

OPTN Transplant Coordinators Committee

Meeting Summary

November 17, 2021

Conference Call

Stacy McKean, RN, Chair

Natalie Santiago-Blackwell, RN, MSN, Vice Chair

Introduction

The Transplant Coordinators Committee (Committee) met via Citrix GoToMeeting teleconference on 11/17/2021 to discuss the following agenda items:

1. IT Update: UNet Two Factor Authentication Implementation
2. OPTN Disease Transmission Advisory Committee: Endemic Disease Screening
3. New Data Definition Template

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

1. IT Update: UNet Two Factor Authentication Implementation

UNOS IT Staff gave a brief presentation to the Committee surrounding the use of two-factor authentication for UNetSM.

Data summary (as applicable):

UNetSM is being updated to require two-factor authentication through a separate application, Authy. This is a contractual obligation from the Health Resources and Services Administration (HRSA), and is expected to go into effect quarter one 2022. It was noted that, at present, users will not be able to link their Authy account to their UNetSM account, but that will change once the two-factor authentication is implemented. UNOS IT Staff offered a link to download Authy, as well as a link for questions or support.

Summary of discussion:

A member mentioned that they had colleagues who worked with a Veterans Affairs (VA) Hospital, and they had had trouble using the Authy app. They were curious if any members of the Committee had had similar issues, and if so, where should they reach out to. IT Staff stated the best place to reach out to would be the UNet helpdesk.

Next steps:

Two-factor authentication will be required for all UNetSM users starting quarter one 2022.

2. OPTN Disease Transmission Advisory Committee: Endemic Disease Screening

The OPTN Disease Transmission Advisory Committee (DTAC) is focusing on three specific endemic diseases, Tuberculosis, Strongyloides, and Trypanosoma Cruzi (Chagas), to evaluate the consistency of donor testing and communication to transplant programs. The Chair of the DTAC presented on these.

Data summary (as applicable):

The DTAC seeks the input of the Committee to better understand the current screening test and identify any potential gaps that may benefit from either education, policy, or data updates.

- Summary
 - Tuberculosis is currently the third most common cause of donor-derived transmission investigated by the Center for Disease Control (CDC)
 - Strongyloides is the most common parasitic disease that is transmitted, followed by Chagas disease
 - All three of these disease are preventable, but have high potential for complications and potential mortality if transmitted to recipients
 - The increase in organ sharing means there is more potential for disease transmissions
- Risk Factors
 - Primary risk factor for all three diseases is birth in, residence in, or travel to an endemic area
 - Tuberculosis (TB) – Central or Southeast Asia, Southern Africa, or South America
 - Strongyloides – South and Central America, Asia, and Africa
 - US Appalachian region has 1-4% positivity rate
 - Chagas – Mexico, Central America, and South America
 - Prevention of the diseases should be done first by identifying donors at risk for any of the diseases
 - Testing is available for all of the diseases, but not all OPOs use this testing when it should be considered
- Use Cases
 - E.g. if a donor is identified as at risk, or positive for TB, prophylaxis or treatment could be initiated in the recipient depending on what was discovered in the donor
 - In the cases analyzed by the DTAC, this approach has minimized the risk of disease transmission
 - If a donor tests positive for Strongyloides, it is very feasible to initiate treatment on the recipient
 - When adequately instituted, this approach completely eliminated the risk of donor derived Strongyloides
 - When a donor tests positive for Chagas, the recipient must be monitored for disease transmission
 - When not adequately monitored and diagnosed late, the mortality rate can be up to 75%
- Ultimately, these are preventable diseases with the correct approaches
- What information should be conveyed to transplant centers?
 - Donor birth, residence, and travel locations
 - This information is not currently captured in discrete fields, may be in attachments
 - Testing results
 - No testing field for TB, only Chagas and Strongyloides
 - May also be in attachments
 - Donor history
 - No field for TB history, Chagas history

Summary of discussion:

The DTAC Chair inquired what specific steps should be taken to educate OPOs and transplant programs, as well as what the current practices surrounding endemic disease testing comprised at different programs. A member noted that they had a specific team member at their program who reviewed organ offers and will request additional testing that they deem appropriate. However, they did note that when receiving an organ, they will sometimes run into difficulty when requesting specific testing be done on a

donor; they also remarked that there is a lack of consistency for where donor risk criteria for endemic diseases can be found. The Chair did agree with the DTAC Chair that there was variability in the testing requirements, anecdotally mentioning that at one center, they did not consider the Appalachian region to be an indication for Strongyloides testing, whereas another did. Additionally, they also agreed that there was too much variability in where disease testing or risk factors were reported.

The DTAC Chair proceeded to ask what the Committee felt of current OPO disease testing requirements. The Chair replied that there was variability amongst centers, and they felt it was a reaction to which programs had an infectious disease physician guiding and assisting them in developing policies. Additionally, they also felt there was a lack of UNOS guidance surrounding these issues, and there needs to be clear direction not just for testing, but also for reporting in UNetSM.

