Surveillance of BPSU Rare Childhood Disease

BRITISH PAEDIATRIC SURVEILLANCE UNIT

BPSU Five-Year Report 2021-2025

BPSU aims

1. To facilitate research into uncommon childhood infections and disorders for the advancement of knowledge and to enable practical improvement in prevention, treatment and service planning.

2. To allow paediatricians to participate in the surveillance of uncommon disorders and to lessen the burden on reporting clinicians of such requests arising from various sources.

3. Increase awareness within the medical profession of the less common disorders studied, and respond rapidly to public health emergencies.

BPSU PARTNERS

Department of Health & Social Care

RCPCH Royal College of Paediatrics and Child Health *Leading the way in Children's Health*

UCL GREAT ORMOND STREET INSTITUTE OF CHILD HEALTH

WITH SUPPORT FROM

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Welcome

Welcome to the BPSU's first multi-year report, bringing together the collective work of the BPSU between 2021 and 2025, a period marked by challenges as well as innovation and transformation across child health research and clinical practice. This report reflects the vital contributions of clinicians, researchers, patient and public representatives, and partners across the UK and Republic of Ireland, whose dedication makes national surveillance possible. We are especially grateful to our reporting clinicians - your engagement is vital to the sustainability of the BPSU's work.

Over the past five years, the BPSU has continued to advance understanding of rare and complex paediatric conditions. This report highlights the studies that have been conducted and demonstrates the impact of our collaborative approach. All of this work leads us towards our 40th Anniversary in July 2026, celebrating four decades of surveillance, research, and service to children and families across the UK and Republic of Ireland.

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Foreword from our Chair

Dr Peter Davis

It is a great privilege to introduce this five-year British Paediatric Surveillance Unit report at a particularly significant moment for the BPSU as we mark our 40th anniversary. Over the past four decades, the BPSU has built a worldwide reputation for excellence in the surveillance of rare childhood conditions, and this report reflects the continued relevance and impact of that work over the last five years.

At the heart of the BPSU's success remains the commitment and support of paediatricians and clinicians across the UK and Ireland. Their engagement and involvement continues to underpin the high-quality data that makes this programme possible. I would like to extend my sincere thanks to all those who, alongside their very busy clinical roles, contribute their time and expertise to completing the monthly "Orange Card" emails and reporting cases of conditions that they have seen. This report showcases an impressive and important body of BPSU studies, addressing a wide range of rare serious conditions and events affecting children. These studies not only advance our understanding of diseases and conditions but can also directly inform clinical practice, policy, and service development. I am grateful to the many research teams whose dedication and collaboration drive this work forward, as well as to the NHS trusts, universities, and organisations that have supported and enabled these studies.

Over the past five years, the BPSU has continued to evolve. We have expanded our engagement with the paediatric community through initiatives such as webinars and strengthened links with subspecialty groups, helping to ensure that our portfolio of studies reflects both clinical priorities and emerging challenges. I would like to thank the Scientific Committee members who have brought a breadth of expertise and a shared commitment to improving child health through high-quality research when reviewing study applications.

The BPSU office team has played a central role in delivering this work, managing a wide range of activities, from study coordination and communications to the development and oversight of new data collection systems. Their efforts have been instrumental in maintaining the Unit's programme of work during a period of significant change in the last five years.

We are grateful for the continued support and collaboration of our key partner organisations, including the Royal College of Paediatrics and Child Health, UCL Great Ormond Street Institute of Child Health, the Department of Health and Social Care, and Great Ormond Street Children's Charity. Their ongoing commitment and partnership are fundamental to the success and impact of the BPSU's work. During the last five years, we have also engaged with developments such as the UK Rare Disease Framework and Forum, highlighting the importance of rare disease surveillance, as well as maintaining our links with rare disease charities.

As we celebrate 40 years of the BPSU, we are also looking ahead. Sustaining and strengthening clinician engagement remains a key priority, alongside continuing to innovate in how we collect data and support research. As clinical practice develops and the recognition of rare diseases through developments such as genomics expands, the need for robust surveillance of rare conditions and events in children is as important as ever, and in potential collaboration with others, the BPSU is well placed to meet this challenge.

I hope that you find this report both informative and inspiring, while also highlighting the collective achievement of all those involved in the BPSU's work.

Dr Peter Davis, Chair of the BPSU Scientific Committee

BPSU governance

High-quality rare disease surveillance depends on trust. Clinicians need confidence that the data they share is handled responsibly, decisions are made transparently, and studies are reviewed with scientific and ethical rigour. The BPSU's governance structures exist to protect that trust and ensure that surveillance continues to serve children, families and the wider health system.

BPSU Governance: Scientific Committee and Partnership Board

Two governance bodies oversee the BPSU: the Scientific Committee and the Partnership Board. Together, they ensure the surveillance programme is robust, ethical, and responsive to the needs of the children, families, and the wider paediatric community.

The BPSU Partnership Board

The Partnership Board (established in 2014) provides strategic oversight of the BPSU, ensuring that the unit is developed, managed, and maintained effectively. It comprises senior representatives from the BPSU's three parent organisations: Royal College of Paediatrics and Child Health (RCPCH), Department of Health and Social Care (DHSC), UCL Great Ormond Street Institute of Child Health (UCL-GOS-ICH) with support from Great Ormond Street Children's Charity.

Current Partnership Board Members:

- Justine Fitzpatrick, Deputy Director, Population Health Analysis, DHSC
- Emily Arkell, Executive Director of Research and Quality Improvement, RCPCH
- Professor Paul Dimitri, Vice President for Science and Research, RCPCH
- Dr Rachel Knowles, Paediatric Epidemiologist and Consultant in Public Health Medicine, UCL-GOS-ICH
- Professor Helen Cross, Director of UCL-GOS-ICH

The BPSU Scientific Committee

The Scientific Committee oversees the scientific matters of the BPSU, providing guidance and support for researchers undertaking surveillance of rare paediatric disorders through the reporting scheme. The Committee ensures that all studies are ethically robust and methodologically sound.

The Scientific Committee brings together a diverse range of expertise. Members include:

- A Chair and Deputy Chair
- Three to four medical advisers
- Two to three Patient and Public Involvement (PPI) representatives
- A Republic of Ireland representative
- Trainee representatives
- Clinical and academic experts with a strong interest in child health research from a wide variety of speciality backgrounds such as neonatology, infectious disease, and endocrinology

This multidisciplinary composition ensures that the BPSU's surveillance activities benefit from high-level professional, academic, and lived experience perspectives.

A full list of all Scientific Committee members who have served during 2021–25 can be found at the end of this report.

"The BPSU's work continues to play a crucial role in identifying emerging trends, supporting early diagnosis, and informing national policy. By enabling clinicians to contribute data on rare disorders, the BPSU provides an unparalleled evidence base that shapes research priorities and improves outcomes for children and families."

Emily Arkell, Partner of the BPSU, Executive Director of Research and Quality Improvement, RCPCH

BPSU Governance: Scientific Committee and Partnership Board

Spotlight: Patient and Public Representatives

The BPSU is proud to work closely with our Patient and Public Involvement (PPI) representatives, who play a vital role in shaping our research and surveillance activities. Their insights ensure that the perspectives of children, families, and carers are at the heart of our studies.

Over the past five years, PPI representatives have:

- Provided advice on study design and questionnaires to make the research more relevant and accessible to families.
- Reviewed study information materials, ensuring clarity and sensitivity for participants.
- Contributed to Scientific Committee discussions, helping prioritise research questions and interpret findings from a patient perspective.

Their dedication strengthens the BPSU's mission and ensures that the voices of children and families inform paediatric research and surveillance.

Thank you to all our PPI representatives for their invaluable contributions!

"As a parent of a child with a rare disease, not knowing and not being heard carries heavy burdens. Families with rare diseases often feel isolated and face long diagnostic journeys. The BPSU ensures the active engagement of its PPI representatives so that the patient and public voice is heard throughout the research design phase of each study, and beyond. By involving PPI representatives, the BPSU ensures that studies are not just scientifically sound but also socially acceptable and beneficial to the patient community.

The patient voice helps create more accessible and user-friendly public information leaflets, and helps researchers understand the patient perspective, which can lead to better clinical practice and improved care.

It is a shining example of how systematic, patient-centred, and collaborative research can bridge the gap between "not knowing" and "having hope" so that even the rarest of childhood conditions are not overlooked, providing answers that can have a positive impact on improving the way health and care services are funded."

Madeleine Wang, BPSU Scientific Committee Patient and Public Representative

BPSU activities

Surveillance requires strong engagement. Behind our data are thousands of clinicians who actively report, respond and stay connected to the BPSU. Over the past five years, the BPSU's activities, ranging from collaborations and outreach to strategic initiatives, have supported this engagement, ensuring that rare disease surveillance remains visible and valued across the UK and the Republic of Ireland.

How the BPSU works

Rare and complex paediatric conditions, while individually uncommon, collectively affect thousands of children in the UK and Republic of Ireland. The BPSU was established in July 1985 to enable consultant paediatricians to actively identify, report, and study these conditions, generating high-quality data to inform research, clinical practice, and policy. The BPSU operates an active surveillance system, sending monthly eCards to consultant paediatricians across the UK and Republic of Ireland. Clinicians are expected to respond even if they have no cases to report, ensuring accurate monitoring and completeness of reporting.

Figure 1: How the BPSU reporting system works

BPSU surveillance activity (2021–2025)

Surveillance activity

Between 2021 and 2025, the BPSU continued its active surveillance of rare and complex paediatric conditions across the UK and Republic of Ireland, supporting clinicians and researchers in the identification and study of uncommon childhood disorders.

During this period, several new studies commenced:

- Avoidant/Restrictive Food Intake Disorder (ARFID)
- Button battery ingestion, inhalation, or insertion
- Neonatal stroke
- Near-fatal asthma
- Acute hepatitis in children
- Rapid-onset obesity with hypothalamic dysfunction (ROHHAD)

In addition, several existing studies had their surveillance extended:

- Herpes simplex virus infection
- Neonatal complications of COVID-19
- Multisystem inflammatory syndrome, Kawasaki disease, and toxic shock syndrome
- Chronic recurrent multifocal osteomyelitis/ chronic nonbacterial osteomyelitis (CRMO/CNO)

Overall, the 2021–25 period reflects a continued expansion of the BPSU's portfolio, with new studies addressing emerging paediatric issues and extended surveillance ensuring ongoing data collection for established conditions.

