Introduction

The Broader Distribution Data Collection Workgroup (the Workgroup) met via Citrix GoToMeeting teleconference on 09/15/2020 to discuss the following agenda items:

1. Follow Up Information from 8/18 Call
2. Review and Discussion: Data Collection Project Scope and Process
3. Next Steps

The following is a summary of the Workgroup’s discussions.

1. Follow Up Information from 8/18 Call

There were some proposed data elements that, upon further review, will not be able to be addressed within this Workgroup’s project: (1) Cost, as it is outside the scope of the project and beyond the purview of the OPTN to collect directly; (2) Data from TransNet because there is variability in data and how organs are checked in as well as not all transplant programs have capability to scan organ labels; (3) Late turndown data, as the OPTN Data Advisory Committee (DAC) is currently evaluating this data.

2. Review and Discussion: Data Collection Project Scope and Process

Staff from Data Governance (DG) within UNOS reviewed data collection processes and standards.

Summary of discussion:

Data review processes were developed to improve the quality of officially OPTN data by:

- Improving definitions of data elements in order to maintain consistency in data entry
- Monitoring completeness and accuracy of data collected to help in evaluating whether to modify and update or remove data elements
- Adding data elements supported by outcomes-based evidence to predict outcomes

Data elements that are incomplete, outdated, or unnecessary should be removed to reduce the burden of data collection for OPTN members. A guiding principle for the Workgroup: what is the minimum amount of data we can ask members to report to receive the needed information to achieve a certain task or goal.

Staff is creating a spreadsheet detailing proposed data elements and comparing each to the Data Element Standard of Review Checklist. Once the Workgroup receives this spreadsheet, the members are encouraged to analyze and give feedback on the data elements themselves as well as the content of the spreadsheet.

There were no questions or comments from the Workgroup.
3. **Next Steps**

The Workgroup will receive a spreadsheet detailing data that is collected in relation to travel. The Workgroup will review and discuss data to identify gaps and recommend data element changes.

**Upcoming Meeting**

- October 20, 2020 (teleconference)
- November 17, 2020 (teleconference)
Attendance

- Workgroup Members
  - Dominic Adorno
  - Alden Doyle
  - Anna Mello
  - Asif Sharfuddin
  - Daniel Stanton
  - James Trotter
  - Jillian Wojtowicz
  - Susan Stockemer
  - Susan Weese

- HRSA Representatives
  - Raelene Skerda

- UNOS Staff
  - Joann White
  - Kim Uccellini
  - Grace Acda
  - Katrina Guantt
  - Kristine Althaus
  - Lauren Motley
  - Matthew Prentice
  - Meghan McDermott
  - Sarah Taranto