

Primary Ciliary Dyskinesia (PCD) Diagnosis and Management 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 |
| E13/S(HSS)/g-19-101 | Domain 2: Enhancing quality of life for people with long-term conditions | Outcome measure | Annual review | | Proportion of patients in the PCD management service offered an annual review appointment | Of those in the denominator, the number of patients in the PCD management service offered an annual review | Active caseload in the reporting period | Annual | Annual | Provider submitted data | Provider submitted data | | Higher is better | | N/A | N/A | N/A | Apr 19 - Mar 20 |
| E13/S(HSS)/g-19-102 | Domain 2: Enhancing quality of life for people with long-term conditions | Outcome measure | Physiotherapist | | Proportion of patients seen by a physiotherapist at annual review | Of those in the denominator, the number of patients seen by a physiotherapist at annual review | Active caseload in the reporting period | Annual | Annual | Provider submitted data | Provider submitted data | | Higher is better | | N/A | N/A | N/A | Apr 19 - Mar 20 |
| E13/S(HSS)/g-19-103 | Domain 2: Enhancing quality of life for people with long-term conditions | Outcome measure | Nurse Specialist | | Proportion of patients seen by a nurse specialist at annual review | Of those in the denominator, the number of patients seen by a nurse specialist at annual review | Active caseload in the reporting period | Annual | Annual | Provider submitted data | Provider submitted data | | Higher is better | | N/A | N/A | N/A | Apr 19 - Mar 20 |
| E13/S(HSS)/g-19-104 | Domain 2: Enhancing quality of life for people with long-term conditions | Outcome measure | ENT Specialist | | Proportion of patients seen by an ENT specialist at annual review | Of those in the denominator, the number of patients seen by an ENT specialist at annual review | Active caseload in the reporting period | Annual | Annual | Provider submitted data | Provider submitted data | | Higher is better | | N/A | N/A | N/A | Apr 19 - Mar 20 |

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