

Beckwith-Wiedemann syndrome with Macroglossia service (Children) 2020/21

| Indicator Reference Number | Domain | Theme | Measure | Rationale | Name of Indicator/KPI | Numerator | Denominator | Period Type | Frequency | Data Source Numerator | Data Source Denominator | Target | Interpretation Guidance | Notes | Reporting Periods | | | |
|----------------------------|--|------------------|-------------|-----------|---|---|---|-------------|-----------|-----------------------|-------------------------|--------|-------------------------|-------|-------------------|-----|-----|-----------------|
| | | | | | | | | | | | | | | | Q1 | Q2 | Q3 | Q4 |
| E02/S(HSS)a-19-101 | Domain 2: Enhancing quality of life for people with long-term conditions | Clinical outcome | Improvement | | Proportion of patients achieving improvement at the 3 - 6 months post-operative assesment of resting tongue position | Of those in the denominator, the number of patients achieving improved target resting tongue position | Number of patients (children) operated on in the reporting period | Annual | Annual | Provider Submitted | Provider Submitted | | Higher is Better | | N/A | N/A | N/A | Apr 20 - Mar 21 |
| E02/S(HSS)a-19-102 | Domain 2: Enhancing quality of life for people with long-term conditions | Clinical outcome | Improvement | | Proportion of patients achieving improvement at the 3 - 6 month post-operative assessment in the reduction or cessation of drooling | Of those in the denominator, the number of patients achieving a reduction or cessation of drooling | Number of patients (children) operated on in the reporting period | Annual | Annual | Provider Submitted | Provider Submitted | | Higher is Better | | N/A | N/A | N/A | Apr 20 - Mar 21 |
| E02/S(HSS)a-19-103 | Domain 2: Enhancing quality of life for people with long-term conditions | Clinical outcome | Improvement | | Proportion of patients achieving improvement at the 3 - 6 month post-operative assessment in the reduction or elimination of Macroglossia related errors | Of those in the denominator, the number of patients achieving a reduction or elimination of Macroglossia related errors | Number of patients (children) operated on in the reporting period | Annual | Annual | Provider Submitted | Provider Submitted | | Higher is Better | | N/A | N/A | N/A | Apr 20 - Mar 21 |
| E02/S(HSS)a-19-104 | Domain 2: Enhancing quality of life for people with long-term conditions | Clinical outcome | Improvement | | Proportion of patients achieving improvements at the 3 - 6 month post-operative assessment in the reduction or elimination of oral stage difficulties related to the Macroglossia | Of those in the denominator, the number of patients with a reduction or elimination of oral stage difficulties relating to the Macroglossia | Number of patients (children) operated on in the reporting period | Annual | Annual | Provider Submitted | Provider Submitted | | Higher is Better | | N/A | N/A | N/A | Apr 20 - Mar 21 |
| E02/S(HSS)a-19-105 | Domain 2: Enhancing quality of life for people with long-term conditions | Clinical outcome | Improvement | | Proportion of patients achieving improvements at the 3 - 6 month post-operative assessment in the reduction or elimination of parental concerns related to the Macroglossia | Of those in the denominator, the number of patients with a reduction or elimination of parental concerns relating to the Macroglossia | Number of patients (children) operated on in the reporting period | Annual | Annual | Provider Submitted | Provider Submitted | | Higher is Better | | N/A | N/A | N/A | Apr 20 - Mar 21 |

Data collection has been approved by the Review of Central Returns - ROCR
ROCR/OR/2230/001MAND