Participation in the scheme

The notable decline in reporting rates seen between 2021 and 2023 could reflect the significant pressures facing paediatric services during and following the COVID-19 pandemic. Increased clinical demand, service backlogs, workforce shortages and staff burnout may have affected the capacity of clinicians to undertake activities beyond direct patient care, including surveillance reporting.

Evidence from the RCPCH's 2024 rota gaps survey highlighted the scale of these workforce challenges. Paediatric services across England, Scotland and Northern Ireland were operating with rota gaps of over 20%, with combined general paediatric and neonatal rotas among the most affected. The survey identified less than full-time working and insufficient trainee allocation as the principal causes of these gaps, against a backdrop of increasing demand, post-pandemic referral backlogs and growing workforce pressures.

These challenges to a certain extent may have affected participation in the BPSU surveillance scheme through 2022 and 2023. In addition, the acclimatisation of participating clinicians to the new data collection platform in 2023 led to a reduced response rate of approximately 67%.

To address this decline, the BPSU undertook a comprehensive review of its participant database in 2024. Records were audited to remove clinicians who had retired or moved hospitals, update contact details and ensure reporting responsibilities were assigned appropriately.

Early indications suggest these interventions have had a positive impact. The estimated average response rate increased to 79% in 2024 and remained at 79% in 2025 based on data available to date.

Continued monitoring and engagement with participants will help maintain high reporting rates and ensure the surveillance system continues to capture robust and representative data on rare childhood conditions.

DO YOU RECEIVE OUR REPORTING CARDS?

SCAN TO SIGN UP

Reporting patterns

Understanding how many cases clinicians report helps illustrate engagement with the BPSU surveillance system and the effort required to support national monitoring. This section summarises the distribution of reporting activity, showing how many clinicians submitted single cases, multiple cases, or a larger number of cases during the 2021–2025 period. Between January 2021 and December 2025, there were a total of 4571 cases reported to the BPSU.

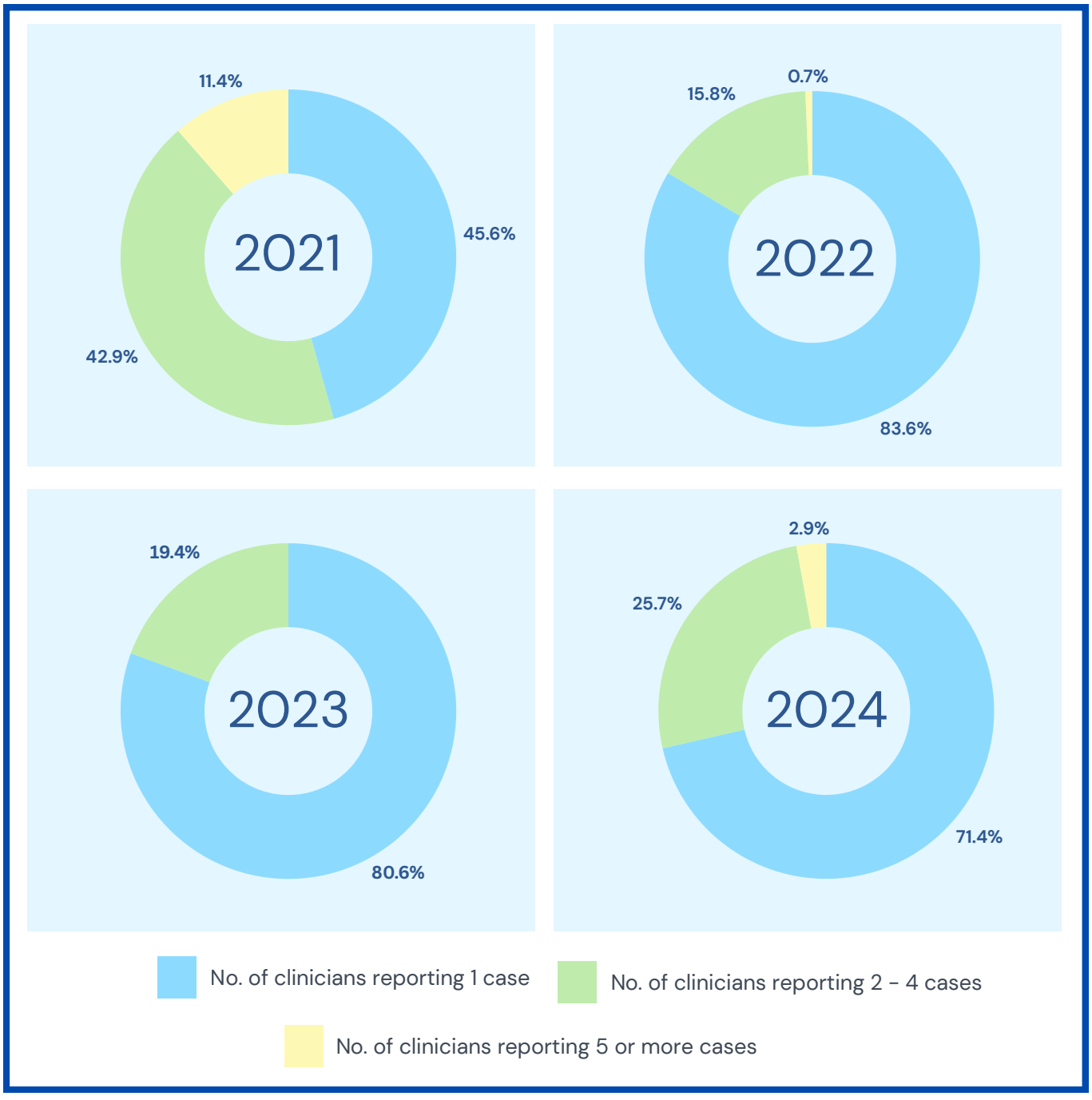

Figure 2: Percentage breakdown of number of cases reported by paediatricians on the BPSU scheme

BPSU regional response rates

Monitoring eCard return rates across regions helps us understand clinician engagement and ensures comprehensive surveillance of rare paediatric conditions. The map below illustrates reporting compliance across the UK and Republic of Ireland, highlighting areas of strong participation and identifying opportunities for improvement.

Figure 3: Map displaying regional response rates as of 2025

UPDATE YOUR DETAILS WITH US

BPSU engagement activities

Webinars

The BPSU continues to promote learning and collaboration through its regular webinar series, which provides opportunities for researchers to share study findings and for clinicians to learn about emerging and rare paediatric conditions. These webinars are open to all members of the paediatric community and aim to translate surveillance data into meaningful clinical and public health insight. We have held the following webinars, many of which have recordings available.

- Behcet's Syndrome in children and young people (2021)
- Type 2 Diabetes in Children and Young People (2021)
- Lead Toxicity in Children – a continuing problem (2021)
- Listeria infection in Young Infants in the context of neonatal infections (2022)
- Juvenile-onset Systemic Lupus Erythematosus (2023)
- Vision impairment is a sentinel child health event: findings from the British Childhood Vision Impairment Study (2024)
- ARFID in Children and Young People Study – What did we learn? (2024)
- Don't forget rheumatic fever (2025)

BPSU Rare Disease Symposium

To mark World Rare Disease Day 2023, the BPSU hosted a Rare Disease Symposium at the Royal College of Paediatrics and Child Health on 28 February 2023. This was the first BPSU symposium in three years and provided an excellent opportunity to highlight current developments and collaborative efforts across the UK's rare disease landscape.

The event brought together leaders from government, healthcare, academia, and the voluntary sector to share progress and priorities in rare disease research, policy, and care delivery. Reflecting the diversity of the field, the symposium explored themes such as national rare disease strategies, emerging clinical services, surveillance innovation, and public engagement.

The symposium received excellent feedback and underscored the importance of partnership and cross-sector collaboration.

ARE YOU INTERESTED IN LEARNING MORE FROM OUR WEBINARS?

BPSU at RCPCH Conference 2025

We were proud to play an active role at the RCPCH Conference 2025, hosted at the SEC, Glasgow. As a leading centre for rare paediatric disease surveillance, we used this opportunity to connect with the wider paediatric community, raise awareness of our work, and engage with clinicians and researchers.

The BPSU collaborated closely with the RCPCH and leading charities, academics, and industry partners to deliver a compelling programme across several days. The Rare Disease Hub featured presentations, panel discussions, and networking opportunities. We hosted two workshops:

- Understanding Rare Disease: From Genomics to Surveillance – This interactive workshop explored how genomic advances intersect with population-level surveillance. We discussed how early genetic diagnosis can be linked to long-term follow-up via the BPSU system, helping improve understanding of disease progression and outcomes.
- Rare Disease and the Paediatrician – In our presentation, we highlighted the vital role paediatricians play in identifying rare conditions, reporting them through the BPSU eCard system, and contributing to evidence that can shape clinical care and public health policy.

Sir Peter Tizard Bursary

Purpose and background

The Sir Peter Tizard Bursary, offered annually by the BPSU, honours the pioneering work of Professor Sir Peter Tizard, a leading figure in British neonatology. The award is designed to nurture the next generation of paediatricians by enabling early-career paediatricians to lead national surveillance studies on rare childhood diseases — conditions that are often under-researched but have a profound impact on affected children and families.

Each year, the successful applicant receives a bursary to fund a BPSU surveillance study. The Bursary also provides a stipend to support their training and development, ensuring they can build both the practical skills and the confidence to lead high-quality epidemiological research.

By targeting clinicians who may not yet be research-active, the Bursary opens the door to new voices and perspectives in rare disease research. It contributes directly to the evidence base needed for improved diagnosis, treatment, and policy development, while helping embed a culture of research in everyday clinical practice.

Impact and significance

These awards have empowered early-career clinicians to lead surveillance studies with nationwide reach, enabling the collection of critical, actionable data on rare conditions. This aligns strongly with the BPSU's mission to broaden research participation and enhance paediatric surveillance in the UK and Republic of Ireland.

The outcomes are tangible: findings have informed clinical guidelines, shaped future research priorities, and strengthened the evidence base for rare childhood diseases. For example, one Bursary-run study on Chronic Recurrent Multifocal Osteomyelitis CRMO) collected the most comprehensive surveillance data on the condition to date. It identified important differences in disease presentation between male and female patients and established a crucial baseline for ongoing research. These results are now encouraging improvements in both care and care guidelines for children living with CRMO.

By supporting studies like these, the bursary not only develops the skills of emerging clinician-researchers, but also delivers evidence that can directly influence practice and policy, ultimately improving the lives of children and families affected by rare diseases.

