**Patient Notification**

**Congenital Hypothyroidism: Prevalence and Risk Factors**

**Who are we?**

We are researchers at University College London (UCL) Great Ormond Street Institute of Child Health.

**What is congenital hypothyroidism?**

Hypothyroidism is the name given to the condition resulting from an underactive thyroid gland; this means that the thyroid is not producing enough thyroid hormone for the body’s healthy growth and development. Children who are born with congenital hypothyroidism are born without a thyroid gland, a thyroid gland that has not developed properly, or is in the wrong position, or a thyroid gland that is not producing enough thyroid hormones. Without early detection and treatment, congenital hypothyroidism can result in severe learning disability.

**Why are we doing this project?**

All children in the UK are offered screening for several rare conditions at five days of age. One of these conditions is congenital hypothyroidism. Since the start of newborn screening for congenital hypothyroidism 40 years ago, there has been an increase in the proportion of babies born with this condition, particularly a type called congenital hypothyroidism with gland in situ (CH-GIS). We do not know why CH-GIS is becoming more common, or how it affects health, development and learning as children grow up. We want to know why more babies are being diagnosed with CH-GIS, and what health and development is like for children living with this condition.

**The data used in this project**

This study will include data from babies born in the North Thames region (including North London, Bedfordshire, Hertfordshire and Essex) and whose newborn screening blood spot samples were tested at the Great Ormond Street Hospital (GOSH) newborn screening laboratory between January 2000 and December 2020.

The following data sources will be used to create the study dataset:

* North Thames Newborn Screening Database. This database contains demographic data and screening test results.
* GOSH Congenital Hypothyroidism Database. This dataset contains information on 1800 children who have screened positive for congenital hypothyroidism through the North Thames newborn screening programme since 2006. The database also contains genetic data for ~50 children with congenital hypothyroidism.
* Hospital Episode Statistics (HES). HES contains data on all admissions to NHS hospitals, Accident and Emergency (A&E) attendances and outpatient bookings.
* Births and Death registration data from the Office of National Statistics (ONS).
* Department for Education (DfE) National Pupil Database (NPD). This database holds data on demographics, phonics and key stage results, and special educational needs provision for all children in state primary and secondary schools; 93% of all school children in England.
* NHS Business Service Authority (NHSBSA) community dispensing data, which contains data on medicines dispensed in community (non-hospital) pharmacies.

The study dataset will be de-personalised, meaning researchers analysing the dataset will not be able to see identifying information such as NHS numbers, names, or addresses.

**Where do I find more information about the study?**

You can find more information about this research study on our website (<https://www.ucl.ac.uk/child-health/research/population-policy-and-practice/child-health-informatics-group>) where you will also find a Privacy Notice (<https://www.ucl.ac.uk/child-health/research/population-policy-and-practice-research-and-teaching-department/cenb-clinical-4>) with more information on how we comply with general data protection regulations (GDPR).

**How do I contact the Research team?**

If you would like to know more about the project and how we use your data, please contact the principal investigator, Dr Pia Hardelid via email, or by phone or post, via the UCL Great Ormond Street Institute of Child Health:

UCL Great Ormond Street Institute of Child Health

30 Guilford Street

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Telephone: 020 7242 9789/020 7905 2000

Email: p.hardelid@ucl.ac.uk

**What if I do not want my data (or child’s data) to be used in this study?**

You are entitled to object to your data, or your child’s data (if you are their legal guardian), being used for this study. The UCL research team will not be able to identify you and cannot remove your records from the study directly at your request. However, if you do not wish your, or your child’s, data to be used for this study, please contact us, using the contact details above.