

Data Advisory Committee: Update and Activities

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

Spring 2015

DAC Charge and Functions

Seek broad input in developing a long term, innovative vision for the OPTN/SRTR data set

Systematic and smoothly functioning process for the identification of OPTN data to be collected

Methods of collection

Types of products to be supported by the system



Analyze and consider advances in both organ transplantation and technology in order to inform this vision

DAC Goals

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

Maintain principles of data collection

Develop policy requirements for OPTN data collection

DAC Projects

Modify
OPTN/UNOS
Data Release
Policy

Evaluate
Current and
New Data
Elements for
OPTN
Database

Improve OPO
and Tx Ctr
Metrics and
Measures

Secure
Enterprise
Solutions for
OPTN
Database

OPTN/UNOS Data Release Policy

Problems

- OPTN/UNOS Data Release policy is currently more restrictive than the Final Rule, making it noncompliant
- OPTN/UNOS Data Release policy is inconsistent with SRTR's data release policy

Project Goals

- Make the OPTN/UNOS data release policy consistent with the Final Rule
- Align the OPTN and SRTR data release policies
- Align the OPTN and SRTR data release processes

Timeline

- August 2015 public comment

Evaluate Current and New Data Elements for OPTN Database

Problems

- Collecting additional data imposes resource burden on transplant centers, OPOs, labs, and OPTN
- Community recognizes need to improve risk adjustment through PSRs by collecting additional data
- OPTN Database may collect data that are no longer relevant or not collect data that are relevant to improving PSRs and improving monitoring of OPTN policies
- No systematic review process for reviewing data elements in OPTN database

Goals

- Reduce data burden by eliminating extraneous data elements
- Improve data collected in the OPTN database
- Reduce cost of entering data by creating IT infrastructure capable of integrating with outside data sources
- Revise principles of data collection

Timeline

- One proposal per Board meeting

Improve OPO Metrics & Measures

Problems

- OPO Community suggests the use of O:E as a metric outside of measuring organ yield, no model currently exists
- Currently lack data to analyze authorization rates and insights into reasons for not donating
- CMS metrics for OPO performance are built into CMS regulations

Goals

- Analyze Deceased Donor Potential Study to help improve donation rates
- Collect more donor-related data (and data on non-donors) to improve metrics, recognize risks, and dispel misinformation
- Help build metrics for future use by CMS

Timeline

- Not yet established – In process

Secure Enterprise Solutions for OPTN Database

Problems

- Entering data into OPTN Database is major burden for users
- Getting data out of the OPTN Database is difficult for users
- Cost of collecting additional data is high

Goals

- Automate data transfers between external users and OPTN Database
- Create a data lake to collect and store data
- Data lake will interface with users' external applications so data can be accessed and organized for the users' needs

Timeline

- Ongoing project performed by UNOS IT Department

DAC Roster

Name	Committee Position	Institution Name
Charles Alexander RN, MSN, MBA	Chair	The Living Legacy Foundation of MD
S. Joseph Kim M.D., FRCPC	Vice-Chair	Toronto General Hospital
Yael Coppleson	At Large	New York-Presbyterian Hospital
Sandy Feng MD, PhD	At Large	UCSF Medical Center
Alexandra Glazier JD, MPH	At Large	New England Organ Bank
Richard Hasz Jr , MFS	At Large	Gift of Life Donor Program
Ian Jamieson MBA, MHA	At Large	Duke University Medical Center
Maryl Johnson MD	At Large	University of Wisconsin
Alan Leichtman MD	At Large	University of Michigan Medical Center
Robert Merion MD	At Large	University of Michigan Medical Center
Mike Peterson PhD	At Large	NeuStar, Inc.
Jesse Schold PhD, M.Stat, M.Ed	At Large	Cleveland Clinic Foundation
Stuart Sweet M.D., Ph.D.	At Large	St. Louis Children's Hospital
James Wynn M.D.	At Large	University of Mississippi Medical Center

OPTN Support Staff

OPTN/UNOS Liz Robbins Callahan, Esq. – Policy, Liaison/Policy Analyst

Jen Wainright PhD – Research Scientist

Chrystal Oley-Graybill – Regional Administrator

Elizabeth Miller JD – Senior Policy Analyst, Membership Quality

Leah Slife – Analyst, Membership Quality

Trevi Wilson – Membership Quality

Adreania Tolliver – Curriculum Development Instructor

OPTN Management Support Staff

OPTN/UNOS	Maureen McBride PhD –	Chief Contracts Operations Officer
	Alex Tulchinsky –	Chief Technology Officer
	Ryan Ehrensberger PhD –	Director of Research
	James Alcorn JD –	Director of Policy
	Erick Edwards PhD –	Assistant Director/ Senior Research Scientist
	Leah Edwards PhD –	Assistant Director/ Senior Research Scientist

SRTR Support Staff

SRTR

Bert Kasiske MD, FACP – Project Director

Jon Snyder PhD, MS – Director of Operations

Ajay Israni MD, MS – SRTR Deputy Director,
Nephrologist

Nick Salkowski PhD – Biostatistician

Susan Leppke MPH – Program Manager