Bursary winners

From 2021-25 the Sir Peter Tizard Bursary has been awarded to the following early-career paediatricians:

- 2021–22: Natural History of Epilepsy in Children after Cooling for Neonatal Hypoxic-Ischaemic Encephalopathy — Dr Alessandra Glover Williams
- 2022–23: The Incidence of Hospital Admission with Carbon Monoxide Poisoning in UK Children — Dr Ilsa Haeusler
- 2023–24: The Incidence, Diagnosis and Management of Congenital Hyperinsulinism (CHI) in the UK — Dr Helen Couch
- 2024-25: Acute Infectious Myocarditis in Children - Dr Sally Siu

INTERESTED IN RUNNING A SURVEILLANCE STUDY?

Publication highlights and surveillance studies

Over the past five years, the BPSU's studies have not only expanded understanding of rare and complex paediatric conditions but have also informed clinical practice, policy, and research priorities. This chapter highlights the breadth and impact of that work, showcasing how data collected through national surveillance translates into evidence that makes a real difference for children and families.

Publication highlights

Over the past four years, BPSU surveillance studies have produced an impressive range of publications in peer-reviewed journals. These findings have informed clinical care, public health policy, and future research priorities across the UK and Ireland.

Between 2021 and 2025 there have been a total of 35 BPSU studies published as either abstracts or papers in peer-reviewed journals. Details of the papers can be found in the appendix.

Publications from 2025

In 2025, BPSU publications continued to demonstrate the value of national paediatric surveillance in identifying rare but serious childhood conditions and informing clinical care. Research on **Progressive Intellectual and Neurological Deterioration (PIND)**, published in both Developmental Medicine & Child Neurology and Archives of Disease in Childhood, provided updated epidemiological insights from over two decades of surveillance and confirmed the continued absence of new childhood cases of variant Creutzfeldt–Jakob disease (vCJD) in the UK after 27 years of active monitoring.

A national study of **Herpes Simplex Virus** infection in infants under 90 days, published in Archives of Disease in Childhood, described the burden, presentation, and outcomes of neonatal and early infant HSV disease across the UK and Ireland, highlighting the importance of rapid recognition and treatment in this vulnerable age group.

Additional 2025 outputs included the first nationwide prospective study o**f Severe Accidental Poisonings** in children, which characterised the substances involved, clinical severity, and patterns of harm associated with poisoning episodes requiring paediatric care. The findings provide important evidence to support prevention strategies, public health messaging, and clinical management of serious accidental poisonings in children.

Publications from 2024

This year saw a cluster of publications, reflecting the breadth of BPSU research. A series of papers on **Avoidant/Restrictive Food Intake Disorder (ARFID)**, published in BMJ Open, Archives of Disease in Childhood, eClinicalMedicine (The Lancet) and Cutting Edge Psychiatry in Practice, offered the first UK and Republic of Ireland wide data on the incidence, clinical presentation, and management of ARFID, as well as identifying distinct subtypes. These findings will guide both paediatric and psychiatric services in recognising and treating the disorder.

Other 2024 outputs included the first national study of **Glucocorticoid-Induced Adrenal Suppression**, revealing the scale and clinical features of this serious treatment side-effect, and the most comprehensive surveillance to date of **Chronic Recurrent Multifocal Osteomyelitis (CRMO)**, which uncovered key differences in presentation between boys and girls. Research on Pierre Robin Sequence improved understanding of airway management in affected infants, while a major **Neonatal COVID-19** follow-up study assessed developmental, respiratory, and healthcare impacts in early childhood. Additional studies reported on Severe Chronic Fatigue/ME in young people, refining management recommendations.

Publications from 2023

Published BPSU studies in 2023 spanned infectious disease, neurodevelopmental disorders, and rare congenital conditions. Work on **Neonatal COVID-19** described how different SARS-CoV-2 variants affected outcomes in hospitalised newborns. Publications on **Haemolytic Uraemic Syndrome** and **Sydenham's Chorea** provided vital epidemiological data to inform diagnosis and treatment. Studies on **Fetal Alcohol Syndrome** and **Severe Microcephaly** shed light on prevalence and associated disabilities, supporting early intervention strategies.

Groundbreaking research into **Pierre Robin Sequence** delivered the first active surveillance-based epidemiology of the condition in the UK and Republic of Ireland, while investigations into **Glucocorticoid-Induced Adrenal Suppression** highlighted the need for heightened clinical awareness. Rare dermatological and metabolic conditions were also addressed, including national surveillance on **Congenital Ichthyosis.**

Publications from 2022

Outputs from 2022 advanced knowledge on visual impairment, autoimmune disorders, and rare paediatric syndromes. Studies from the **British Childhood Visual Impairment and**

Blindness Study examined the role of screening and surveillance in early detection, as well as avoidable causes of blindness in high-income countries. National surveillance identified key ṣocio-demographic features of children and adolescents with **Gender Dysphoria**, and the first prospective epidemiological study of **Juvenile-Onset Systemic Lupus Erythematosus** in the UK and Republic of Ireland provided a benchmark for clinical services.

Additional publications included data on **Behçet's Syndrome** in young people and a protocol for a national Neonatal Stroke study, setting the stage for future research.

Publications from 2021

Early in this reporting period, BPSU research contributed critical insights during the COVID-19 pandemic, with landmark studies on **Multisystem Inflammatory Syndrome (PIMS-TS) and Neonatal COVID-19 in** The Lancet. Other surveillance studies published in 2021 detailed the incidence and outcomes of Listeria Infection in infants, **Food Protein-Induced Enterocolitis Syndrome (FPIES),** and **Life-Threatening Bronchopulmonary Dysplasia**. Research on surgical management of Patent Ductus Arteriosus informed neonatal care practice, while work from the **British Childhood Visual Impairment and Blindness Study** tracked temporal trends in severe vision impairment.

Congenital rubella

January 1990 - April 2022

Key details

What is already known on this topic?
Congenital rubella syndrome (CRS) can cause serious birth defects if rubella is contracted during early pregnancy. Surveillance had been ongoing for over 30 years, but cases are now rare in the UK due to high vaccination coverage. Antenatal screening was discontinued in England in 2016.

What the surveillance adds
Since 2005, only 13 confirmed cases have been reported, mostly in children born to mothers infected abroad. No cases were reported to the BPSU between April 2021 and March 2022. CRS remains a risk for unvaccinated women, especially through travel or migration.

How this surveillance affects research, practice, or policy
Continued surveillance is essential to monitor rare cases and inform public health policy. Findings support the need for awareness among clinicians and public health teams, particularly regarding travel-related exposure risks.

Introduction

Rubella has been a notifiable disease since 1988 and is monitored by the UK Health Security Agency (UKHSA) rubella surveillance programme team, part of the National Infection Service based at UKHSA Colindale. In addition, the Integrated Screening Outcomes Surveillance Service (ISOSS), part of the NHS Infectious Diseases in Pregnancy Screening (IDPS) programme, previously undertook national surveillance of congenital rubella (CR) cases in England. This was an important measure for the immediate period following the discontinuation of screening for rubella susceptibility in pregnant women in England in April 2016.

The IDPS programme commissioned the BPSU to provide case notifications of CR in England to the ISOSS team based at UCL's Institute of Child Health. Data collected on confirmed cases of CR were then reviewed with the IDPS and NIS team to ascertain contributory factors until 2022 and inform any potential policy or programme reviews. However there were no cases reported through the surveillance.

Analysis

Between April 2021 and March 2022 there were no reports of CR to the BPSU. Since active surveillance was established 35 years ago, 68 children and 4 stillborn infants with confirmed or compatible CR have been born and reported; 54 (76%) reported through the BPSU notifications.

From 2005-2018 there have been 13 confirmed reports of CR. None of the mothers were UK-born, and none had a previous pregnancy in the UK. 7 of the women acquired their infection abroad in early pregnancy and 6 were exposed to rubella in the UK.

Discussion

Very few cases of CR have been reported in the last decade, with none since 2018. Most reports concern infants with neonatal symptoms who also had serious rubella-associated defects identified at birth or soon afterwards. In the last 15 years, only half of the maternal infections were acquired in the UK. Pregnant women may enter the UK having acquired infection in early pregnancy elsewhere, and susceptible women resident in the UK who travel abroad during early pregnancy may also come into contact with rubella.

All health professionals, particularly paediatricians, those working in primary care and antenatal care, or with refugees or other recent migrants, must continue to be aware of the potential serious implications of rash or rash illness in early pregnancy. Updated guidelines for the management of viral rash in pregnancy and a quick reference guide are available via the UKHSA Viral illness (plus syphilis) in pregnancy document.

Since cessation of rubella susceptibility screening in pregnancy in 2016, there have been no cases of CR reported where the mother acquired rubella in the UK. To achieve continued population level control of rubella, the key action is still MMR vaccination. The measles and rubella elimination

UK strategy 2019 focuses on 4 core components required to maintain elimination of measles and rubella:

- Achieve and sustain ≥ 95% coverage in the routine childhood programme.
- Achieve ≥ 95% coverage with 2 doses of MMR vaccine in older age cohorts through opportunistic and targeted catch-up.
- Strengthen measles and rubella surveillance.
- Ensure easy access to high-quality, evidence-based information.

Funding

The NHS England Infectious Diseases in Pregnancy Screening Programme.

ISOSS

Integrated Screening Outcomes Surveillance Service (ISOSS) is part of the NHSE Infectious Diseases in Pregnancy Screening (IDPS) Programme, commissioned by NHS England. ISOSS conducts surveillance of the three infections screened for in pregnancy: HIV, hepatitis B and syphilis and follows up all infants exposed to these infections and any vertical transmissions in infants born in England.

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Progressive intellectual and neurological deterioration

May 1997 - December 2023

Key details

What is already known on this topic?
After variant Creutzfeldt-Jakob disease (vCJD) was reported in adults in 1996, surveillance in children became a public health priority.

What this study adds
Six children with vCJD were identified. No cases have been detected in the UK since the last two children died in 2003.

How this study might affect research, practice, or policy
The progressive intellectual and neurological deterioration (PIND) study has provided the only means of screening UK children for vCJD. It is not clear how this screening will be carried out now that the study has ended.

Introduction

In 1997 a new variant of Creutzfeldt-Jakob disease (vCJD) was reported in adults, raising the possibility that children might develop vCJD.

The main objective of this study was to provide prospective on-going surveillance for vCJD in children. This was done by identifying all diseases that met the case definition for progressive intellectual and neurological deterioration (PIND). The study provided the only means of searching for vCJD in children.

The study strategy was to investigate the broad group of rare neurodegenerative disorders affecting children, carefully examining the clinical details and determining whether there were cases of vCJD amongst these PIND cases. This unique dataset provided the opportunity to detect vCJD cases and highlight the variety of PIND conditions in the UK.

