The Importance of Getting It Right

Research's new DQ group focusing on proactivity

Editor's note: Results of a recent UNOS member survey indicated that many transplant professionals are unaware of the services and resources various UNOS departments provide. To help busy professionals understand how different UNOS departments function and to inform them of the many tools available, we are kicking off a new series, Introducing Ourselves.

In each issue we'll focus on a different department or service. We'll illustrate how various departments' activities translate to the day-to-day routines of staff in OPOs, transplant centers and histocompatibility labs. We'll also highlight the tools and services available to help you perform your job and let you know how to access them.

We begin this series by explaining recent organizational changes in UNOS' research department and how those changes will enhance the quality of OPTN data. If there is a UNOS job, department or function you would like to see explained, please call Karen Sokohl, UNOS member communications specialist, at (804) 782-4651 or send an e-mail to sokohlka@unos.org.

BY MATTHEW HARRISON

Data quality has been an integral component of the UNOS mission since it began managing the OPTN in 1986. While UNOS' research department has always monitored discrepant data, other departments through the years also have played an active role in confirming the data submitted to UNOS by OPTN/UNOS members.

Thanks to a recent reorganization of the UNOS information technology department, research now is home to the data quality (DQ) team. Ultimately, the change will help UNOS more efficiently investigate potential data integrity issues.

Deborah B. "Deb" Ormond, a SAS analyst with 10 years' experience in OPTN data collection and analysis, is DQ's data quality manager. She oversees six data specialists and a SAS analyst, all of whom have joined the DQ group from other departments at UNOS.

When there are errors in the data submitted, Ormond explained, the DQ team will handle the database updates and also work with the Service Desk (formerly, the HelpDesk) and others in research to hasten data correction.

"Other UNOS SAS analysts and statisticians will forward work to DQ, so data discrepancies will filter through us," she said.

A special asset in DQ is its diversity—team members come from both policy analysis and information technology. Each member has unique insights into the intricacies of UNOS data, and Ormond expects their combined knowledge will help proactively identify data quality concerns.

"The data specialists are learning structured query language (SQL) so they will be able to query the system, finding and resolving discrepancies themselves," she explained. That kind of proactivity will save UNOS and transplant centers valuable time.

"We enjoy what we do and why we do it," Ormond said, "and especially who we do it for."

ASSESSING DATA DISCREPANCIES

Maureen A. McBride, Ph.D., director of research, expects that the change also will allow UNOS to expand its assessment of discrepant data. Historically, data quality at UNOS has focused on the TIEDI® system, the database in which transplant registration and follow-up forms are completed by member transplant centers across the country.

"I'd like to make the investigation of data quality more tied to how the data are used, incorporating data collected through multiple sources within the UNet℠ framework," Dr. McBride said, "and not limiting our examination to ensuring that UNet forms operate logically and correctly."

UNOS engages its members regularly to educate transplant coordinators and their staff about the importance of accurate data entry, and the UNOS Service Desk will continue to communicate with members to fix errant data. However,

Dr. McBride anticipates help from the DQ group in rectifying errors expeditiously. She also hopes that more focused investigations of data quality concerns will illuminate potential gaps in member training.

"Maybe we can identify some further education we need to provide to members," she said. "We also may identify additional options so that members can make these changes themselves."

The highest priority in improving OPTN data is ensuring patient safety. Dr. McBride noted that improving data quality is a continuous goal. For instance, data based on organ recoveries and organs utilized per donor are combined with other factors to highlight areas in need of improvement—or achievement.

IMPROVING TRANSPLANT PROCEDURES

Data quality is also vital to the Scientific Registry of Transplant Recipients (SRTR), which uses OPTN data to create statistical and simulation models used to develop transplant policy. Collaboration between UNOS and SRTR yields information that helps patients and doctors decide the most appropriate treatment options.

Higher standards of data quality are essential for improving the success of transplant procedures. OPTN captures data on corporate and academic medical research across the country. The research is aimed at identifying and exploring patient characteristics that can prolong a patient's life and well-being after transplant surgery.

OPTN data also have a global impact. International organizations, such as the International Society for Heart and Lung Transplantation, collaborate with UNOS to investigate worldwide trends in thoracic transplantation.

"Having high-quality data underpins most OPTN/UNOS decisions on how policies are developed and how patients are treated," Dr. McBride said. OPTN data also are integral to how transplant centers and OPOs conduct business.

"The work of research and its new DQ team," Dr. McBride said, "has a direct impact on people's lives." U

ONLINE For more information on the types of data UNOS collects and analyzes, visit *unos.org/data/about/collection.*

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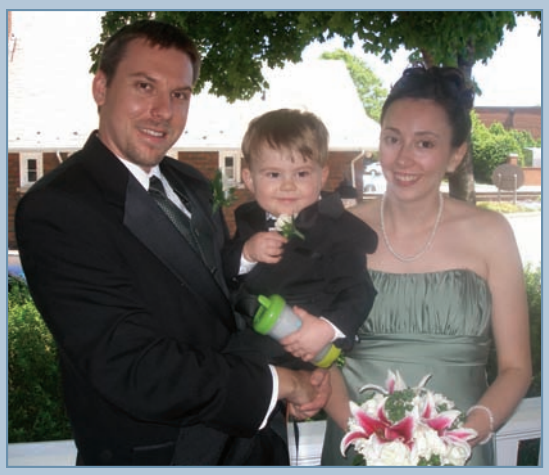

The photo on the author's desk, which constantly reminds her that the names in the databases with which she works are people. In the photo is the author with her husband, Pete, and their son, Peter. The occasion was her sister's wedding, taken in May 2007 at the Henry Clay Inn in Ashand, Va.

A DIFFERENT KIND OF PATIENT ADVOCACY

BY CATHERINE MONSTELLO

On my desk at UNOS sits a framed photograph of my family. I don't keep this picture just because they're cute (they are) but also to remind me that every name in the OPTN database—every candidate, donor and recipient name—is family to someone.

I began my career as a respiratory therapist. I remember some of the patients I cared for as a student most vividly. My first ventilator-dependent patient was a 34-year-old liver recipient with cancer. My first patient who died was a heart recipient who had suffered a perforated bowel (not related to the transplant). Maybe I was fated to eventually work in transplantation.

What I recall so clearly about all of these patients is their families. The liver recipient's wife used a letter board to help him communicate with her. In the heart recipient's room, the glass walls were filled with pictures drawn by her children. These kids didn't go home to play after school; they headed to the ICU to visit their mom.

When I perform my daily tasks, I think of these recipients, their families and all of the people connected to each "name" in the database. I consider these people when I am fulfilling a data request or trying to make sure a database record includes the correct information. If I'm ready to stop, I ask myself if my level of effort has been enough for them. If the answer is no, then I keep going.

I realize that I am fortunate to have cared for these patients and to be able to draw their faces from my memory as motivation, but everyone has family. And most likely, your family is similar to their family; once you make that connection, the individual is no longer just a "name" in a database.

Patient advocacy doesn't start or stop in the hospitals; each of us has the opportunity to contribute to the shared knowledge of transplant, the knowledge that will have a ripple effect on patients and their families. By striving to produce high-quality work in all aspects of transplantation—clinical work or policy work—we all have the capacity to further the field of transplantation and improve patients' lives.

In that respect, we all have the potential, and privilege, to be patient advocates. U

Catherine Monstello, RRT, CPHQ, is a SAS programmer in UNOS' research department.