

**OPTN/UNOS Data Advisory Committee
Meeting Summary
October 15, 2014
Conference Call**

**Charlie Alexander RN, MSN, MBA Chair
Joseph Kim PhD, MHS, FRCPC, Vice Chair**

Discussions of the full committee on October 15, 2014 are summarized below and will be reflected in the committee's next report to the OPTN/UNOS Board of Directors. Meeting summaries and reports to the Board are available at <http://optn.transplant.hrsa.gov>.

Introduction

The Data Advisory Committee (DAC) met via Citrix GoToTraining and teleconference on 10/15/2014 to discuss the following agenda items:

1. DAC's Initial Priorities and Path Forward

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

DAC's Initial Priorities and Path Forward

The Committee Chair welcomed the members to the first, full committee conference call. He explained that during the first call the committee would discuss DAC's initial priorities and path forward.

OPTN support staff presented the committee roster, OPTN committee support staff, and SRTR support staff. And OPTN support staff reminded members to complete the online orientation modules.

Summary of discussion

The Chair explained that DAC has several initiatives, some of which will be achieved over a few years, and others which can be achieved in a shorter period. Specifically, DAC will seek broad input in developing a long term, innovative vision for the OPTN/SRTR data set. DAC members will look at the data that is currently being collected and will look at how the currently collected data may be best used, and DAC will look at data that may be meaningful to measurement, process improvement, patient safety, etc. that is either not currently collected or not consistently currently collected on a routine basis. DAC will discuss how to incorporate this into future OPTN data systems.

DAC will have to work within the current process and will have to obtain community support for any recommended changes in order to make sure the community has the same understanding of the proposed changes to the data system and that the proposed changes will in fact lead to an enhanced OPTN data collection system.

The DAC will also analyze and consider advances in both organ transplantation and technology in order to inform this vision. The Chair acknowledged that this statement could have different meanings. It could reference the evolution of data system at UNOS and how to more efficiently collect organ transplantation data from the beginning of the process, or reference the fact that

technology continues to change (for example, EVLP and the profusion of lungs) and the OPTN data collection system needs to continue to change with it.

The charge of the Committee's work is to develop specifications for and advise the OPTN Board of Directors on collecting data pertinent to the operation of the OPTN and SRTR and further the state-of-the-art in organ transplantation, including continuous quality and patient safety improvements. The Chair explained that we want to make the data collection and the use of the data collection system state-of-the-art.

The Chair explained that SRTR's involvement is a conscious choice and the S-TAC's previous work will help assist DAC in its projects. DAC should look at the work that S-TAC has accomplished thus far and ensure that it (DAC) is not reinventing the wheel, as well as learn from S-TAC's experiences.

Ongoing work of the Committee will include re-defining the principles of data collection and sell the benefit of this new vision to the members and community. Additionally, ongoing work of the Committee will be to further develop policy requirements for OPTN data collection – and to ensure that an enhanced OPTN data collection system is administered consistently and with clear guidance from the OPTN.

The Chair explained the importance of agreeing on the Committee's ultimate goals. As such, the committee's initial tasks include:

- Agreeing on DAC's ultimate goal
- Agreeing on initial priorities and projects
- Reviewing the work already accomplished (for example, S-TAC or organ specific committees' work associated with creating or adjusting risk adjustment models) and assigning tasks for initial projects

The Chair explained that DAC should review work that has been completed thus far regarding data collection. Specifically, look at what the S-TAC and organ-specific committees have accomplished regarding metrics and data collection.

The Chair explained that the committee needs to begin to think in terms of building a framework. DAC will build the framework by:

- Solidifying the vision and objectives
- Identifying the key tasks and contract deliverables
- Creating timelines
- Contributing expertise
- Begin accountable by fulfilling assignments

The Chair emphasized that the members will work from within the committee and reach out to the community for additional expertise, as needed. The members should view themselves as orchestrating the projects and reaching out to the community for additional support and information.