Research question

Was vCJD hiding amongst the many rare neurodegenerative diseases in UK children?

Research methods

From May 1997 paediatricians were asked to notify all children with PIND, as this wide group would include any possible cases of vCJD. A PIND Study Expert Group provided expert advice about the classification of cases.

Findings

Surveillance commenced in May 1997. Active surveillance ceased at the end of December 2023. Follow up information was collected until April 2024. By then the study had been running for 27 years and 5222 children had been notified. The notified cases were classified into 4 groups – 1) 6 vCJD cases, 2) 2367 cases with an underlying diagnosis other than vCJD, 3) 2540 "not cases" that did not meet the PIND criteria for inclusion and 4) 309 undiagnosed cases that met the PIND criteria but did not have a diagnosis to explain their deterioration.

There were 2 boys and 4 girls with vCJD. They developed their first symptoms between 12 years and 15 years of age. Disease onset was between 1998 and 2000. Sadly they all died – the last two in 2003. No childhood vCJD cases have been detected since then. The 2367 diagnosed children were a heterogeneous group containing 259 different diseases other than vCJD. This group, resulting from surveillance of neurodegenerative disease in UK children for 27 years, provided unique research data.

Contributions

In the absence of a reliable screening test for vCJD the PIND Study has provided the only means of searching for vCJD in UK children, giving reasonable certainty that vCJD cases have not been missed. The study has published 16 peer-reviewed papers and given 77 presentations at scientific meetings.

Recommendations

There is the possibility of a resurgence of childhood vCJD cases with a new genotype in the future, so it seems imperative that surveillance for vCJD continues. It is not clear how this can be reliably done in children now that the PIND Study has ceased.

Patient and public involvement

- Creutzfeldt-Jakob Disease Support Network
- Batten Disease Family Association
- Society for Mucopolysaccharide diseases
- ALD Life (Adrenoleukodystrophy)
- The Cure & Action for Tay-Sachs (CATS) Foundation

Funding

PIND data in this report is based on independent research commissioned and funded by the NIHR Policy Research Programme (PR- ST-1216-10001). Views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR, the Department of Health and Social Care, arm's length bodies or other government departments.

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Place of birth/report	Confirmed cases	Duplicate	Errors	Not yet known
England*	2282	586	1445	122
Wales	53	19	46	0
Scotland	150	26	101	2
Northern Ireland	49	16	35	0
Republic of Ireland	0	0	82*	0
Total	2534	647	1709	124

Figure 3: PIND case breakdown by nation

Neonatal herpes simplex virus

July 2019 - January 2022

Key details

What is already known on this topic?
Neonatal herpes simplex virus (HSV) infections are rare but can be extremely serious, leading to significant morbidity and mortality.

What this study adds
Neonatal HSV incidence in the UK and Ireland has risen from 1.65 to at least 6.0 cases per 100,000 live births (1986–1991 vs. 2019–2022), with lab data suggesting it may be as high as 13.7. Despite aciclovir treatment, mortality remains high, particularly in premature infants and those with disseminated disease or HSV-2. Over 25% of survivors show neurodevelopmental impairment by age two.

How this study might affect research, practice, or policy
Healthcare professionals should maintain a low threshold for HSV testing in neonates, as they often present without fever, raised infection markers, or maternal history of herpes. CNS and disseminated cases may lack typical skin, eye, and mouth lesions. Follow-up for at least two years is recommended to monitor neurodevelopmental outcomes.

Introduction

Neonatal herpes simplex virus (HSV) disease is a potentially devastating condition which can lead to significant morbidity and death. Transmission typically occurs during delivery through an infected birth canal, or after delivery, following exposure to HSV infections such as cold sores. Transplacental transmission can also occur, although this is rare. Before commencing this study it was known that sexually transmitted herpes infections in adults had increased in the last decade and suspected that the number of cases of neonatal HSV was also rising.

Prior to the study commencing, the UK incidence increased from 1.65 to 3.58 / 100,000 live births between the first national BPSU study (1986-1991) and the second (2004-2006) and in one area, Nottingham, the rates were 17.5 / 100 000 live births, ten times higher than the first BPSU study.

There was a lack of clarity as to the optimum management of mothers and babies with a number of different guidelines available for clinicians to follow, resulting in variation in practice across sites. This is of specific relevance to neonates presenting to the emergency department or the neonatal unit with non-specific signs of sepsis. Prior to the study commencing, not all babies were treated for HSV, however, as the prevalence of HSV has increased significantly this may need to be considered in specific scenarios.

Research methods

In addition to BPSU methodology, further information on the number of deaths from neonatal HSV disease was obtained from the National Child Mortality Database and the Office of National Statistics. Information on the number of reports of HSV cases was requested from the national reference laboratories. This information was used to ensure that the reporting methods were accurately capturing cases of neonatal HSV.

Findings

The annual number of cases of neonatal HSV infection has previously been estimated at 30–65 cases per year (approximately 2.5– 5.5 cases per month), based on earlier BPSU studies and Public Health England data.

Between 2019 and 2022, 117 confirmed cases of neonatal HSV infection in infants under 90 days were identified. Most infants were born at term, though a notable minority were preterm. In the majority of cases, the source of infection could not be identified. Where transmission was attributed, maternal infection was most common, but many mothers had no known history of genital HSV, limiting the usefulness of maternal history for identifying infants at risk.

Cases were evenly distributed across the three recognised clinical presentations: skin, eye and

mouth (SEM) disease; central nervous system (CNS) disease; and disseminated infection. HSV-1 and HSV-2 occurred in similar proportions. The timing and nature of clinical presentation varied, with many infants presenting without features typically associated with infection. Fever and characteristic skin lesions were frequently absent, particularly among infants with severe disease, and inflammatory markers were often low. As a result, neonatal HSV infection was difficult to recognise clinically.

Delays in initiating antiviral treatment were common. Although most infants received aciclovir, treatment was often not started on the day of presentation, reflecting diagnostic uncertainty and atypical presentation. This delay has important implications given the rapid progression and severity of neonatal HSV infection.

Outcomes varied substantially by disease severity and gestational age. Overall mortality was high, particularly among infants with disseminated disease, where more than half died. Infants born very preterm also experienced poorer outcomes. Among survivors with follow-up data, a significant proportion had neurodevelopmental impairment by two years of age, especially those with CNS involvement.

Overall, this study highlights that neonatal HSV infection continues to cause substantial mortality and long-term morbidity in the UK despite its low incidence. The frequent absence of fever, skin lesions and raised inflammatory markers contributes to delayed diagnosis and treatment. These findings emphasise the importance of maintaining a low threshold for considering HSV infection and initiating early empiric antiviral therapy in unwell neonates, regardless of maternal history or the presence of classic clinical features.

Discussion

This is currently the largest population-based surveillance study of HSV in infants under 90 days of age in the UK and Ireland.

The rise in neonatal herpes cases is likely due to several factors. Improved PCR testing has enhanced HSV detection compared to older methods, while electronic health records have made case identification and reporting easier. Additionally, shifts in HSV1 epidemiology—fewer childhood oral infections and more adult genital infections—mean more infants are born to mothers with primary genital HSV1, increasing transmission risk during birth or via maternal viraemia.

These infants lack passive immunity and are also vulnerable to postnatal infection from contacts with oral HSV1 lesions, such as grandparents or religious figures.

Funding

This study has been funded by the Rockinghorse Charity, Brighton and the Kit Tarka Foundation, Brighton.

Patient and public involvement

- Kit Tarka Foundation

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Bursary winner

Clinical characteristics of children with pneumococcal meningitis

January 2020 - January 2022

Key details

What is already known on this topic?
Pneumococcal meningitis can cause severe illness and long-term disability in children. Vaccines have reduced disease from common strains, but cases from non-vaccine strains are rising.

What this study adds
Over two years, 81 confirmed cases were identified across the UK and Ireland, with most caused by strains not covered by current vaccines. Despite high vaccination rates, disease severity remained high, with a 9.9% fatality rate and many children requiring intensive care.

How this study might affect research, practice, or policy
The rise in cases caused by non-vaccine serotypes highlights the need to review and potentially expand current vaccine coverage. Surveillance should also continue. Data will inform clinical care, public health planning, and future vaccine policy.

Introduction

Streptococcus pneumoniae is a leading cause of meningitis in children, often resulting in serious long-term disabilities such as deafness, epilepsy, and cerebral palsy. Although vaccines introduced in the UK and Ireland have significantly reduced disease caused by common strains, infections from non-vaccine strains are increasing. This study monitored how many children developed pneumococcal meningitis, which strains were involved, and the severity and outcomes of these cases. The findings will support clinical care, inform public health surveillance, and guide future vaccine policy.

Research methods

Cases of pneumococcal meningitis in children were identified through the BPSU reporting system. To estimate the total burden of disease across the UK and Ireland, additional data were obtained from national surveillance systems operating within each country. These sources were used to cross-check and supplement BPSU reports, ensuring comprehensive case ascertainment. Clinical details, including strain type, severity, treatment, and one-year outcomes, were collected via clinician-completed questionnaires and linked datasets.

Findings

Between January 2020 and January 2022, 63 report cards were submitted to the BPSU, with successful follow-up for 86.5% of cases. After excluding duplicates and ineligible cases, 81 confirmed cases of pneumococcal meningitis were included in the analysis. Most cases occurred in 2021 (n=49), with the majority reported from England (87.7%). Over half of the affected children were male (54.3%) and 74% were of White ethnicity. Comorbidities were present in 19.8% of cases, particularly among children aged two years and older. Serotype data were available for 62 cases: only 8.1% were covered by PCV13, while most were PPV23 (64.5%) or non-vaccine types (27.4%). Despite this, 80% of children were fully vaccinated for age. Clinical severity varied, with 27% presenting in shock and 21.3% experiencing seizures. A third required PICU admission, and 80% of those were ventilated. There were eight fatalities (case fatality rate: 9.9%), with most deaths occurring in children aged 6 months to 2 years.

Discussion

The childhood pneumococcal vaccination programme has significantly lowered the incidence of pneumococcal meningitis. However, during the two-year surveillance period, 81 cases were identified across the UK and Republic of Ireland, with an overall incidence of 0.44 per 100,000—highest in Wales and England. Most cases were caused by non-PCV13 serotypes, highlighting the limited coverage of current vaccines.

Children with comorbidities, especially those over two years, were more affected. Clinical severity was notable, with many presenting in shock or with seizures, and over a third requiring intensive care. Despite high vaccination rates, the case fatality rate remained high at 9.9%, with most deaths occurring in infants aged 6 months to 2 years. These findings suggest that additional strategies beyond current vaccines are needed to reduce the burden and mortality of pneumococcal meningitis in children.

