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Advancing Outcomes Analysis within and Across Transplant Centers Using the OMOP CDM

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Abstract: *Transplantation centers are monitored by the Centers for Medicare and Medicaid (CMS) using transplantation center level metrics that include risk adjusted allograft and patient outcomes to ensure quality healthcare is being delivered. To facilitate this each transplant center extracts the required patient level data and outcomes and reports them to the United Network for Organ Sharing (UNOS) which is also responsible for equitable allocation of organs from deceased donors. The current reporting system is associated with inconsistent and incomplete data associated with infrequent (bi-annual) analysis that limit the ability of a center to extract, report and adjust clinical practice in response to adverse events. We have extracted the dictionary tables from United Network for Organ Sharing (UNOS) and mapped each specific transplantation variable to a standard coding system. Data analysis from multiple transplantation centers will now be able to compare data using a standard forum. This will provide a consistent process of transplantation data analysis in the hopes of improving quality healthcare and patient outcomes.*

Introduction: Organ transplantation is a complex, rapidly expanding and evolving area of medicine that is associated with significant regulatory oversight including close monitoring of early organ and patient level outcomes. End Stage Kidney Disease (ESKD) is of particular concern given that there are over 600,000 patients with ESKD at present, representing 0.7% of the Medicare population and using almost 9% of the Medicare budget [1]. Kidney transplantation is the treatment of choice for ESKD and is associated with an increase in patients' quality of life, fewer hospitalizations and significantly longer overall survival [2,3]. Despite this, the process for access to the transplantation waitlist is complex and associated with significant disparities. Disparities in transplantation persist even among transplanted recipients while early (1 year) national post-operative success rates are currently greater than 90% graft and patient survival [4]. Transplant centers are thus held to a high standard nationally lowering the ability of these centers to early adverse events. Understanding outcomes and the true risk factors associated with poor outcomes requires the ability to capture and report clinical variables of interest to UNOS while also retaining the ability to analyze center level data frequently to inform clinical practice [5]. We believe the OMOP Common Data Model (CDM) used in OHDSI is the ideal infrastructure for developing standard, shareable transplant outcomes analysis that allow more nimble response to changes in outcomes by individual centers.

Methods: We extracted the data dictionary from UNOS. A clinician with transplant experience mapped each specific transplantation variable to a standard code using the USAGI tool. A second transplant clinical provider then reviewed codes that were difficult to map. A subset of variables that are specific to deceased donors and organ preservation techniques were left unmapped variables after a second careful review.

Results: There were 3,143 discrete codes identified in the UNOS data reporting requirements including a smaller subset of variables that are included in the UNOS risk adjustment model used to evaluate center level patient outcomes. Of those, 2,980 UNOS codes were mapped to an OMOP standard concept. The remaining unmapped codes were elements that pertain specifically to donor characteristics as well as to techniques associated with organ storage and preservation techniques.

Discussion: The transplantation dictionary data from UNOS was successfully mapped to a standard coding system using the USAGI tool. Due to the specific nature of transplantation we encountered limitations with the standard coding system. Variables that were specific to the donor organ such as organ procurement procedures and techniques as well as organ disposition (i.e., whether the organ was transplanted or subsequently failed) could not be mapped. Clear assignment of clinical parameters to donor organ or to the recipient is essential for any form of meaningful analysis of outcomes following transplantation. Examples of donor organ specific variables include the type of techniques used for organ preservation, the duration that the organ was stored under hypothermic conditions while awaiting allocation. Similarly, simultaneous organ transplantations while infrequent, are now considered standard of care such as a simultaneous transplant of a heart and kidney or a liver with a kidney. However, while we were able to map some combinations of organ transplants to the OMOP dataset, there were others that we were not.

Conclusion: Based on the UNOS to OHDSI vocabulary coverage there is potential of using the OHDSI infrastructure to enable transplant specific fields that would eventually facilitate the development of center level standardized outcomes analysis while improving the ability of transplant centers to collaborate using appropriately structured datasets. In the future, we plan to work with the OHDSI vocabulary group to incorporate donor-specific data elements and to build an ETL for UNOS data that can be shared among all transplant centers in the US.

References

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