OPTN Policy Oversight Committee Equity in Access Subcommittee Meeting Minutes October 28, 2019 Conference Call

Chair: Martha Pavlakis, MD

Introduction

The subcommittee met via Citrix GoToMeeting on 10/28/2019 to discuss the following agenda items:

1. Equity in Access

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

Summary of discussion:

- The subcommittee recapped the POC's discussions regarding strategic policy priorities and the goals of the subcommittee.
- The subcommittee next discussed what steps the OPTN should perform before committees could begin work on this topic. For example, is there data that the OPTN should collect or analyze to understand the causes and impact of this problem? Alternatively, does the OPTN need consistent principles on this topic before the OPTN begins organ-specific projects?
- The subcommittee agreed that data collection regarding referrals is the next logical step. It is difficult to assess whether patients have appropriate access to the waiting list without having a clear vision of the total population of patients in need. The committee discussed using resources to calculate the population at risk of end stage organ failure and potentially eligible for transplant but agreed that population was too broad because not all of these patients would be appropriate for organ transplantation. Therefore, they agreed to focus on patients that are referred for transplant.
- The subcommittee also agreed that an early step would be to have clear definitions regarding referrals. For example, does a phone inquiry from a potential candidate count as a referral or must it be in writing?
- Dr. Patzer described her research in this area, which confirmed the need to standardize data definitions.¹ Subcommittee members saw this as a potential starting point for the OPTN to begin collecting cross-organ, referral data.
- Next, the subcommittee discussed whether and where transplant hospitals stored this data. They agreed that all transplant hospitals store this data and it is typically in the patient's EMR but that the form of this data can vary between hospitals.
- Next, the subcommittee discussed who in each hospital is typically involved in reviewing referrals. All subcommittee members agreed that transplant coordinator typically perform this work. Some subcommittee members stated that it would also be helpful to have some

¹ Patzer RE, Plantinga LC, Paul S, et al. Variation in Dialysis Facility Referral for Kidney Transplantation Among Patients With End-Stage Renal Disease in Georgia. JAMA. 2015;314(6):582–594. doi:10.1001/jama.2015.8897

physicians involved in the project were the OPTN also to consider the collection of clinical data for referrals. Finally, for this to be successful, we should standardize the approach across the organs.

Next steps:

- The Chair will present a summary of the subcommittee's discussions and recommendation to the full Policy Oversight Committee (POC) at their in-person meeting.
- Dr. Patzer will also present an overview of her research in this area.

Upcoming Meeting

• October 30, In-person Policy Oversight Committee meeting

Attendance

- Subcommittee Members
 - Martha Pavlakis
 - Paula Martins
 - Rachel Patzer
- UNOS Staff
 - o James Alcorn
 - o Read Urban