Impact

This study will help provide more evidence-based guidance for paediatricians to better manage the condition. This study will also inform future pneumococcal vaccine policy. The research team would be interested in conducting international comparison with other surveillance units, run a case control study and clinical trial.

Funding

The Sir Peter Tizard Bursary Award 2017.

Patient and public involvement

- Meningitis Research Foundation
- Meningitis Now

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Multisystem inflammatory syndrome, Kawasaki disease and toxic shock syndrome

March 2020 - March 2022

Key details

What is already known on this topic?
Paediatric Multisystem Inflammatory Syndrome temporally associated with SARS-CoV-2 (PIMS-TS) emerged in April 2020 during the first wave of the COVID-19 pandemic. The condition shares features with Kawasaki Disease and Toxic Shock Syndrome, and early reports suggested a possible link with SARS-CoV-2 infection.

What this study adds
This study identified 268 children with PIMS-TS in the UK and Ireland between March and June 2020, with nearly half requiring intensive care and three deaths reported. Cases showed strong links to SARS-CoV-2 infection and varied in presentation and severity, particularly in those with a Toxic Shock phenotype.

How this study might affect research, practice, or policy
The findings confirm a strong association between PIMS-TS and SARS-CoV-2 and highlight the importance of limiting community transmission to reduce risk in children. They also informed vaccination policy and emphasise the need for long-term follow-up to monitor complications.

Introduction

Paediatric Multisystem Inflammatory Syndrome temporally associated with SARS-CoV-2 (PIMS-TS), first identified in April 2020, shares features of both Kawasaki disease (KD) and toxic shock syndrome (TSS).

The study aimed to provide more information on a large prospective cohort of children with PIMS-TS, providing additional evidence of an epidemiological link between the syndrome and SARS-CoV-2. It also aimed to describe in more detail the epidemiology and clinical characteristics of PIMS-TS in the United Kingdom and Ireland.

Research methods

Public Health England initiated prospective national surveillance of PIMS-TS through the BPSU. Paediatricians were contacted monthly to report PIMS-TS, KD and TSS cases electronically and complete a detailed clinical questionnaire. Cases with symptom onset between 01 March and 15 June 2020 were included.

Findings

There were 216 cases with features of PIMS-TS alone, 13 with features of both PIMS-TS and KD, 28 with features of PIMS-TS and TSS and 11 with features of PIMS-TS, KD and TSS, with differences in age, ethnicity, clinical presentation and disease severity between the phenotypic groups. There was a strong geographical and temporal association between SARS-CoV-2 infection rates and PIMS-TS cases. Of those tested, 14.8% (39/264) children had a positive SARS-CoV-2 RT-PCR, and 63.6% (75/118) were positive for SARS-CoV-2 antibodies. In total 44.0% (118/268) required intensive care, which was more common in cases with a TSS phenotype. Three of five children with cardiac arrest had TSS phenotype. Three children (1.1%) died.

Discussion

There was a strong association between SARS-CoV-2 infection and PIMS-TS, and this emphasises the importance of maintaining low community infection rates to reduce the risk of this rare but severe complication in children and adolescents. It also highlights the variation in incidence of PIMS-TS by race, ethnicity and comorbidity. This has helped in policy decision making on COVID-19 vaccines. Close follow-up will be important to monitor long-term complications in children with PIMS-TS.

Funding

This study was funded through a grant from Public Health England.

Patient and public involvement

- Societi, the UK Kawasaki disease foundation
- COVID-19, Mutual Aid UK

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Neonatal complications of coronavirus (COVID-19)

April 2020 - April 2022

Key details

What is already known on this topic?
Transmission routes and illness severity in neonates were unclear early in the pandemic. COVID-19 raised concerns about risks to newborns, especially those born to infected mothers.

What this study adds
This national study identified 344 newborns with SARS-CoV-2 infection requiring hospital care, nearly half of whom needed respiratory support, but most recovered well. Severe illness was more common during the delta variant wave, possibly linked to maternal disease and preterm birth.

How this study might affect research, practice, or policy
Findings informed national COVID-19 guidance for maternity and neonatal care with continued follow-up (e.g. SINEPOST study) which will assess long-term outcomes. Future surveillance should include variant-specific impacts and support early identification of at-risk infants.

Introduction

Understanding how COVID-19 affects newborn babies and those born to mothers infected during pregnancy was critical during the pandemic. This national study collected data on babies who either required hospital care due to COVID-19 or were born to mothers with the virus. UK clinicians reported cases to the BPSU, enabling the study team to analyse patterns of infection, illness severity, and possible transmission routes. Findings were regularly shared with health authorities and professional bodies to inform clinical guidance and national response efforts, and have contributed to international research through peer-reviewed publications.

Research methods

From 01 April 2020 to 31 March 2021, weekly reports of cases were requested (rather than monthly) due to this being an urgent public health study; this moved back to monthly which continued until April 2022. Additional sources of data:

- Lists of all neonates under 29 days with a positive test for COVID-19 provided by Public Health Scotland and Public Health England
- Records from the UK Obstetric Surveillance System – COVID-19 in Pregnancy study, which collects data on any woman admitted to hospital with confirmed COVID-19 infection in pregnancy
- PICANet admissions to paediatric intensive care
- MBRRACE-UK perinatal mortality surveillance

These sources are cross-checked regularly with BPSU cases. Where they identify cases not already reported, site reporters are approached to complete data collection forms for the neonates in these cases.

Findings

Over the study period, 192 babies were reported through the BPSU system, with an additional 116 identified from other sources. Of those who received neonatal unit care, 99% were successfully linked to data in the NNRD. In total, 344 newborns were diagnosed with SARS-CoV-2 infection within the first 28 days of life and received inpatient care - most in England (320), with smaller numbers in Scotland (16), Wales or Northern Ireland (6), and two with missing location data.

Cases were distributed across COVID-19 variant waves: 146 during wildtype, 123 alpha, 57 delta, and 18 omicron. Nearly half (44.7%) of babies required respiratory support, but short-term outcomes were generally positive—93.6% were discharged home. Eleven babies died, with four deaths attributed to SARS-CoV-2 and seven unrelated. There was no difference in a parent reported measure of child development on follow up among babies affected by SARS-CoV-2 in the antenatal or neonatal period, when compared to non-affected babies.

Discussion

Inpatient care for babies with SARS-CoV-2 was uncommon throughout the first two years of the SARS-CoV-2 pandemic and short-term outcomes were good. Severe neonatal illness, although still rare, was more common during the delta variant period; this may reflect more severe maternal disease with more very or extremely preterm babies being born during this period.

Impact

We are co-investigators on a follow-up study of neurodevelopment of the babies infected with SARS-CoV-2 (SINEPOST study) funded by Action Medical Research which is being led by Dr Ela Chakkarapani from the University of Bristol. This study will follow up babies with perinatal and neonatal exposure to SARS-CoV-2 infection including neonates with SARS-CoV-2 infection identified though this BPSU surveillance.

We will be linking the babies identified in England from both categories to ONS and HES data to identify any future mortality and longer-term morbidity in a future study funded as part of the work of the DH funded NIHR Policy Research Unit in Maternal and Neonatal Health and Care, University of Oxford.

Funding

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Patient and public involvement

- Sands, the stillbirth and neonatal death charity
- Bliss

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Symptomatic glucocorticoid-induced adrenal suppression

September 2020 - September 2022

Key details

What is already known on this topic?
Glucocorticoids (GC), widely prescribed in paediatrics, can suppress the hypothalamo-pituitary-adrenal (HPA) axis, leading to inappropriately low cortisol levels and increased risk of adrenal crisis.

What this study adds
This study estimates a minimum UK incidence of 0.09 new cases of unexpected GC-induced adrenal suppression (AS) per 100,000 children annually. The lower rate may reflect greater prescribing awareness. All cases were promptly managed with endocrinology input. Continued education for families and clinicians remains key to preventing adrenal crises.

How this study might affect research, practice, or policy
Further development of tools like computerised alerts could support early identification and prompt treatment of GC-induced AS in at-risk patients presenting to hospital.

Introduction

Glucocorticoids (GC) are widely prescribed to children for conditions such as asthma, eczema, arthritis, and cancer. However, prolonged use of supraphysiological doses can suppress the hypothalamo-pituitary-adrenal (HPA) axis, leading to adrenal suppression (AS) and risk of life-threatening adrenal crises, especially during illness or after abrupt discontinuation. Symptoms of AS can be non-specific and easily overlooked. Despite being preventable with appropriate education and timely treatment, data on GC-induced AS in UK children are limited. This study aimed to document the incidence and characteristics of GC-induced AS and adrenal crisis in the UK to inform strategies for improved prevention and management.

Research methods

A 25-month prospective surveillance study (Sept 2020–Sept 2022) of suspected or confirmed cases of unexpected glucocorticoid (GC)-induced adrenal suppression (AS) or adrenal crisis in children under 16 across the UK and Ireland was conducted using the BPSU monthly reporting system. Clinicians reporting cases received a structured questionnaire developed and piloted by the study team. The study aimed to estimate the incidence of symptomatic GC-induced AS, describe patient characteristics and management, assess alignment with clinical guidelines, and identify potential areas for improved recognition and response. Primary outcome was the incidence of unexpected symptomatic AS; secondary outcomes included patient demographics, GC therapy history, and time to treatment.

Findings

Over 25 months, 190 case notifications were received; 22 confirmed cases of glucocorticoid (GC)-induced symptomatic adrenal suppression (AS) or adrenal crisis met inclusion criteria, giving a minimum incidence of 0.09 per 100,000 children aged 0–15 per year in the UK. Most patients were male (73%), with a mean age of 10.3 years. Asthma was the most common underlying condition. Symptoms were diverse, and 81% presented with multiple signs; 4 children presented in adrenal crisis. Biochemical confirmation was obtained in 86% of cases, most commonly via failed synacthen test. In three cases, treatment was given before testing due to emergency presentation. Emergency GC therapy was administered promptly in 8 cases, and all were reviewed by endocrinology. Post-diagnosis, most patients received either physiological GC replacement or stress dose cover. One child experienced ongoing symptoms. Clinicians reported delayed diagnosis in 8 cases, highlighting opportunities for earlier intervention.

