



Ref: FOIA Reference 2023/24-729

Date: 24<sup>th</sup> June 2024

Email [foi@uhnm.nhs.uk](mailto:foi@uhnm.nhs.uk)

Dear

I am writing to acknowledge receipt of your email dated 30th January 2024 requesting information under the Freedom of Information Act (2000) regarding Congenital cytomegalovirus screening

As of 1<sup>st</sup> November 2014 University Hospitals of North Midlands NHS Trust (UHNM) manages two hospital sites – Royal Stoke University Hospital, and County Hospital (Stafford). Therefore the response below is for the two sites combined from that date where appropriate.

**Q1 The questions have been designed so that they can be answered within the limits (on time, cost, type of information etc.) set out in the Freedom of Information Act and the Information Commissioner's Guidelines. If it is not possible to provide the exact information requested, please supply the underlying information in narrative form or whichever format you have available.**

**Definitions of acronyms and terms used in the FOI request:**

**CMV: cytomegalovirus**

**cCMV: congenital cytomegalovirus**

**SNHL: sensorineural hearing loss**

**'Practices' refers to any standard operating procedures or clinical protocols, guidelines, practices or pathways.**

**'Information' refers to any recorded information required to be disclosed in response to requests under the Freedom of Information Act.**

**If different hospitals or services within your Trust have different Practices or data availability, please provide separate Information or data for each hospital or service (indicating clearly which hospital or service the Information relates to).**

**Q1. Please provide copies of any Information containing or evidencing Practices used within your Trust whereby newborns who are referred to audiology following their newborn hearing screening test, or newborns/children who demonstrate abnormal hearing at a later stage, are tested for cCMV. Such Practices could include, but are not limited to, early cCMV detection pathways whereby newborns are tested at point of referral to audiology from the newborn hearing screening programme. Please include details about the intended timescales for testing, carrying out tests and returning test results, if this information is recorded.**

A1 Children that have confirmed hearing loss (from audiology) are referred to paediatric aetiology of hearing loss clinic. Investigations for hearing loss are undertaken if parents/carer wish. Guidelines from British association of audio-vestibular physicians for aetiological investigations in hearing loss are used for guidance. Cytomegaly virus (CMV) can be tested for as part of the investigations.

CMV infection can be congenital (around birth) or acquired later as an infant/ child. A child may have a previous or current (active) infection. Also see attached

**Q2 If your Trust does employ Practices whereby newborns/children with abnormal hearing are tested for cCMV, please indicate at which stage samples are taken (you may select more than one):**

- By the newborn hearing screener at the point of referral  By the audiologist at the first appointment after babies have been referred from the newborn hearing screen  By the audiologist at detection of SNHL in a baby referred from the newborn hearing screen  By another healthcare professional (not an audiologist) following detection of SNHL in a baby referred from the newborn hearing screen  At detection of SNHL in older babies and children (i.e. after the newborn hearing screening and testing period)  Unknown  Other, please provide details:

A2 Once a sensorineural hearing loss is detected, the baby is referred to community Paediatrician for aetiology investigations into the cause of the hearing loss. Testing for cCMV would form part of these investigations .( Infants/children may be tested for cCMV as part of investigations by paediatrician in aetiology of hearing loss clinic.)

**Q3 If your Trust does employ Practices whereby newborns/children with abnormal hearing are tested for cCMV, please indicate what type of sample is taken (you may select more than one):**

- Saliva swab  
 Urine  
 Blood test for the infant  
 Blood test for the mother  
 Infant blood spot (Guthrie) card testing  Unknown  Other, please provide details:

A3 Depending on the type of hearing loss, age of the child and medical history the following maybe used for testing for cCMV;

- Urine
- Saliva swab
- Blood test for the infant
- Blood test for the mother
- Infant blood spot (Guthrie) card testing

These tests help identify if the child has a previous or current infection and if the CMV is congenital or acquired later.

**Q4 Please provide copies of any Information containing or evidencing Practices used within your Trust whereby children are tested for cCMV as part of investigations of**

symptoms (in either the mother or child) that are unrelated to hearing. These could include:

**Maternal symptoms of CMV (flu-like symptoms) Symptoms of congenital infection identified before or after birth, such as:**

- **Antenatal abnormalities e.g. on ultrasound scan**
- **Characteristic rashes caused by cCMV (petechiae or blueberry muffin rash)**
- **Intrauterine Growth Restriction**
- **Microcephaly**
- **Jaundice**
- **Hepatosplenomegaly**
- **Neonatal visual signs/symptoms**
- **Neonatal seizures**

**Symptoms of congenital infection in older children, such as:**

- **Neurodevelopmental delays**
- **Special educational needs and disabilities (e.g. autism, ADHD)**
- **Cerebral palsy**
- **Seizures**
- **Visual or sensory impairment**

A4 For the older children we would only consider CMV if they had an abnormal MRI and a cerebral palsy type presentation or a visual impairment. We would not consider it in ADHD or ASD. We don't have any set protocols or guidelines for this age group.