The committee has two projects that it needs to address in its initial path forward. The first is reviewing the OPTN Principles of Data Collection to determine if there are updates needed and if so, identifying those updates. The second is reviewing the OPTN Data Release Policy to ensure the policy complies with the Final Rule. HRSA representatives pointed out that there are data release requirements in the Final Rule.

As a long-term project, DAC will develop a document that lays out an innovative vision for the OPTN data system. The data system should be systematic and smoothly functioning. In addition, the data system should provide members with a healthy data set and encourage members to promote patient safety, system improvement, increased quality, and increased the number of transplants. The Chair acknowledged that this a lofty goal – and in order to achieve the goal, DAC will need to look at data that is currently collected.

The Chair further explained that the goal is to collect data pertinent to the operation of the OPTN and SRTR because this is where peer review meets measurement. The community, hospitals, and patients need to be in-step together in this process. Lastly, DAC members should keep in mind DAC's vision and, in the future, routinely ask if a particular project promotes the vision.

The following over-arching considerations are items committee leadership and support staff identified when establishing DAC's vision:

- Establishing process for organ-specific committees to make data-related changes
- Addressing areas of improvement with current performance metrics
- Determining if the system has the capacity needed for predicting outcomes
- Re-defining what is a successful transplant
- Streamlining data collection process to make it as efficient and useful as possible
- Assess ability to merge OPTN data with other national sources
- Keeping in mind our work's impact on research

The organ specific committees believe there are ways to strengthen the risk adjustment, outcome measurement, and effectiveness scale models. This can be accomplished by adding and deleting data fields that are currently available. If DAC reaches out to organ specific committees and OPOs then DAC would probably receive a working list of data fields, which would take a while to sort through – this will probably be the first step. DAC wants to know what the community thinks will be meaningful measures that will drive improvement, patient safety, increase donation, and increase the number of transplants.

DAC wants to be able to address areas of improvement with current performance metrics. There is room to improve existing measures and metrics and build a better system. SRTR will assist by helping DAC members understand how the statistical modeling can allow the OPTN to build predictive outcomes. The Chair explained this leads to re-defining what is a successful transplant.

The one thing that the data system has been unable to do so far is to fully risk adjust the subtleties and nuances of each specific organ with the subtleties and nuances of each specific recipient. If there is success in creating systems that allow members to look at matching of a specific organ to a specific recipient, across all organ systems, then DAC can go back to the community and payers and allow the system to define what will be the tolerance for a successful transplant. There is a need to create a system that allows the system to determine what is a successful transplant.

A member opined whether “transplant” was the operative word – the member suggested that what is being described is, “what is successful engagement within the system?” Therefore, it is not looking at transplant and forward, but asking, “Did we meet the needs of the patient that entered into the system how are those needs defined?” The Chair supported this suggestion

and emphasized the importance of looking at pre-transplant metrics, in conjunction with center performance, as well.

A member suggested the committee look at the following additional considerations as well:

- Where are there gaps in currently collected data and how will the committee narrow those gaps?
- Time associated with creating a new data field to when the data for the new data field will be available to use
- The people cost of adding data elements and the burden on transplant centers to import additional data

A HRSA representative explained that part of the idea and desire for the new DAC is for DAC to look at data system topic from a broad perspective and not make just marginal changes to the current data system. There is a vision that in 5 to 8 years centers will be able to download information from the medical records into UNet's successor. Moreover, the work involved will be significantly less, but there will be a better data set (i.e. better product), while providing information necessary to generate desired analysis. In other words, if we were creating a new data system today what would that data system be?

OPTN IT leadership explained there is an opportunity to take advantage of new technology and interactions with other health care systems to a degree that practically makes sense from a governing perspective. This opportunity is to make data entry easier by not having to rely on manual data entry.

The Vice-Chair said that the article, "Big Data in Organ Transplantation: Registries and Administrative Claims" will be of interest to the committee. The Vice-Chair suggested that a review of available data systems might be beneficial to the committee as a first step.

Upcoming Meeting(s)

- November, 2014
- December, 2014
- January, 2014