

**Freedom of Information Request**

**Ref: 24-101**

23 February 2024

By Email

Dear Sir/Madam

Thank you for your request for information under the Freedom of Information Act 2000. The Trust's response is as follows:

- We can confirm that we do hold the information you are requesting

**The purpose of this FOI request is to ascertain your Trust's approach to screening for and treating congenital cytomegalovirus (cCMV).**

**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.**

Please see the attached documents.

**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:**

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)

**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** Yes  
 **Blood test for the infant** Yes  
 **Blood test for the mother** Yes  
 **Infant blood spot (Guthrie) card testing** Yes  
 **Unknown**  **Other, please provide details:**

**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

**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

Please see the attached documents.

**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.**

**Q6. 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.** Please note, the Trust does not hold the data in a format that would enable us to fully respond to your request to the level of detail required and a manual trawl for this information would significantly exceed the 18 hours limit set down by the FOI as the reasonable limit. Section 12 of the FOIA provides that we are not obliged to spend in excess of 18 hours in any sixty-day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time.

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

Please note, the Trust does not hold the data in a format that would enable us to fully respond to your request to the level of detail required and a manual trawl for this information would significantly exceed the 18 hours limit set down by the FOI as the reasonable limit. Section 12

of the FOIA provides that we are not obliged to spend in excess of 18 hours in any sixty-day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time.

**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.**

Please note, the Trust does not hold the data in a format that would enable us to fully respond to your request to the level of detail required and a manual trawl for this information would significantly exceed the 18 hours limit set down by the FOI as the reasonable limit. Section 12 of the FOIA provides that we are not obliged to spend in excess of 18 hours in any sixty-day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time.

**Q9. Of the children who were diagnosed with cCMV between 28 days and 18 years of age in this time period (Q8), 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**

Please note, the Trust does not hold the data in a format that would enable us to fully respond to your request to the level of detail required and a manual trawl for this information would significantly exceed the 18 hours limit set down by the FOI as the reasonable limit. Section 12 of the FOIA provides that we are not obliged to spend in excess of 18 hours in any sixty-day period locating, retrieving and identifying information in order to deal with a request for information and therefore we are withholding this information at this time.

This concludes our response. We trust that you find this helpful, but please do not hesitate to contact us directly if we can be of any further assistance.

If, after that, you are dissatisfied with the handling of your request, you have the right to ask for an internal review. Internal review requests should be submitted within two months of the date of receipt of the response to your original letter and should be addressed to:

Data Protection Officer  
University Hospitals Bristol and Weston NHS Foundation Trust  
Trust Headquarters  
Marlborough Street  
Bristol  
BS1 3NU

Please remember to quote the reference number above in any future communications.

If you are not content with the outcome of the internal review, you have the right to apply directly to the Information Commissioner for a decision. The Information Commissioner can be

contacted at: Information Commissioner's Office, Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF

### Publication

Please note that this letter and the information included/attached will be published on our website as part of the Trust's Freedom of Information Publication Log. This is because information disclosed in accordance with the Freedom of Information Act is disclosed to the public, not just to the individual making the request. We will remove any personal information (such as your name, email and so on) from any information we make public to protect your personal information.

To view the Freedom of Information Act in full please click [here](#).

Yours sincerely

**Freedom of Information Team**  
**University Hospitals Bristol and Weston NHS Foundation Trust**