

## What is the British Paediatric Surveillance Unit (BPSU)?

The aim of the BPSU is to encourage the study of rare conditions in children. It was founded in 1986 by the Royal College of Paediatrics and Child Health, Public Health England and the University College London- Institute of Child Health.

### What does the BPSU do?

It allows doctors and researchers to find out how many children in the UK and the Republic of Ireland are affected by a particular disease or condition each year - this is called epidemiological surveillance. Doctors can also gather information about all the cases of a particular rare condition to study what might have caused it, how to diagnose and treat it. Future patients with rare conditions will benefit from it.

### How does the BPSU work?

Each month the BPSU sends an orange card to almost 3500 consultant paediatricians and specialists; the card lists the rare conditions currently being studied. If a doctor has seen a child affected by one of these conditions they tick a box on the card and send it back. The BPSU informs the research team who send the doctor a short confidential questionnaire asking for more information. Researchers are not told the names and addresses of patients, and families are not contacted.

### What has the BPSU achieved?

The BPSU has now helped to undertake surveys of over 90 rare conditions which may affect children. These have helped to increase understanding of why the conditions occur and can help to provide better diagnoses and treatments.

### For further information, contact

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BRITISH PAEDIATRIC SURVEILLANCE UNIT

## Public Information Sheet

# Pierre Robin Sequence

This leaflet provides information about a new study of Pierre Robin Sequence. It aims to provide information about the condition, why this study is important and what we hope to show by doing it. It also provides contact details of the researchers undertaking the study and a link to the website where the results will be published.

## What is Pierre Robin Sequence?

Pierre Robin Sequence (PRS) is a condition present from birth which causes babies to have a small jaw, cleft palate, and large tongue. Together, these features can cause affected babies to have problems with their breathing and feeding in the new-born period and early childhood.

## What treatment is available?

In some cases feeding difficulties can be overcome by using special feeding bottles, and mild breathing problems can be treated by nursing the baby on their front to move the jaw and tongue forward. In more severe cases some babies may need support from an artificial airway or feeding tube for a period of time until their jaw grows. In the most severe of cases an operation may be needed to help the child to breathe safely.

## Why does Pierre Robin Sequence develop?

We do not yet fully understand what causes PRS to develop. In some cases it seems to run in families. In other cases it may be caused by the baby having a lack of space in the womb which may prevent their jaw from growing normally.

## What are the aims of this study?

Currently we do not know how many babies in the UK and Ireland are affected by PRS, or the best ways to manage any feeding and breathing difficulties they may have.

With this study, we aim to identify how many babies with PRS are born in the UK and Ireland over a 13 month period. We will gather information about the breathing and feeding difficulties these children encounter and how they are treated. We will follow these children up at 12 months to find out what treatment they have required and whether their problems have resolved.

We hope that the results of this study will help us to better understand how common PRS is, which health professionals are involved in treating affected children, and how children with PRS progress over time.

## How will the information be collected?

Doctors caring for children with PRS will be asked to complete a confidential questionnaire about each baby's medical condition in the newborn period. A second questionnaire will be sent after 12 months to collect more anonymous information about each baby's progress.

The doctors completing the questionnaire will not disclose the babies' names or addresses to the researchers, and confidentiality will be maintained at all times. The care and treatment that children included in the study will receive will not change as a result of their participation in this study. Information collected will not identify any individual and confidentiality will be maintained at all times.

The NHS uses medical records for audit or research to improve future health and care, which includes sharing information with

doctors who run BPSU research studies. More information about this can be found in the following leaflet:

[www.nhs.uk/Conditions/Clinical-trials/Documents/Research1.pdf](http://www.nhs.uk/Conditions/Clinical-trials/Documents/Research1.pdf)

If a patient (or legal guardian) does not want their notes to be used for audit or research, this is known as dissent. If you want to dissent from your NHS records being used for any type of research, which includes your information being used in BPSU studies, you must let your GP and hospital doctors know so that this can be recorded clearly in your medical notes. Dissenting from participation in research will not change the care you receive from your doctors or medical team in any way.

## Where is this study happening?

The study will be taking place across the United Kingdom, the Republic of Ireland and we hope to collect information about all babies in the UK and Republic of Ireland with PRS.

## How long will the study go on for?

The study will initially take place over a 13 month period starting in January 2016.

## Who is supporting this study?

This study is being funded by the Sir Peter Tizard Research Bursary and is supported by the Cleft Lip and Palate Association ([www.clapa.com](http://www.clapa.com)).

## Who to contact if you have any questions

Dr Marie Wright, Specialty Registrar in Paediatric Respiratory Medicine, Royal Brompton Hospital, Sydney Street, London SW3 6NP

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## Further information

**BPSU:** <http://www.rcpch.ac.uk/bpsu/prs>

**Cleft Lip and Palate Association:** <http://www.clapa.com>