Recommendations

This study highlights the need for increased awareness among healthcare professionals of the risk of glucocorticoid (GC)-induced adrenal

suppression (AS) in children, regardless of dose, route, or regimen. Clinicians should aim to prescribe the lowest effective GC dose for the shortest duration and use regimens that minimise HPA axis suppression, such as alternate-day dosing. Proactive monitoring and structured weaning plans are essential for children on GC therapy for more than two weeks. Early involvement of paediatric endocrinology teams, prompt recognition of AS symptoms—particularly during illness—and timely administration of emergency hydrocortisone are key to preventing adrenal crises. All children and their families should receive clear education about AS risks, symptom recognition, and emergency management, including the use of steroid alert cards and ready access to injectable hydrocortisone.

At the system level, there is a strong case for developing electronic alert systems to identify at-risk patients in emergency settings and for implementing national clinical guidelines to standardise care. Regular medication reviews are also recommended to reduce unnecessary GC polypharmacy. Further research is needed to improve case definitions, establish the incidence of asymptomatic AS, explore genetic susceptibility, and gather data based on the population actually exposed to GC therapy. Together, these measures could significantly reduce preventable morbidity and mortality associated with GC-induced AS in the paediatric population.

Funding

Funding was obtained from the JRE Scientific Committee in Newcastle-Upon-Tyne to run the first year of the study and Nottingham Hospital's Children's charity for the second year. CW is funded by a personal NIHR advanced fellowship.

Patient and public involvement

- Duchenne Research Fund
- Addison's Disease Self-Help Group
- Pituitary Foundation

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Bursary winner

Chronic Recurrent Multifocal Osteomyelitis (CRMO)

October 2020 - October 2022

Key details

What is already known on this topic?
Though first described over four decades ago, before this BPSU study, researchers did not know how common CRMO/CNO was.

What this study adds
This study collected the most comprehensive surveillance data on CRMO to date. It also identified a difference in presentation between male and female patients - males being more likely to present with multifocal disease.

How this study might affect research, practice, or policy
Findings from this study establish a crucial baseline for ongoing research into the condition and encourages improvement in the care and care guidelines of individuals with CRMO.

Introduction

Chronic Recurrent Multifocal Osteomyelitis (CRMO), also known as chronic nonbacterial osteomyelitis (CNO), is a rare autoinflammatory condition affecting the bones in children and teenagers. The actual incidence of CRMO remains uncertain.

The objective of this study was to identify the incidence of CRMO in children and young people under the age of 16 years in the United Kingdom (UK) and Republic of Ireland (ROI). We also aimed to delineate the demographics, clinical presentation, investigations, initial management and healthcare needs for children and adolescents with CRMO.

Research methods

Data of newly diagnosed patients was collected from BPSU reports and from cases seen by BSCOS (British Society for Children's Orthopaedic Surgery) members. The surveillance period was 01 October 2020 – 31 October 2022, with a 24-month follow-up phase, ending November 2024.

Findings

Over the surveillance period, 288 patients were reported, among which, 165 confirmed and 20 probable cases were included in the analysis. The highest incidences were among 8-10 year-olds. A two-to-one female-to-male difference in incidence was observed, and male patients were more likely to present with multifocal disease. A negative correlation was observed between reporting clavicular and leg pain. Investigation-wise, 80.0% of patients were reported to have undergone whole-body MRI and 51.1% had bone biopsies. The most common initial treatments were NSAIDs (93.9%) and bisphosphonates (44.8%).

This study estimates an average annual CRMO incidence of 0.65 cases per 100,000 children and adolescents in the UK and ROI. These findings establish a crucial baseline for ongoing research and improvement in the care of individuals with CRMO.

Analysis of data collected during the follow-up phase is currently ongoing.

Funding

The study was funded through the Sir Peter Tizard Bursary, two grants from Addenbrooke's Charitable Trust and a grant from the British Society of Skeletal Radiologist (BSSR). C.S. is supported by an NIHR clinical lectureship.

Patient and public involvement

- Rare Autoinflammatory Conditions Community - UK (RACC-UK)

Contributions

This is the first national prospective CRMO cohort which provides a national incidence estimates and two-year outcomes. This study highlights the

need to raise awareness of chronic recurrent multifocal osteomyelitis (CRMO) among general paediatricians, orthopaedic surgeons, and other non-rheumatology specialists to reduce diagnostic delays. NSAIDs and bisphosphonates have been used as the first-line and second-line treatment in most centres. The findings may also support the development of national clinical guidelines and further research into long-term outcomes, treatment strategies, and imaging features.

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Outcome of resuscitation for term babies with no heart rate at 10 minutes

November 2020 - December 2022

Key details

What is already known on this topic?
Prolonged resuscitation in term babies is associated with a high risk of death or neurodisability. International recommendations suggest considering stopping resuscitation efforts if there is no response by 20 minutes of age. However, these recommendations are based on evidence from retrospective studies of small numbers of infants.

What this study adds
National outcome data for term babies who require prolonged resuscitation after birth. Among term infants, not detecting a heartbeat at 10 minutes of age is a rare event. Nearly one third of infants survived to two years of age. Less than one third of survivors had severe neurodevelopmental impairment.

How this study might affect research, practice, or policy
This study will contribute outcome data to inform international recommendations on neonatal resuscitation.

Introduction

The decision to stop resuscitation efforts in a newborn baby remains challenging for healthcare professionals. The International Liaison Committee on Resuscitation recommends considering stopping if there is no response by 20 minutes of age. However, this is based on limited data from historical retrospective studies, and outcomes have improved following the introduction of therapeutic hypothermia for hypoxic ischaemic encephalopathy.

The aims of this study were:

(1) To identify how many term babies born in the United Kingdom and Republic of Ireland receive prolonged resuscitation after birth and have no heartbeat detected at 10 minutes of age.
(2) To describe the demographic characteristics, clinical features, initial management and neonatal outcomes.
(3) To describe the neurodevelopmental outcomes of survivors at two years of age.

Research methods

Surveillance was carried out over 25 months (December 2020 to December 2022). Infants were eligible for inclusion if they were delivered at ≥37 weeks gestation, received resuscitation after birth and had no heartbeat at 10 minutes of age.

Findings

There were a total of 171 case notifications, and 92 cases were identified after removal of duplicates and reporting errors. Estimated incidence was 6 per 100,000 births. Mean time to first heartbeat was 20.5 (SD 7.6) minutes. Mean lowest cord/neonatal pH was 6.78 (SD 0.20) and mean highest lactate was 19.1 (SD 6.4).

Fourteen (15%) infants died in the delivery room, 49 (53%) infants died on a neonatal unit and 29 (32%) survived to discharge. At two years, 26 are known to be alive; the status of the remaining three children is unknown. Eight (31%) children have severe neurodevelopmental impairment (cerebral palsy with GMFCS score of IV or V, blindness, deafness or cognitive/language scores ≥3 SD below the mean). Six of these children also have a seizure disorder. Four (15%) children have moderate impairment (cerebral palsy with GMFCS scores of II or III, correctable hearing or visual impairment or cognitive scores 2-3 SD below the mean). Six (23%) children have mild impairment (cerebral palsy with GMFCS score of I, mild hearing or visual impairment or cognitive/language scores 1-2 SD below the mean). Eight (31%) children have normal neurodevelopment.

Funding

This study was funded through a grant from Public Health England.

Patient and public involvement

- Sands, the stillbirth and neonatal death charity
- Bliss

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Prof Colm O'Donnell , Co-investigator
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Bursary winner

Button battery ingestion, inhalation or insertion

February 2021 - February 2022

Key details

What is already known on this topic?
Button batteries are common in household items and can cause rapid and severe internal injury if swallowed or inhaled, particularly in young children. Most previous evidence has come from case reports rather than national surveillance.

What this study adds
This study captured 417 confirmed cases, showing high imaging use, frequent injuries, and that one-fifth of children required endoscopic removal. Including paediatric surgeons in surveillance improved case capture and revealed the burden across both medical and surgical settings.

How this study might affect research, practice, or policy
Findings highlight the need for clearer public health messaging, improved product safety, and stronger warnings on loose batteries. The data support refining clinical guidance to reduce unnecessary imaging and guide safer conservative management. Results also reinforce the importance of multi-specialty surveillance for high-risk ingestion injuries.

Introduction

Button batteries are used to power many household devices, including toys and novelty greeting cards. They are small and round in shape, often the size of a small coin. If a button battery were to be accidentally swallowed or inhaled by a child and became lodged in the food or wind pipe it can cause very serious injury potentially leading to severe disability or even death.

In the UK there have been many case reports and also media attention surrounding the damage that button batteries can cause to children who have either accidentally swallowed (ingested) or breathed in (inhaled) them. The purpose of this study was to establish the number of children who require a hospital admission with medical intervention in the UK and Ireland after swallowing or inhaling a button battery accidentally, over the period of one calendar year.

It is felt that children aged 1-3 years are particularly at risk because of their increasing independence, mobility, and curiosity.

The tendency for these young children to investigate their environment with their hands and mouths puts them at particular risk and in this age group they are at danger from aspiration from various foods such as grapes, raisins, nuts, seeds, as well as any object less than 1.5 cm in diameter.

If a child has accidentally ingested or inhaled a button battery then their presentation to a healthcare professional may vary upon whether the event has been witnessed or not. Even if witnessed, there remains a lack of understanding in parents and medical personnel alike as to the emergency nature of such an event.

In this study, we will describe the number of new cases (incidence) needing hospital admission and intervention. We will look at contributing reasons (factors), and outcomes of children who require an admission to hospital after a button battery ingestion or inhalation within our defined population, and use the data to inform prevention campaigns, policy change, and clinical care.

Research methods

Routine BPSU methodology was used for this study, with monthly active surveillance through the national reporting scheme to identify new cases. Case ascertainment was strengthened by adding paediatric surgeons to the BPSU mailing list for this study. As children with suspected or confirmed button battery ingestion are frequently managed in surgical settings, including paediatric surgeons ensured that relevant cases presenting directly to surgical teams were captured and reduced the risk of under-reporting.

Discussion

Over the 18-month surveillance period, clinicians reported 569 suspected button battery ingestions, with 417 confirmed. Including paediatric surgeons in the reporting network clearly strengthened case capture and reflects the shared clinical responsibility for managing these incidents.

Most confirmed cases occurred in young children, with a smaller second peak in adolescents (median age 3.5 years). Boys and girls were affected equally, and ingestion was confirmed in the vast majority of eligible reports. When known, batteries most often came from toys, loose or unpackaged batteries in the home, lights/torches, and remote controls—highlighting the ongoing risk posed by common household items.

Most children ingested a single battery, typically 12 mm or 20 mm in diameter. Many passed the battery spontaneously, while around one-fifth required endoscopic removal. Imaging use was high, reflecting the need for careful monitoring.

