

**OPTN Data Advisory Committee
Meeting Summary
December 14, 2020 5:00 PM EST
Conference Call**

**Rachel Patzer, Ph.D., Chair
Sumit Mohan, M.D., M.P.H., Vice Chair**

Introduction

The Data Advisory Committee (DAC) met via Citrix GoToMeeting teleconference on 12/14/2020 to discuss the following agenda items:

1. Heart Transplantation Committee: New project, check-in #1
2. Social Determinants of Health Presentation
3. Project Updates and Closing Remarks

The following is a summary of the Committee's discussions.

1. Heart Transplantation Committee: New project, check-in #1

The UNOS Policy Analyst supporting the OPTN Heart Transplantation Committee provided an overview of a new project *Review of Extension Requirements in Adult Heart Allocation Policy*.

Summary of discussion:

The purpose of this project is to promote that candidates are maintaining status most appropriate to their medical urgency by modifying heart allocation policy to add criteria and/or require Regional Review Board (RRB) approval to extend at certain statuses. This project also includes proposed changes to the eligibility criteria associated with *Policy 6.1.C.iv: MCSD with Pump Thrombosis*.

This project will impact data collection by modifying extension forms to capture new data or changes to existing data, and may change data validation requirements.

Updated data or confirmation that status eligibility criteria are still being met may be required when submitting extension requests. This data may be similar to what is collected when requesting the candidate's initial status. The proposed modifications would impact Waitlist and require the creation of new adult heart status extension forms for the following policies:

- *Policy 6.1.A.ii: Non-dischargeable, Surgically implanted, Non-Endovascular Biventricular Support Device*
- *Policy 6.1.B.vi: Ventricular Tachycardia (VT) or Ventricular Fibrillation (VF)*
- *Policy 6.1.C.vi: Mechanical Circulatory Support Device (MCSD) with Device Infection*
- *Policy 6.1.C.v: Mechanical Circulatory Support Device (MCSD) with Right Heart Failure*

The proposed changes align with the OPTN Data Collection Principle of develop transplant, donation, and allocation policies. The proposed data collection would aid in confirming heart status eligibility which improves allocation and utilization of hearts for transplantation and would support policy development as well as assessment to promote better outcomes. These changes would also help provide more clarity to members who have questions relating to status extension criteria.

This project is early in its development and is being worked on by a recently formed subcommittee of the Heart Committee. The next check in with DAC is scheduled for February. The target is to have this project approved by the Board of Directors in December 2021.

UNOS staff invited the DAC members to provide feedback. A member asked about the frequency of the data collection required. Discrete fields would be required on extension forms to indicate that the status eligibility criteria are still being met.

A member asked if there are objective data elements that could be collected rather than just a check box indicating the criteria is still being met. UNOS staff shared that the Committee is still discussing these issues.

The Chair asked if the Committee could be given visual examples of the proposed changes in order to provide more context as well as an overview of how many patients would be impacted. UNOS staff will follow up with more information to share with the DAC at the next check in.

A member raised a concern about the administrative burden associated with providing additional data to request status extensions. The Chair commented that this burden needs to be considered along with the value the data would add.

The members decided to initially endorse this project and will continue to provide guidance as the project progresses. The Chair urges the Committee to include an impact assessment as part of the problem statement before presenting to the Policy Oversight Committee (POC).

Next steps:

UNOS staff will provide the DAC members' feedback to the project's Subcommittee and include the requested information to the DAC members at the next check in.

2. Social Determinants of Health Presentation

UNOS Research staff provided an overview of a new project, *Social Determinants of Health: Data Acquisition and Feasibility Study*, and requested feedback from the Committee.

Summary of discussion:

Social Determinants of Health (SDoH) are conditions in the environments where people live, work, and age that affect a wide range of quality-of-life and health outcomes. Domains and elements can differ across SDOH frameworks. The Healthy People 2020 framework has been adopted for this project and includes the domains:

- Economic stability
- Education
- Health and health care
- Neighborhood and built environment
- Social and community context

Currently, the OPTN does not collect extensive SDoH data. More data are needed to better understand the connections between SDoH and health outcomes in transplant. This project is determining the feasibility of acquiring and linking to external data sources, both public and private.

At this phase in the project, the team is evaluating vendors based on the budget, availability, and services provided. Data currently collected by the OPTN is also being assessed for its usability in analyzing relationships between SDoH factors and waitlist and transplant outcomes.

The Chair asked about the level of detail possible for the linkage of patient identifier variables. UNOS staff responded that some of the vendors are able to drill down to the individual level and are even able to provide the residential history of individuals. The Chair asked about time lags associated with these types of variables as they tend to change. UNOS staff commented that a challenge is that some of the residential information are snapshots so the best approach may be to look ahead six or 12 months. Another challenge may be that the residential history provided is limited due to regulations. The Chair commented that data sources such as Medicare claims data have a two-year time lag. UNOS staff commented that there is no time lag with the data sources being considered.

A member asked if information would be provided for both pre transplant and post-transplant. They commented that they have identified that SDoH factors are often barriers for listing patients. This data may also assist in better assessing potential outcome risks associated with social economic status factors. UNOS staff shared that both recipients and a cross section of the waiting list population will be included in the feasibility study.

The Vice Chair raised a concerns about this data being used to inform wait listing practice and the potential for issues with linking the dataset. UNOS staff commented that accurately identifying and linking patient data is a concern and is a primary consideration during the feasibility stage.

The Chair asked if this data will be shared with external organizations for analysis purposes. UNOS staff responded that findings will be shared but the data sharing capabilities will be restricted to the terms of the vendor.

Next steps:

DAC members are invited to provide feedback by email. UNOS Research will provide updates as the project progresses.

3. Project Updates and Closing Remarks

The Vice Chair provided an updated on the work of the Refusal Codes and Late Turndowns Workgroup.

Summary of discussion:

The Workgroup has assessed all existing and proposed refusal codes. There is one round of reviews left before the list is finalized. The Workgroup is ensuring that all codes are mutually exclusive and appropriately categorized to allow coordinators to easily find the most accurate code. The goal is to produce better data to better understand why organs are being declined and potentially discarded. The new refusal codes will be monitored once implemented to determine if any modifications need to be made.

Next steps:

The Workgroup is finalizing the list of refusal codes and presenting the list to various Committees to gather community feedback. In January, the Workgroup will begin addressing late turndowns.

Upcoming Meeting

- January 11, 2020 (teleconference)

Attendance

- **Committee Members**
 - Alicia Redden
 - Anna Mello
 - Daniel Stanton
 - Farhan Zafar
 - Krishnaraj Mahendraraj
 - Kristine Browning
 - Lauren Kearns
 - Macey Levan
 - Melissa McQueen
 - Rachel Patzer
 - Sumit Mohan
- **HRSA Representatives**
 - Adriana Martinez
 - Arjun Naik
- **SRTR Staff**
 - Bertram L. Kasiske
 - Nick Salkowski
- **UNOS Staff**
 - Adel Husayni
 - Alex Garza
 - Andrew Placona
 - Bob Carrico
 - Brooke Chenault
 - Craig Connors
 - Eric Messick
 - Janis Rosenberg
 - Keighly Bradbrook
 - Kimberly Uccellini
 - Laura Cartwright
 - Leah Slife
 - Meghan McDermott
 - Peter Sokol
 - Randall Fenderson
 - Robert Hunter
 - Sara Rose Wells
 - Sarah Konigsburg
 - Sarah Taranto
 - Susan Tlusty