Finally, the DTAC Chair asked what steps can be taken to improve testing and reporting at programs. The Vice-Chair and a member agreed that a guidance document could be helpful, as well as leveraging the current tools already available in UNOS Connect, for education. Furthermore, the Vice-Chair added that there needs to be one spot within UNetSM where results should be recorded in complete clarity. A member added that this testing could be treated similar to how Public Health Service (PHS) guidelines for HIV, HBV, and HCV transmission are treated, where the testing and documentation requirements are clearly stipulated. The Chair cautioned this approach, though, as they don't want to increase the data burden on programs and OPOs.

Next steps:

The DTAC will consider the feedback provided by the Committee.

3. New Data Definitions Template

The Data Advisory Committee (DAC) has created a new template for data definitions, and UNOS Staff from the DAC provided a presentation on the functions and usability of the template.

Data summary (as applicable):

- Improving data quality is one of the DAC's performance standards
 - This can be done by improving the consistency and accuracy of data submissions
 - The DAC is attempting to identify "pain points" within data collection that the DAC can focus on
- Function of DAC
 - Operating Committee under HRSA contract reevaluation
 - Broad oversight over all OPTN data collection efforts
 - This includes additions, removals, and modifications
 - Annually report to the Board on data quality and DAC efforts to date
- Usage of Data Definitions
 - More commonly known as Help Documentation
 - Explains the data requested by a specific field
 - Data definitions are sometimes not known by newer coordinators or data quality professionals
 - Steers more towards a data dictionary style, including technical details, versus a business glossary
 - Data definitions function as a source of truth to help members report accurate data
- Inconsistencies in Data Definitions
 - Format and structure can vary across systems, content required can vary, and the possible options can vary

- Additionally, some fields are outdated
 - Some are too specific, some are too general
- Data Definition Improvements
 - DAC has created a new template designed to engage more with transplant coordinators and administrators that is less technical and more accessible
 - Requesting review from end users to ensure that they meet the right level of specificity
- Proposed Data Definition Template

Structure of Data Elements

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|---|---|
| <ul style="list-style-type: none"> ▪ Label Name: <ul style="list-style-type: none"> ▪ Label visible to user ▪ Intent: <ul style="list-style-type: none"> ▪ Why is the OPTN collecting this data element? What is its specific purpose and what is its purpose in the general context of organ donation and transplantation ▪ Description: <ul style="list-style-type: none"> ▪ Category ▪ unit of measurement ▪ timeframe ▪ synonyms or related terms ▪ Expected/absolute values ▪ response options ▪ rounding rules, converting b/t units of measure, etc. | <ul style="list-style-type: none"> ▪ unique cases ▪ Source or related standards: <ul style="list-style-type: none"> ▪ External standard or definition ▪ Related elements/locations: <ul style="list-style-type: none"> ▪ Indicate whether field cascades from another system, dependent on other values or to describe parent/child ▪ Clarifications: <ul style="list-style-type: none"> ▪ formerly know as “Note” ▪ Revision History: <ul style="list-style-type: none"> ▪ document the date and changes made to the definition |
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Summary of discussion:

The Chair inquired whether, during the process of standardizing the data elements, the DAC was also considering which were no longer relevant and removing them. The presenter replied that, while it is not part of this project, part of DAC’s charge is reviewing existing data for relevancy. Furthermore, DAC can be assisted by the community on elements they believe need review. They concluded by requesting feedback from the Committee. The Vice-Chair supported including the definition at the beginning, rather than after the “Intent” field. They also appreciated the addition of a “History” field, which helps a reader understand how up-to-date a field is. A member noted they would prefer the “History” section to be separate from the main page, for ease of reading, which the Chair also endorsed. The presenter added that they were not quite sure what the technical limitations of the page were, but they could bring the feedback back to their Committee to consider.

Next steps:

The DAC will consider the feedback from the Committee.

Upcoming Meetings

- December 15, 2021
- January 19, 2022

Attendance

- **Committee Members**
 - Stacy McKean
 - Natalie Santiago-Blackwell
 - Donna Campbell
 - Jill Campbell
 - Maria Casarella
 - Alexandria Dillard
 - Lisa Gallagher
 - Sharon Klarman
 - Angele Lacks
 - Sergio Manzano
 - Kelsey McCauley
 - Heather Miller-Webb
 - Jamie Myers
 - Stacy Sexton
 - Melissa Walker
- **HRSA Representatives**
 - Raelene Skerda
- **UNOS Staff**
 - Brooke Chenault
 - Mike Ferguson
 - Cole Fox
 - Isaac Hager
 - Courtney Jett
 - Elizabeth Miller
 - Susan Tlusty
 - Kimberly Uccelini
 - Ross Walton
- **Other Attendees**
 - Ricardo La Hoz