Injuries were common, including burns, bleeding, and less frequent but serious perforations and strictures. Just over half of children were discharged directly from ED, but others needed emergency transfer or admission, with length of stay varying widely.

Overall, the findings demonstrate the significant clinical burden of button battery ingestion and the value of enhanced reporting in understanding risks, complications, and care pathways across the UK.

Impact

This surveillance study demonstrates the prevalence of life-changing injury associated with button battery in our setting, with one-fifth of children experience serious adverse sequelae.

The study has also demonstrated that a cohort of children can be safely managed conservatively, but even this population experience a significant radiation and healthcare use burden, which may be amenable to reduction through modified guidance.

Whilst product safety should be reviewed for items such as toys, lights, and remote controls, the high proportion of episodes related to loose and packet batteries highlights the need for public health measures including clearer warnings, highlighting awareness, and purchase restriction.

Funding

This study was funded by the Sir Peter Tizard Research Bursary.

Patient and public involvement

- Child Accident Prevention Trust
- Royal Society for the Prevention of Accidents

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Avoidant restrictive food intake disorder (ARFID)

March 2021 - March 2022

Key details

What is already known on this topic?
Information regarding ARFID incidence, clinical features, and care pathways in children and young people in the UK and Ireland was limited prior to this study.

What this study adds
This is the largest dataset on ARFID in the UK and Ireland to date, highlighting ARFID as an important public health concern, with distinct subtypes requiring tailored pathways. Findings inform service development, training, and provide evidence to guide pathway development for ARFID assessment and management across different service provisions.

How this study might affect research, practice, or policy
Future research should include younger children and broader care settings. Service planning should prioritise multidisciplinary approaches and clinician training.

Introduction

Avoidant/Restrictive Food Intake Disorder (ARFID), introduced as a diagnosis in 2013, an umbrella term used to describe restrictive eating patterns which result in significant health problems, including weight loss, poor growth, nutritional deficits or poor emotional wellbeing. Unlike in anorexia nervosa, restrictive eating in ARFID is not associated with concerns about body image, weight or shape, rather by sensory sensitivities, lack of interest in food, or fears of aversive consequences.

Prior to this study, little was known about ARFID incidence, clinical features, and care pathways in children and young people in the UK and Ireland. The study aimed to determine the incidence of ARFID in children and adolescents presenting to secondary healthcare in the UK and Ireland, examine referral pathways, describe clinical characteristics and comorbidities, and explore management strategies and outcomes. This will allow the comparison of rates, presentation, and management of ARFID with other countries, as well as generating new priority research questions that could in turn inform decision making to better match patient need with sufficient funding allocations.

Research methods

An observational surveillance study was conducted in collaboration with the BPSU and the Child and Adolescent Psychiatry Surveillance System (CAPSS). 4,298 consultant paediatricians and 695 consultant child and adolescent psychiatrists were asked to report cases between March 2021–March 2022. Cases meeting a broad surveillance definition were confirmed against study criteria. Follow-up at 12 months assessed clinical outcomes.

Findings

A total of 319 cases were identified, with an incidence rate of 2.79 per 100,000 in the UK and 0.73 per 100,000 in Ireland, higher among males. The mean age was 11.2 years, with comorbid autism spectrum disorder and anxiety common. Four distinct subtypes were identified: fear, sensory, lack of interest, and combined (most common). Presentations differed by referral source: paediatric cases were younger, often with chronic restrictions and autism, while psychiatric referrals more often involved acute weight loss and fear of aversive consequences of eating. Management included medical monitoring, dietetic support, nutritional supplements, psychoeducation, and multidisciplinary care, with 11.6% requiring paediatric admission and 3.6% requiring psychiatric admission. At one-year follow-up, around half had improved with treatment, around a quarter had persisted unchanged, and the remainder either improved without treatment, changed in presentation, worsened, or the outcome was unknown.

Recommendations

Future research should extend surveillance to younger children, primary care, and allied health professionals. Service planning should prioritise multidisciplinary approaches and ensure clinician training to improve recognition and outcomes.

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Conservative care in end-stage kidney disease

March 2021 - March 2022

Key details

What is already known on this topic?
Children with kidney failure may be treated with kidney replacement therapy (KRT) or managed conservatively without KRT but national data on children managed conservatively is limited.

What this study adds
This study estimates that 1 in every million UK children develops kidney failure managed without KRT, accounting for around 10% of paediatric cases. Compared to children who commenced KRT in the same timeframe, children who received conservative kidney care were younger, from non-White ethnic backgrounds and often have hereditary conditions.

How this study might affect research, practice, or policy
Routine data collection should include conservatively managed cases to support research and care improvement. Multidisciplinary collaboration is key to guiding complex treatment decisions and supporting families.

Introduction

End-stage kidney disease (ESKD) in children is a life-threatening condition that typically requires kidney replacement therapy (KRT), such as dialysis or transplantation, to sustain life. While KRT can offer survival, it is not a cure and may be associated with significant physical, emotional, and practical burdens for children and their families. In some cases, KRT may not be feasible or in the child's best interests, leading to a decision to pursue conservative management - supportive care without dialysis or transplant. Conservative care focuses on managing symptoms, maintaining quality of life, and providing emotional and palliative support to the child and family. However, little is known about how many children in the UK and Ireland receive this type of care, what conditions lead to ESKD in these cases, and how treatment decisions are made. This study aims to describe the scale and characteristics of conservatively managed ESKD in children, explore the decision-making process, and assess access to specialist and palliative care services. The findings will help improve clinical guidance and ensure families receive informed, compassionate, and high-quality care.

Research methods

BPSU methodology was used for surveillance period. Due to difficulties engaging the nominated Republic of Ireland (RoI) representatives, the study team couldn't be sure of the representativeness of returns from the RoI. Following discussion with the wider team, it was decided to focus efforts on data collection within the UK.

A separate, secondary project using data from the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS) in England is planned to identify children with congenital kidney abnormalities who died within a short space of time after birth and/or prenatally during the same study period, to identify patients who may not have had an opportunity to receive comprehensive conservative kidney care.

Findings

The study anticipated up to 26 cases per year, which was not observed over the two-year surveillance period, suggesting a lower-than-expected incidence of conservatively managed ESKD in children. Under-reporting may have contributed, particularly as no cases were reported from Wales, although duplicate reports indicate that known cases were captured where possible.

A total of 74 notifications were received, of which 33 were ineligible, 8 were duplicates, and 2 could not be followed up. This resulted in 27 confirmed cases, with 4 still pending review. Most cases were reported from England, with an incidence of 1.8 per million age-related population (pmarp). Higher incidence rates were observed in Scotland and Northern Ireland.

Within England, regional variation was noted: 8 cases from the North, 6 from the Midlands, and 5 from the South.

Discussion

This is the first prospective, nationally representative study to estimate the incidence of conservatively managed end-stage kidney disease (ESKD) in children across the UK and Ireland. Over two years, 27 confirmed cases were reported in children under 16 years for whom a decision was made to pursue conservative care rather than kidney replacement therapy (KRT).

Using mid-2021 population estimates, the incidence of conservatively managed paediatric kidney failure in the UK was 2.0 per million of the age-related population. Higher rates were observed in Northern Ireland and Scotland, while no cases were reported from Wales, raising questions about potential under-reporting. When considered alongside UK Renal Registry data, these findings suggest that conservatively managed cases may represent around 11% of the total paediatric kidney failure cohort.

International comparisons show limited data. For example, the ItalKid registry identified only 16 conservatively managed cases over a decade, and historical UK data reported an incidence of just 0.02 per million. Although formal analysis is ongoing, this study suggests a higher incidence in the UK than previously recognised, with notable variation across devolved nations.

A significant proportion of initial notifications were ineligible, often due to being prevalent cases, children not yet in kidney failure, or those outside the study's age or treatment criteria. One case was withdrawn following a change in treatment decision, highlighting the complex and evolving nature of decision-making in paediatric kidney care. These findings underscore the importance of improving supportive care pathways and ensuring families receive clear, compassionate guidance when facing difficult treatment choices.

Impact

Due to the involvement in this work the lead investigator, Dr Lucy Plumb now sits on a national specialist interest group for conservative care of kidney disease hosted by the UK Kidney Association, whose aim is to develop national guidance to support the delivery of standardised, high-quality conservative kidney care for children across the UK.

International comparisons have not yet been drawn but there has been interest in the study from other nations in the outcome of this study. The findings will also inform collection of routine data through the UK Renal Registry, which now has ethical approval to collect data on children with kidney failure not receiving KRT.

Patient and public involvement

- British Association for Paediatric Nephrology
- UK Kidney Association Paediatric conservative care specialist interest group
- Kidney Research UK

Funding

This study was funded by the Children's Research Fund and supported by Kidney Research UK: Paediatric research project grant (reference: Paed_RP_002_20180927).

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Bursary winner

Neonatal stroke presenting or diagnosed in the first 90 days of life

April 2022 - May 2023

Key details

What is already known on this topic?
Due to a lack of recent prospective multinational population studies, the true burden of neonatal stroke, incidence rates, and clinical presentation and management, is unclear.

What this study adds
Three-quarters of cases were arterial ischaemic stroke, presenting at a median of 2 days of age with seizures. Haemorrhagic stroke presented later, with poor feeding and altered consciousness. Variation in clinical management and follow-up plan was noted.

How this study might affect research, practice, or policy
The study highlighted the differences in clinical presentations of the different neonatal stroke subtypes, alongside variation in clinical management and follow-up. National guidance is needed to standardise care in investigating and managing infants with neonatal stroke.

Introduction

Neonatal stroke is a devastating condition that causes brain injury in babies and often leads to lifelong impairment.

Before this BPSU Neonatal Stroke study, there was insufficient information about the number of babies who had experienced neonatal stroke. Most clinicians will see only a few cases in their career. Little was known about which babies are most at risk and what problems they will likely face. There is also no agreed guidance on how clinicians should investigate and treat babies with stroke. This is unlike stroke in older children and adults where much more is known. Therefore, it was vital to conduct surveillance into the condition.

Research methods

Active surveillance of neonatal stroke cases presenting in the first 90 days of age between March 2022 and April 2023 in the UK and ROI was done using the BPSU monthly reporting card and a purpose-built data platform. Neuroimages were reviewed to ensure the case definition was met. Live births were used to estimate the incidence, with the 95% confidence interval (CI) determined using binomial exact method. Study protocol was published before study commencement.

