**TITLE**

**Authors:**

**Affiliations:**

The recent availability of large multi-clinic Electronic Medical Records (EMR) can be a powerful tool in observing the cooccurrence of complications for patients with inherited disorders such as Sickle Cell Disease (SCD). By following patients past their diagnosis of secondary conditions, researchers can observe and assess the response of medical teams faced with this unique situation. Unfortunately, we found the situation described above as idealized – as it is found that we’re unable to rely on diagnosis codes and procedure codes from these multi-clinic EMR.

Using the multi-clinic EMR database, TriNetX, a cohort of both children and adults with SCD (defined as: encounters >= 3, etc.) between 2015-2019 showed poor agreeability (kappa < ….) in end stage Chronic Kidney Disease (CKD) diagnosis and Hemodialysis procedures. The lack of agreement in this CKD diagnosis and its most common treatment suggests a poor reliability for EMR in this particular setting, and is discouraging for its use in rare cooccurring complications.

**KIDS**

|  |  |  |  |
| --- | --- | --- | --- |
| **End Stage Only** | | | |
|  | | **Procedure Code** | |
| 0 | 1 |
| **Diagnosis**  **Code** | 0 | 4482 | 21 |
| 1 | 31 | 25 |

Kappa = 0.4845

|  |  |  |  |
| --- | --- | --- | --- |
| **Stage 5 & Up** | | | |
|  | | **Procedure Code** | |
| 0 | 1 |
| **Diagnosis**  **Code** | 0 | 4475 | 21 |
| 1 | 38 | 25 |

Kappa = 0.4583

|  |  |  |  |
| --- | --- | --- | --- |
| **Stage 4 & Up** | | | |
|  | | **Procedure Code** | |
| 0 | 1 |
| **Diagnosis**  **Code** | 0 | 4460 | 20 |
| 1 | 53 | 26 |

Kappa = 0.4085

|  |  |  |  |
| --- | --- | --- | --- |
| **Stage 3 & Up** | | | |
|  | | **Procedure Code** | |
| 0 | 1 |
| **Diagnosis**  **Code** | 0 | 4422 | 17 |
| 1 | 91 | 29 |

Kappa = 0.3398

|  |  |  |  |
| --- | --- | --- | --- |
| **Stage 2 & Up** | | | |
|  | | **Procedure Code** | |
| 0 | 1 |
| **Diagnosis**  **Code** | 0 | 4400 | 16 |
| 1 | 133 | 30 |

Kappa = 0.3069

|  |  |  |  |
| --- | --- | --- | --- |
| **Stage 1 & Up** | | | |
|  | | **Procedure Code** | |
| 0 | 1 |
| **Diagnosis**  **Code** | 0 | 4391 | 16 |
| 1 | 122 | 39 |

Kappa = 0.2921

|  |  |  |  |
| --- | --- | --- | --- |
| **All Stages (Unspecified Included)** | | | |
|  | | **Procedure Code** | |
| 0 | 1 |
| **Diagnosis**  **Code** | 0 | 4333 | 13 |
| 1 | 180 | 33 |

Kappa = 0.2423

**ADULTS**

|  |  |  |  |
| --- | --- | --- | --- |
| **End Stage Only** | | | |
|  | | **Procedure Code** | |
| 0 | 1 |
| **Diagnosis**  **Code** | 0 | 6358 | 33 |
| 1 | 58 | 38 |

Kappa = 0.4481

|  |  |  |  |
| --- | --- | --- | --- |
| **Stage 5 & Up** | | | |
|  | | **Procedure Code** | |
| 0 | 1 |
| **Diagnosis**  **Code** | 0 | 6350 | 33 |
| 1 | 66 | 38 |

Kappa = 0.4268

|  |  |  |  |
| --- | --- | --- | --- |
| **Stage 4 & Up** | | | |
|  | | **Procedure Code** | |
| 0 | 1 |
| **Diagnosis**  **Code** | 0 | 6333 | 32 |
| 1 | 83 | 39 |

Kappa = 0.3958

|  |  |  |  |
| --- | --- | --- | --- |
| **Stage 3 & Up** | | | |
|  | | **Procedure Code** | |
| 0 | 1 |
| **Diagnosis**  **Code** | 0 | 6286 | 29 |
| 1 | 130 | 42 |

Kappa = 0.3354

|  |  |  |  |
| --- | --- | --- | --- |
| **Stage 2 & Up** | | | |
|  | | **Procedure Code** | |
| 0 | 1 |
| **Diagnosis**  **Code** | 0 | 6265 | 27 |
| 1 | 151 | 44 |

Kappa = 3199

|  |  |  |  |
| --- | --- | --- | --- |
| **Stage 1 & Up** | | | |
|  | | **Procedure Code** | |
| 0 | 1 |
| **Diagnosis**  **Code** | 0 | 6254 | 27 |
| 1 | 162 | 44 |

Kappa = 0.3064

|  |  |  |  |
| --- | --- | --- | --- |
| **All Stages (Unspecified Included)** | | | |
|  | | **Procedure Code** | |
| 0 | 1 |
| **Diagnosis**  **Code** | 0 | 6172 | 23 |
| 1 | 244 | 48 |

Kappa = 0.2513