Organ Procurement and Transplantation Network Database on the Open Science Data Cloud

Work on the OSDC to Explore and Improve Healthcare Outcomes

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The Organ Procurement and Transplantation Network (OPTN) is responsible for collecting and managing scientific data about organ donation and transplant procedures performed throughout the United States. The accessibility of OPTN data on the OSDC would provide a edge to transplant focused research. Utilizing this data in conjunction with geographic and demographic data could provide many potential research opportunities in healthcare.

1 Introduction

There are currently over 118,000 people on the waiting list for an organ transplant in America[1]. Each month, the number of transplants needed grows faster than the number of donors. The Organ Procurement and Transplantation Network (OPTN) has a secure transplant information database that contains all national data on the organ waiting list, organ donations and transplantations. The data is broken down in multiple useful demographic categories including, but not limited to, ethnicity, blood type, and reason for transplant. The United Network for Organ Sharing (UNOS) staff has over 400 publication based on or relating to OPTN data[1].

Availability of the OPTN database on the OSDC would allow researchers in the field to easily access and analyze the data without having to perform queries on the OPTN website or request that data from OPTN. This collaboration could lower the barrier of entry to the resources and encourage research in the area. The placement of this database on the OSDC could also facilitate new and innovative research with the ability to cross-reference OPTN data with data from the U.S. Census and Hospital data from the U.S. Medicare database.

2 Background

Patients with a need for an organ can be placed on the transplant waiting list after completing an evaluation by the transplant center. Patients are evaluated for transplant suitability based on their mental and physical health as well as their social support system[2]. All

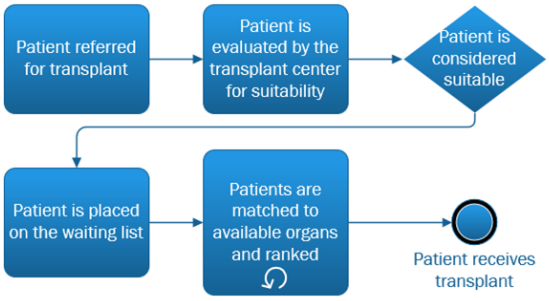

Figure 1: Simple outline of the transplant process. Patients begin with an initial referral to a transplant center. This step is followed by an evaluation of suitability. Suitable patients are then placed on the transplant waiting list and are then constantly matched against available organs. The process ends when a patient receives a transplant or is otherwise removed[2].

of these factors can have a large impact on the success of the transplant. While on the waiting list, the patient information is kept in the database and the patient is then included in the matching process against donor characteristics. For every available organ the systems at UNOS generate a ranked list of candidates for each available organ. Various factors have an influence on the ranking. The OPTN tracks kidney, pancreas, liver, heart and lung transplants among others.

Following placement on the waiting list, patients can wait anywhere from days to years to receive either a living or deceased donor transplant. There is a large amount of data and analysis that is involved in determining whether or not a patient will receive an organ.

Data is not only collected on the waiting list portion of the transplant process, but for the entire treatment. Data is kept on patients removals from the waiting list. Additional information is also stored on the survival rates of patients.

3 Possible Directions for Work

This data is critical for health care providers and statisticians working on the organ shortage crisis. Currently, researchers have very limited access to the data through the OPTN website, as they are only able to download select portions of the database via a formal request.

The ideal vision for this collaboration would be to host a periodically updated copy of the entire database. The data would dovetail well with other sets already available on the OSDC to perform previously difficult correlations. For instance, leveraging the data the latest US Census may show strong correlations in recipient backgrounds and time on the waiting list or transplant success rates, exposing external factors that influence the process.

Another example would be the comparative quality of care data collected by the Medicare Program. Cross-referencing between the datasets would provide a possible correlation between aspects of hospital care and successful transplants, delivering providers with targeted suggestions for improving their facilities.

The ability for researches to preform queries on these databases, outside the constrains imposed by the current gateway, would promote focused work on transplants. This area is oft overlooked for lack of data.

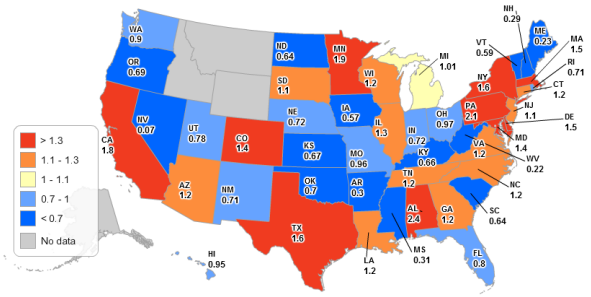

Figure 2: Distribution of the waiting list size normalized to the population of each state. What becomes apparent are the states with an unusally high number of patients on the waiting list.[1]

4 Current Work

In the short time since beginning this effort, several important strides have been made in order to expedite the process of making the OPTN data available and usable on the OSDC. The latest data from the U.S. Census (2010) has been added to the OSDC. Additionally, data from the Official Hospital Compare Database has been stationed on the OSDC.

The Official Hospital Compare database is a comprehensive data set provided by the Centers for Medicare and Medicaid Services. This collection allows for comparisons of the quality of care at more than four thousand Medicare-certified hospitals in the country. The Hospital Compare Database along with the 2010 U.S. Census database are valuable collections of data that have many potential areas of research even as individual sets of data.

Initial contact has also been made with UNOS, inquiring about gaining access to the database. The director of research has requested a short research proposal explaining the objectives of the OSDC as well as the intentions for the OPTN database.

Future work will first involve continuing the effort to make the OPTN database available on the OSDC. There are potential difficulties for this portion of the process. Privacy concerns with the database are a concern that have been mentioned by UNOS in communications. UNOS also has this database for sale to non-member organizations. For this reason, the organization might not want the entire database publicly available.

Other imminent work in the future for this collaboration includes determining the needs to make the databases of interest able to cooperate. Work must be done to the 2010 Census data to be able to perform queries by region, state or zip code. Data from the Official Hospital Compare database would also need to be looked over to determine available data fields that can be queried on along with the other databases.

While waiting for access to the database, simple initial research can be performed in order to investigate research areas of interest. Modest queries and visualization can be made to provide insight to particular areas of interest.

5 Research Questions

- Research the correlation of locations vs. the quality of the transplant process. Geographic factors: Wealth, overall area health, hospital rankings, household size, local industries Transplant factors: Length of waiting list, time waiting, transplants performed, transplant survival
- Where do differences exist? Can we determine why? Can an improved awareness help the situation?
- Could improvements be made to the current transplant process to increase the number of transplants performed and/or improve the survival rates of transplanted patients?

References

[1] Health Resources and Services Administration, Data. 2013 [cited 2013 March 30]; Available from: http://optn.transplant.hrsa.gov/data/.

[2] United Network for Organ Sharing [cited 2013 June 20]; Available from: http://www.unos.org/.

[3] World Atlas United States Populations. 2013 [cited 2013 June 20]; Available from: http://www.worldatlas.com/.