Findings

Over the surveillance period 68 cases were identified. The incidence of neonatal stroke was 9.0 (95% CI 6.9 to 11.6) per 100,000 live births. Over three-quarters of the cases were arterial ischaemic stroke (53 cases) and unilateral (52 cases). The median (interquartile range (IQR)) age at presentation was 2 (1 to 3) days, with seizures being the most common symptom (61 cases). Haemorrhagic stroke presented later at a median (IQR) of 10 (3 to 34) days with poor feeding and altered consciousness. 25.5% of reporting hospitals have a neonatal stroke guideline. <5 infants received aspirin.

Although most infants received anticonvulsants (55 cases) during the acute period, only 23 infants were discharged on anticonvulsants. At the time of study reporting, no infants died, and 56 infants (82.4%) were discharged home at a median (IQR) of 12 (9 to 16) days with neonatal/ paediatric follow-up (90.7%). Only 76.5% and 62.7% infants had physiotherapy and paediatric neurology follow-up.

Discussion

This is the first study demonstrating the true burden of neonatal stroke in the UK and ROI, alongside its clinical presentation variation depending on the subtype. National guidance for neonatal stroke is needed to standardise care and follow-up, as its presentation and management are different from childhood stroke.

Funding

This study was funded by the Sir Peter Tizard Bursary.

Patient and public involvement

- BLISS

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Acute hepatitis

May 2022 - May 2023

Key details

What is already known on this topic?
Acute hepatitis in children is usually caused by viral infections and is often self-limiting, though severe cases can lead to liver failure, transplantation, or death. In early 2022, an unexpected increase in severe cases of unknown cause was reported in otherwise healthy children.

What the surveillance adds
This study provided rapid, national clinician-reported surveillance of acute hepatitis in children during a period of public health concern. Between September 2022 and August 2023, it was the only system directly requesting case reports from clinicians across the UK and Republic of Ireland.

How this study might affect research, practice, or policy
The surveillance raised awareness among paediatricians, supported earlier recognition and reporting, and generated evidence to inform clinical management, future research, and national public health surveillance strategies for paediatric liver disease.

Introduction

As a rapid response to the increasing number of cases of acute hepatitis reported to the UKHSA, this study was urgently needed to understand viral, non-viral or unidentified causes of acute hepatitis. When the study commenced, it was hoped it would increase awareness of the condition among doctors and the public, improve early recognition, potentially enhance the way doctors look after children with acute hepatitis and develop national strategies to further prevent such cases occurring in the first place.

Children with acute hepatitis can become very unwell with fever, jaundice, abdominal pain and vomiting. In some children, the condition can be so severe that it could lead to liver failure and liver transplantation. Most cases of acute hepatitis in children are caused by viruses such as hepatitis A and hepatitis B, although other viruses and bacteria can also cause acute hepatitis. In a prior study run between 2014 and 2015, the BPSU identified only 81 cases acute hepatitis, with only two requiring liver transplantation.

In early April 2022, the UKHSA received reports suggesting unusually high numbers of acute hepatitis cases not caused by hepatitis viruses (A-E) in otherwise healthy children. The earliest cases occurred in January 2022. There was no known association with travel, SARS-CoV-2 infection or vaccination. Adenovirus was identified in many of the cases. Similar cases were reported in other countries including Ireland, United States, Spain and New Zealand among others.

This collaborative study between the BPSU and the UKHSA was developed to rapidly collect information about children who developed acute hepatitis since 1 January 2022. It was hoped this study may help find the cause of acute hepatitis among the recent cases. The study also planned to collect information about their symptoms when they were first diagnosed, what tests were performed, how long they stayed in hospital, what treatments they received and whether they completely recovered from their illness or had any continuing health problems after 6 and 12 months. By collecting information about all cases of acute hepatitis in children, the team can develop a better idea of the different viruses that were responsible for this condition and also to identify cases where no cause was determined. It was hoped that this surveillance will raise awareness of the condition among paediatricians.

The BPSU surveillance will provide useful information about the condition for doctors looking after children with such conditions, public health specialists and researchers who would like to better understand the condition and develop effective treatments.

Whilst it remains possible for clinicians to directly report to UKHSA, the BPSU surveillance became the only surveillance system between 1 September 2022- 31 August 2023 where clinicians were asked directly to report cases.

Findings

Of the 111 cases, 85 (77%) were from England, 12 (11%) from Northern Ireland, 8 (7%) from Wales and 6 (5%) were from Republic of Ireland. 61 (55%) were female and 50 (45%) were male. 2 children had liver transplant and 2 died.

A manuscript with the full data from the study is in preparation.

Funding

Funding for this study was provided by the UK Health Security Agency.

Patient and public involvement

- Children's Liver Disease Foundation

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Near fatal asthma

October 2022 - April 2024

Key details

What is already known on this topic?
Children and young people who experience near fatal asthma (NFA) are at increased risk of future severe or fatal asthma attacks. However, the frequency, characteristics, and clinical care of NFA, as well as environmental exposures, had not previously been described in this defined group.

What the surveillance adds
This national surveillance study identified 62 cases of NFA in children aged 5–15 years across the UK and Ireland. The study found high rates of invasive ventilation and cardiopulmonary arrest, significant associations with deprivation and South Asian ethnicity, and widespread exposure to air pollution above WHO-recommended levels.

How this study might affect research, practice, or policy
The findings highlight the importance of identifying children at higher risk due to socioeconomic and ethnic factors, alongside environmental exposures. They also demonstrate wide variation in discharge medication and follow-up care, suggesting the need for more consistent pathways and standardised guidelines to reduce future risk.

Introduction

Near fatal asthma (NFA) is the most severe form of survivable asthma attack, affecting children and young people aged 5–15 years. Those who experience NFA are at increased risk of future severe or fatal asthma attacks, yet the frequency, risk factors, clinical care, and longer-term outcomes in this group had not previously been well described. This study aimed to describe the epidemiology of NFA in the UK and Ireland, including both clinical and socio-demographic risk factors, and to assess how these influenced care and prognosis.

The study examined commonly recognised clinical factors alongside variations in acute and intensive care management, with the goal of identifying opportunities for future clinical trials and guideline development to standardise care. Through data-linkage, socio-demographic influences such as air pollution, pollen, weather, and viral prevalence were also explored, providing insights into environmental risk. By following cases at 12 and 24 months through BPSU surveillance, the study assessed the quality and consistency of ongoing care, with the aim of reducing fragmentation and improving long-term support for children and families at highest risk.

Research methods

From 1st October 2022 to 1st April 2024, a BPSU surveillance study was conducted to investigate near fatal asthma among children and young people aged 5 - 15 years. Clinicians completed monthly e-reporting cards identifying cases.

Findings

This national surveillance study identified 62 cases of near fatal asthma (NFA) in children and young people aged 5–15 years across the UK and Ireland. The median age of cases was 10.9 years, and there was a male predominance (61%), consistent with previous observations that severe asthma episodes are more common in boys during childhood. A substantial proportion of children experienced severe clinical outcomes, with 69% requiring invasive ventilation and 39% experiencing cardiopulmonary or respiratory arrest, underscoring the life-threatening nature of these events. Physiological markers reflected the severity of these attacks with median PaCO2 reaching 11.1kPa and where measurable (13/36 cases), significant hypoxaemia (below 70% SpO2).

Socio-demographic patterns were notable. Over one-third of cases (35%) came from the most deprived quintile of England, and 22% were of South Asian ethnicity, suggesting potential disparities in risk and highlighting the importance of considering social determinants and ethnicity in preventive strategies. Importantly, 17% of cases had no prior asthma diagnosis, indicating that severe exacerbations can occur even in children

not previously recognised as asthmatic, and emphasising the need for early recognition and vigilance in primary care.

The study also revealed wide variability in discharge medication and follow-up care, suggesting inconsistencies in post-attack management that may influence future risk of severe asthma events. Environmental exposures were considerable: 22% of children exceeded WHO-recommended PM10 levels, 94% exceeded PM2.5, and 62% exceeded NO_2 levels, highlighting the potential role of air pollution in precipitating or exacerbating severe asthma attacks.
Taken together, these findings indicate that NFA in children is associated with severe physiological compromise, significant social and ethnic disparities, and high environmental risk. The variability in care and high burden of environmental exposures suggest opportunities for targeted interventions, including standardised clinical pathways, equitable follow-up care, and environmental risk mitigation, to reduce future morbidity and mortality in this vulnerable population.

Discussion

Delphi defined NFA attacks are more common in CYP of lower socioeconomic status and those of South Asian heritage, and have high exposure to outdoor air pollution. Variability of clinical care may contribute to future risk and should be aligned.

Funding

Chief Scientists Office, Scotland (HIPS 20/21).

Patient and public involvement

- Asthma UK Centre for Applied Research
- Asthma UK
- British Lung Foundation

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Currently running

Rapid-onset obesity with hypoventilation hypothalamic dysfunction and autonomic dysregulation

October 2024 - Ongoing

Key details

What is already known on this topic?
Rapid-onset obesity with hypoventilation hypothalamic dysfunction and autonomic dysregulation (ROHHAD) is an extremely rare but serious paediatric condition. Current knowledge is limited to small case series, meaning population-level incidence, presentation, and management patterns remain poorly understood.

What the surveillance will add
This BPSU study provides the first UK- and Ireland-wide prospective data on ROHHAD, helping to establish incidence, describe presenting features, and understand diagnostic and referral pathways. It builds a clearer, more systematic picture of clinical practice and variation, strengthening the evidence base for earlier, more consistent recognition.

How this study might affect research, practice, or policy
Findings may support improved diagnostic pathways, more timely referral to specialist teams, and greater consistency in care. The evidence generated can also inform rare disease policy, guide future research priorities, and strengthen the case for specialist service provision.

Introduction

Rapid-onset obesity with hypoventilation, hypothalamic dysfunction and autonomic dysregulation (ROHHAD) is a rare condition which causes life-threatening obesity, trouble breathing at night, a wide range of hormone problems and an irregular heartbeat. Children often need masks and machines to breathe at night, take hormone tablets and injections for the rest of their lives and have a greater cancer risk.

We do not know why children get this condition and as there is no single test for diagnosis, it can take a long time for families to get a diagnosis. We do not yet know of any treatments that can cure the condition.

This study will help to estimate how many children have ROHHAD and understand more about the condition and how it is being managed.

Patient and public involvement

- ROHHAD association

Funding

The British Society of Paediatric Endocrinology and Diabetes.

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Dr Sarah Clarke | Trainee Representative | Royal United Hospitals Bath NHS Foundation Trust

Dr Jane Sutton | Committee Member | PPI Representative

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