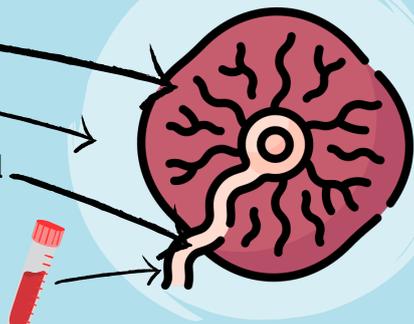
Born in Scotland has recently started collecting samples at the time of birth from some BiS participants, including:

placenta

membranes

umbilical cord

and umbilical
cord blood



This diagram has been designed using placenta image from Flaticon.com and other images from canva stock

The "1970 British Cohort Study"

Pregnancy Cohort studies have led to discoveries which have improved maternity care and public health

The 1970 British Cohort Study

The recruitment for The 1970 British Cohort Study (BCS70) was similar to both the National Survey of Health and Development (1946) and the National Child Development Study (1958), which we covered in previous newsletters. For the BCS70 around 17,000 births in one week across England, Scotland, Wales and Northern Ireland were included (although in subsequent 'sweeps' those from Northern Ireland weren't included). Again, similar to the last cohort study we looked at, it was originally a study focusing on perinatal mortality but this quickly broadened. Evidence from the BCS70 has been instrumental in developing key policies around education, training and employment.

The cohort are now in their early fifties and findings from their time at school are still referred to in debates on education now. It was found that children who read for pleasure had improved cognitive development which

positively impacted not only vocabulary and spelling, but also development and ability in maths!

Research from the BCS70 has also shown a link between childhood disadvantage and adult mental health.

Cohort studies let us see trends in groups of people. Sometimes they confirm things we suspected or already knew. Sometimes we find out things we didn't expect.

Some UK birth cohort studies:

- National Survey of Health and Development (1946)
- National Child Development Study (1958)
- 1970 British Cohort Study
- Millenium Cohort Study
- The Birthplace Cohort study
- Born In Bradford



Image from Unsplash

Since the initial birth study in 1970, the BCS70 has had nine "sweeps" of the full cohort at ages 5, 10, 16, 26, 30, 34, 38, 42 and 46, with some sub-studies. One sub-study looked at twins.

As with the 1946 and 1958 cohort studies, BCS70 is now run by the Centre of Longitudinal Studies, University College London (UCL).

For more information see their website:
<https://cls.ucl.ac.uk/cls-studies/1970-british-cohort-study/>

A cohort study is a 'longitudinal study' - which means it is over a long period of time, sometimes years. It also looks at a large group of people who are all similar in some way. In Born in Scotland our participants are all pregnant when they sign up.



Image from Unsplash

Family Summer Fun

Scottish Summers don't promise sun...!

Things to do indoors

- Be inspired by our article on page 5 looking at the 1970 British Cohort Study and read! Read to your bump, read to your baby, read together as a family.
- Make up a story with your child/ren. Take turns to say a sentence and see where their imagination takes you.
- Visit your local library and join in the Summer Reading Challenge.



Things to do outdoors

- Make the most of a sunny day and go for a picnic.
- Go for a rainy walk!
- Make some outdoor art - use chalk, or even just water on paintbrushes or water bottles for a temporary masterpiece.



Take on our Summer Quiz!

You have to be in it to win it...

Complete this quiz and submit it by **30/09/2023** to ResearchMidwives@NHSLothian.scot.nhs.uk for a chance to win a £10 shopping voucher!



1. At time of print, how many Born in Scotland participants were there?

- a) almost 1000
- b) almost 800
- c) almost 600
- d) almost 400

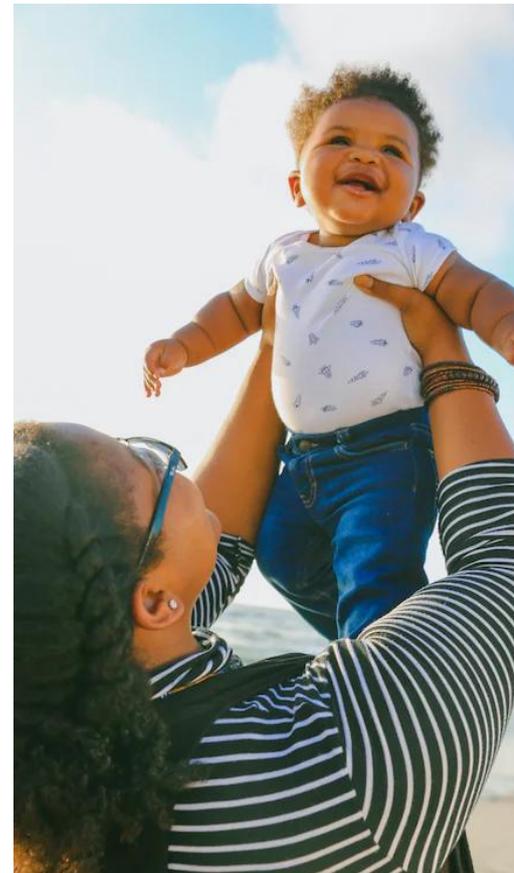
2. What are we looking at in the leftover blood samples?

- a) DNA
- b) Clotting factors
- c) DNA and cotinine
- d) Hb

3. What birth samples are we collecting?

- a) Ovarian sample
- b) Placenta and membranes
- c) Cord blood, sample of membranes, placenta and cord
- d) Umbilical cord

4. Write one of the family activities suggested on page 7



5. Remember to enter your details so we can contact you if you win!

Keep in touch!

There are a few ways to keep up to date with
Born in Scotland

Born in Scotland is a University of Edinburgh and NHS study being run by the Edinburgh Pregnancy Research Team (EPRT). EPRT is a team of midwives, doctors, researchers, laboratory assistants and research practitioners. You can follow our Born in Scotland social media pages, or contact us directly.



BiS Website - ed.ac.uk/cardiovascular-science/born-in-scotland

BiS Email - borninscotland@ed.ac.uk

EPRT Website - ed.ac.uk/edinburgh-pregnancy-research

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