**Q5 Please provide copies of any Information containing or evidencing Practices used within your Trust following a diagnosis of cCMV in a child. This could include, but is not limited to:**

- **Information about any Practices involving the prescribing of antiviral treatments**
- **Details of the department(s) that the child would be referred to**

A5 See below:

- The clinician/team who request investigations for CMV would be the ones looking at the results and making a plan for action.
- This could occur in a variety of areas/clinical context e.g. neonates or paediatrics
- in aetiology for hearing loss clinic is - testing for CMV to investigate hearing loss.
- When testing for cCMV you can test for and get results for either a previous infection or a current/active infection.
- You need to consider what has been tested for and what the results are. E.g. active infection and symptomatic may benefit from treatment vs previous infection.
- If we have a positive result for cCMV, we would discuss this with the infectious diseases team

**Q6 Questions 6-9 relate to the provision of data for a specific five-year period. If you do not hold data for this time period, please supply data for any period for which you have available data (preferably a recent five-year period) and specify the beginning and end dates. If the answer to any question is between 1 and 5 (and therefore the true figure cannot be shared in accordance with Section 40 of the Freedom of Information Act), please indicate this by giving the answer "<5". Please also indicate if the relevant hospitals or services within your Trust have changed during this period.**

**Between 1 January 2018 and 31 December 2022, how many children were diagnosed with cCMV within 28 days of birth, within your Trust? This should include children born outside of your Trust who were diagnosed by services within your Trust.**

A6 I can neither confirm nor deny whether the information you have requested is held by the Trust in its entirety. This is because the information requested in this question is not held centrally, but may be recorded in health records. In order to confirm whether this information is held we would therefore have to individually access all health records within the Trust and extract the information where it is present. We therefore estimate that complying with your request is exempt under section 12 of the FOI Act: cost of compliance is excessive. The section 12 exemption applies when it is estimated a request will take in excess of 18 hours to complete. We estimate that accessing and reviewing all health records and then extracting relevant information would take longer than the 18 hours allowed for. In addition to the section 12 exemption the Trust is also applying section 14 (1) exemption: oppressive burden on the authority

**Q7 Of the children who were diagnosed with cCMV within 28 days of birth in this time period (Q6), how many:**

- a. **Previously had a newborn hearing screening test**
- b. **Had been referred to audiology following their newborn hearing screening test**
- c. **Were given antiviral treatment for cCMV following diagnosis**

A7 I can neither confirm nor deny whether the information you have requested is held by the Trust in its entirety. This is because the information requested in this question is not held centrally, but may be recorded in health records. In order to confirm whether this information is held we would therefore have to individually access all health records within the Trust and extract the information where it is present. We therefore estimate that complying with your request is exempt under section 12 of the FOI Act: cost of compliance is excessive. The section 12 exemption applies when it is estimated a request will take in excess of 18 hours to complete. We estimate that accessing and reviewing all health records and then extracting relevant information would take longer than the 18 hours allowed for. In addition to the section 12 exemption the Trust is also applying section 14 (1) exemption: oppressive burden on the authority

**Q8 Between 1 January 2018 and 31 December 2022, how many children were diagnosed with cCMV between 28 days and 18 years of age, within your Trust? This should include children born outside of your Trust who were diagnosed by services within your Trust.**

A8 I can neither confirm nor deny whether the information you have requested is held by the Trust in its entirety. This is because the information requested in this question is not held centrally, but may be recorded in health records. In order to confirm whether this information is held we would therefore have to individually access all health records within the Trust and extract the information where it is present. We therefore estimate that complying with your request is exempt under section 12 of the FOI Act: cost of compliance is excessive. The section 12 exemption applies when it is estimated a request will take in excess of 18 hours to complete. We estimate that accessing and reviewing all health records and then extracting relevant information would take longer than the 18 hours allowed for. In addition to the section 12 exemption the Trust is also applying section 14 (1) exemption: oppressive burden on the authority

- Q9** Of the children who were diagnosed with cCMV between 28 days and 18 years of age in this time period (Q8), how many:
- Previously had a newborn hearing screening test
  - Had been referred to audiology following their newborn hearing screening test
  - Were given antiviral treatment for cCMV following diagnosis

A9 I can neither confirm nor deny whether the information you have requested is held by the Trust in its entirety. This is because the information requested in this question is not held centrally, but may be recorded in health records. In order to confirm whether this information is held we would therefore have to individually access all health records within the Trust and extract the information where it is present. We therefore estimate that complying with your request is exempt under section 12 of the FOI Act: cost of compliance is excessive. The section 12 exemption applies when it is estimated a request will take in excess of 18 hours to complete. We estimate that accessing and reviewing all health records and then extracting relevant information would take longer than the 18 hours allowed for. In addition to the section 12 exemption the Trust is also applying section 14 (1) exemption: oppressive burden on the authority

\*Please note that any individuals identified do not give consent for their personal data to be processed for the purposes of direct marketing.

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An anonymised copy of this request can be found on the Trust's disclosure log, please note that all requests can be found at the following link: <http://www.uhnm.nhs.uk/aboutus/Statutory-Policies-and-Procedures/Pages/Freedom-of-Information-Disclosure-Log.aspx>

This letter confirms the completion of this request. A log of this request and a copy of this letter will be held by the Trust.

If you have any queries related to the response provided please in the first instance contact my office.

Should you have a complaint about the response or the handling of your request, please also contact my office to request a review of this. If having exhausted the Trust's FOIA complaints process you are

still not satisfied, you are entitled to approach the Information Commissioner's Office (ICO) and request an assessment of the manner in which the Trust has managed your request.

The Information Commissioner may be contacted at:

Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF or via [www.ico.org.uk](http://www.ico.org.uk).

Yours,



**Rachel Montinaro**  
Data Security and Protection Manager - Records