**Note: This report has been updated to allow only procedures which fall between a patient’s first and last encounter date. From this, we lost 3 patient’s in our adults cohort, and zero from our kids cohort.**

Using data pulled from TriNetX, kids and adults were identified in their EMR as having Sickle Cell Disease (SCD), and two cohorts were formed for each group. Analysis was performed to identify individuals in these groups who had dialysis services performed in order to distinguish those with Late-Stage Renal Disease / End-Stage Renal Disease (ESRD). The following procedure codes (CPT) were used to categorize patients as receiving *hemodialysis, esrd services,* and*/*or *miscellaneous dialysis services:*

|  |  |
| --- | --- |
|  | |
| Hemodialysis | 90935, 90937 |
| ESRD Services | 90951 ,90952 ,90953, 90954, 90955, 90956, 90957, 90958, 90959, 90960, 90961, 90962, 90963, 90964, 90965, 90966, 90967, 90968, 90969, 90970, 99512 |
| Miscellaneous Dialysis Services | 90945, 90947, 90997, 90999 |
|  | |

Patients were given a binary identifier per each of these groups if a respective code was found in their encounter data within our follow-up period of 2016-2019. Within each cohort, we further identified patients on whether they were in the **Hemodialysis *or* ESRD Services code group.**

We found that 5 of 4559 (0.10%) children had either a Hemodialysis code or ESRD code, and we found that 150 of 6487 (2.31%) adults had either a Hemodialysis code or ESRD code. The following tables describe these groups:

|  |  |  |
| --- | --- | --- |
| **Kids Cohort (N = 5)** | | |
|  | **Yes** | **No** |
| **Hemodialysis** | 5 | 0 |
| **ESRD Services** | 0 | 5 |
| **Miscellaneous Dialysis Services** | 5 | 0 |

|  |  |  |
| --- | --- | --- |
| **Adults Cohort (N = 150)** | | |
|  | **Yes** | **No** |
| **Hemodialysis** | 148 | 2 |
| **ESRD Services** | 116 | 34 |
| **Miscellaneous Dialysis Services** | 85 | 65 |

As we would expect, we have many more adults than children dealing with late-stage renal disease. We have summarized the group variables further for the adults cohort only:

|  |  |  |
| --- | --- | --- |
| **Adults Cohort**  **Hemodialysis (N=146)** | | |
|  | *Mean* | *Standard Deviation* |
| **Count** | 5.15 | 7.25 |
| **Time (in Months) between first & last encounter** | 12.45 | 17.516 |
| **Rate (Count/Time)** | 0.7486 | 0.338 |

|  |  |  |
| --- | --- | --- |
| **Adults Cohort**  **End Stage Renal Disease (N=34)** | | |
|  | *Mean* | *Standard Deviation* |
| **Count** | 2.54 | 6.84 |
| **Time (in Months) between first & last encounter** | 18.91 | 20.22 |
| **Rate (Count/Time)** | 0.712 | 0.28045 |

|  |  |  |
| --- | --- | --- |
| **Adults Cohort**  **Miscellaneous Dialysis Services (N=64)** | | |
|  | *Mean* | *Standard Deviation* |
| **Count** | 0.797 | 1.183 |
| **Time (in Months) between first & last encounter** | 6.07 | 11.33 |
| **Rate (Count/Time)** | 0.860 | 0.395 |

From the above table - we can see that of the 148 adults who have a Hemodialysis code, each adult has an average of 5 codes in their EMR data. Of these, the time between the first and the last code are on average 19 months – where they’re receiving this code about every month and a half.