

7 October 2021

## **Children with Cleft Lip and Palate from Birth to 24 Months only**

### **1. For Bi-lateral cleft lip and palate**

The mean, mode and range surgical wait times from birth for primary lip repair and primary palate repair for 2018, 2019, 2020 and 2021 so far. If planned second stage palate repair is required please also provide this data.

### **2. For unilateral cleft lip and palate**

The mean, mode and range surgical wait times from birth for primary lip repair and primary palate repair for 2018, 2019, 2020 and 2021 so far.

### **3. For cleft palate**

The mean, mode and range surgical wait times from birth for primary palate repair for 2018, 2019, 2020 and 2021 so far.

### **4. For cleft lip**

The mean, mode and range surgical wait times from birth for primary lip repair for 2018, 2019, 2020 and 2021 so far.

### **5. FSSA**

Please can you also provide data for any palate surgery on infants that has breached priority 2 FSSA guidance set up during covid and and lip surgery that has breached priority 3 FSSA guidance without a specified co-founder.

Please see below figures for births in each of the years 2018, 2019, 2020 and 2021 so far. It should be noted that data is only available from March 2019.

It is important to note that:

- From March 2019 we had only one surgeon which affects our stats quite significantly.
- At the end of 2019/start of 2020, our consultant changed his operating standards in that palates had to be repaired by the age of 13 months, previously he was working with the standard that the palates had to be repaired by the age 18 months, again this affects the figures.
- If a child has an incomplete palate it is sometimes requested that they are repaired around 6 months if possible
- Our numbers are small compared to England, with an average of approximately 35 births per year.

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To provide anything further than what we have below would incur a disproportionate cost. Under Section 12 of the Freedom of Information Act 2000, the limit has been specified as £450 and represents the estimated cost of one or more persons spending 18 hours in determining whether we hold the information, locating, retrieving and extracting this information.

### **Bilateral cleft lip and palate**

| Year of birth                                  | 1 <sup>st</sup> surgery, bilateral lip adhesion             | 2 <sup>nd</sup> surgery, definitive lip repair and hard palate        | 3 <sup>rd</sup> surgery, residual repair of soft palate                                                                                        |
|------------------------------------------------|-------------------------------------------------------------|-----------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------|
| 2018, 3 BCLP births this year, incomplete data | No data                                                     | Mean = 10 months<br>Mode = 7 months and 13 months<br>Range = 3 months | Mean = 16 months<br>Mode = 16 months<br>Range = 0 months                                                                                       |
| 2019, only one BCLP birth this year            | Mean = 4 months<br>Mode = 4 months<br>Range = 0 months      | Mean = 8 months<br>Mode = 8 months<br>Range = 0 months                | Mean = 13 months<br>Mode = 13 months<br>Range = 0 months                                                                                       |
| 2020, 4 BCLP births this year                  | Mean = 5 months<br>Mode = all different<br>Range = 4 months | Mean = 8.6 months<br>Mode = 9 months<br>Range = 5 months              | Mean = 13 months (only one completed, other 3 still within 13 month standard for completion of palate)<br>Mode = 13 months<br>Range = 0 months |
| 2021, no BCLP births this year so far          | Mean<br>Mode<br>Range                                       | Mean<br>Mode<br>Range                                                 | Mean<br>Mode<br>Range                                                                                                                          |

### **Unilateral cleft lip and palate**

| Year of birth         | 1 <sup>st</sup> surgery, Lip and hard palate repair | 2 <sup>nd</sup> surgery, residual repair of soft palate            |
|-----------------------|-----------------------------------------------------|--------------------------------------------------------------------|
| 2018, incomplete data | No data                                             | Mean = 13.85 months<br>Mode = 15 and 17 months<br>Range = 3 months |

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|      |                                                           |                                                                                                                                                                                                                                                                                      |
|------|-----------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 2019 | Mean = 5.25 months<br>Mode = 5 months<br>Range = 6 months | Mean = 14.25 months, one patient didn't have palate repair until 19 months as waiting for PEG procedure at same operation, 13.57 if we don't include this child<br>Mode = 13 months<br>Range = 7 months (which is the child who needed PEG) 5 months if we do not include this child |
| 2020 | Mean = 5.5 months<br>Mode = 6 months<br>Range = 2 months  | Mean = 13 months (only 2 of 4 completed as yet, other 2 still within 13 month standard for completion of palate)<br>Mode = 13 months<br>Range = 0 months                                                                                                                             |
| 2021 | Mean = 3 months<br>Mode = 3 months<br>Range = 0 months    | Mean none completed as yet<br>Mode<br>Range                                                                                                                                                                                                                                          |

### Palate only

| Year of birth         | Palate surgery                                                                                                                                                         |
|-----------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| 2018, incomplete data | Mean = 16.28 months<br>Mode = 16 and 17 months<br>Range = 5 months                                                                                                     |
| 2019                  | Mean = 12 months (some incomplete palates repaired at 8 months)<br>Mode = 13 and 14 months<br>Range = 7 months (again incomplete palates repaired at 8 months)         |
| 2020                  | Mean = 11.84 months (some incomplete palates repaired as early as 7 months)<br>Mode = 13 months<br>Range = 8 months (incomplete palates repaired as early as 7 months) |
| 2021                  | Mean none completed as yet<br>Mode<br>Range                                                                                                                            |