

BRITISH PAEDIATRIC SURVEILLANCE UNIT

Reporting Instructions & Case Definitions – OCTOBER 2022

When reporting a case **PLEASE** keep details of patients for reference.

IMPORTANT NOTICE

Please inform the office of retirements or circumstances that will affect your ability to return the orange card. Complete the report card by ticking "nothing to report" or indicating the number of cases of the listed conditions seen in the month specified.

1. Progressive intellectual & neurological deterioration (Excluding Republic of Ireland)

Case Definition: Any child under 16 years of age at onset of symptoms who fulfils **ALL** of the following three criteria:

- Progressive deterioration for more than three months with
- Loss of already attained intellectual/developmental abilities and
- Development of abnormal neurological signs.

Excluding: Static intellectual loss e.g. after encephalitis, head injury or near drowning.

Including: Children who meet the case definition even if specific neurological diagnoses have been made.

- Metabolic disorders leading to neurological deterioration.
- Seizure disorders if associated with **progressive** deterioration.
- Children that have been diagnosed as having neurodegenerative conditions but not yet developed symptoms

Reporting restricted to: Cases seen in the last month but including those whose conditions began earlier (i.e. including 'old cases' of children in follow-up if seen in that month).

Reporting Instructions: Please report any child seen in the last month who meets the case definition, including those who have already been given a specific diagnosis.

2. Congenital rubella

Case Definition: Any infant (live or still born) or child up to 16 years of age who, in the opinion of the notifying paediatrician, has suspected or confirmed congenital rubella with or without defects, based on history, clinical and/or laboratory findings. Please include "imported cases", including children born in the British Isles where the maternal infection occurred abroad, AND children who were born abroad.

Reporting Instructions: Please report any infant (live or still born) or child seen by you for the first time in the last month who meets the case definition, **REGARDLESS OF COUNTRY OF BIRTH.**

3. Conservative care in end-stage kidney disease

Case definition: Any incident children aged less than 16 years who develops kidney failure, also known as 'end-stage kidney disease' (ESKD), during the study period for whom an active decision has been made in the child's best interests not to pursue long-term RRT* and to instead manage the child's kidney disease conservatively (this decision may have been made before or after reaching ESKD).

** RRT refers to invasive treatments used to substitute the role of the kidneys and includes: Haemodialysis; haemodiafiltration; peritoneal dialysis; renal transplantation; continuous forms of RRT used on Paediatric Intensive Care Units such as continuous venovenous haemodialysis (CVVHD), continuous veno-venous haemodiafiltration (CVVHDF) and slow continuous ultrafiltration (SCUF).*

Reporting instructions: Please report any cases of children and young people <16 years of age who meets surveillance case definition seen in the last month in the UK or the Republic of Ireland.

Please report cases even if you think they may have been reported elsewhere.

4. Chronic recurrent multifocal osteomyelitis / chronic nonbacterial osteomyelitis (CRMO/CNO)

Case definition: Children and young people up to but not including the age of 16 years with a new diagnosis of possible CRMO/CNO, namely those who have the following features:

- The presence of localised bone pain, which could be single site or multiple sites

AND

- The presence of typical radiological findings on plain X-ray (examples include: lysis, sclerosis, cortical thickening or periosteal reaction) or on MRI (examples include: bone marrow oedema on fluid sensitive sequences, or periostitis (periosteal inflammation))

AND

- The treating clinician has determined that the clinical features are not explained by an alternative diagnosis, eg trauma, infection or neoplasm.

Reporting instructions: Please report children/young people up to the age of 16 years with new diagnosis of possible CRMO/CNO in the last month in the UK and Republic of Ireland.

5. Outcome of resuscitated term babies with no heart rate detected at 10 minutes of age

Case definition: Any baby who has been cared for in the last month for whom all three of the following conditions were met:

1. Gestational age 37 or more completed weeks of gestation
2. Cardiopulmonary resuscitation following delivery
3. No heart rate detected at 10 minutes of age.

Reporting instructions: Please report any cases of babies meeting the surveillance case definition whom you have seen in the last month in the UK or the Republic of Ireland.

6. Neonatal stroke presenting/diagnosed in the first 90 days of life

Case definition: Neonatal stroke, of either arterial ischaemic, venous thrombosis or haemorrhagic in origin, suspected in any child from birth till 90 days of age, of any gestation. They must have:

Any neurological symptoms (including seizure, neurological deficit, lethargy, abnormal tone, poor feeding)

AND either

- 2a. Neuroimaging (such as MRI or CT) showing disruption or evidence of disruption of cerebral blood flow
- 2b. Neuropathologic studies showing disruption or evidence of disruption of cerebral blood flow

Excluding: Cases of germinal matrix haemorrhage/intraventricular haemorrhage or periventricular leukomalacia in preterm infants (defined as below 37 weeks of gestational age) or hypoxic ischaemic encephalopathy.

Reporting instructions: Please report any child seen in the last month who meets the case definition seen in the UK or Republic of Ireland.

7. Acute Hepatitis 22

Case definition: Any case where the clinician has made a clinical diagnosis of acute hepatitis with the following:

1. discrete onset of symptoms suggestive of hepatitis (e.g. fever, jaundice, abdominal pain, fatigue, loss of appetite, rash, itch, joint or muscle ache, dark urine, pale coloured stools, nausea or vomiting);
- AND**
2. elevated serum alanine aminotransferase (ALT) levels (>500IU/L)
 3. age between 1 month and 15 years (inclusive)
 4. presenting to hospital any time from 1st Jan 2022

Reporting instructions: Please report any case of acute hepatitis which meets the case definition above that occurred from 1 January 2022 irrespective of whether an infectious agent is identified.

8. Near Fatal Asthma

Case definition: Cases will be defined as **(1) or (2) or (3)**

1. Any child aged 5-15 years surviving* an acute episode of asthma, who when presenting self-ventilating with severe dyspnoea (e.g. inability to speak) and **all** the following features:
 - a. Pulse oxygen saturation below 92% despite maximal oxygen therapy (i.e. 10-15l/min oxygen flow via non-rebreather mask) during acute presentation **and**
 - b. pH \leq 7.2 and/or pCO₂ \geq 60mmHg or 8kPa **and**
 - c. Escalation to use of intravenous bronchodilator infusion
2. Any child aged 5-15 years surviving* an acute episode of asthma, who had a respiratory arrest and/or required cardiopulmonary resuscitation as part of their presentation.
3. Any child age 5-15 years surviving* an acute episode of asthma for which he/she was invasively ventilated.

*surviving to hospital discharge

Reporting instructions: Please report any case that meets the above definition. Clinicians are encouraged to report the event even if final outcome is not yet known or the patient is still receiving ongoing care in hospital.