OPTN Patient Affairs Committee
Meeting Summary
April 18, 2023
Conference Call

Garrett Erdle, MBA, Chair
Molly McCarthy, Vice Chair

Introduction

The Patient Affairs Committee (Committee) met via WebEx teleconference on 04/18/2023 to discuss the following agenda items:

1. Review inactive codes data
2. Review literature on inactive codes
3. Discussion

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

1. Review inactive codes data

The Committee received a presentation on inactive waiting list registrations.

Data summary:

- Percent of inactive registrations at each waiting list snapshot date for heart, kidney, liver, and lung from 2013-2022
  - Kidney: 36-46% of registrations inactive, increasing since around 2019
  - Heart: ~20% of registrations inactive, with a spike to 26% in 2020, likely due to the COVID-19 pandemic
  - Liver: 18-23% of registrations inactive
  - Lung: 15-20% of registrations inactive, with a spike up to 23% in 2020, likely due to the COVID-19 pandemic
- Median number of days in inactive status per year by organ
  - Kidney: 215-220 days per year, with a dip to 180 in 2020 and up to 192 in 2022
  - Liver: 80-90 days per year
  - Heart: 60-70 days per year until 2019, when it dipped to 45-55 days per year
  - Lung: 30-40 days per year, dipping to the 20s from 2017-2019 and then spiking back up in 2020 before settling around 22 days in 2022
- Distribution of days in each inactive code in 2022 for inactive kidney registrations – top 5:
  - Temporarily too well – 360 days
  - Weight currently inappropriate for transplant – 264 days
  - Candidate work-up incomplete – 202 days
  - Medical non-compliance – 185 days
  - Inappropriate substance use – 172 days
- Number and percent of inactive registrations by code on 12/31/2022 – top 6 by organ
  - Kidney
    - Candidate work-up incomplete – 49.73%
    - Temporarily too sick – 23.93%

        - Temporarily too well – 8.27%
        - Insurance issues – 6.21%
        - Candidate choice – 3.87%
        - Weight currently inappropriate for transplant – 2.98%
    - Liver
        - Temporarily too sick – 22.75%
        - Candidate work-up incomplete – 21.24%
        - Temporarily too well – 18.24%
        - Candidate choice – 13.35%
        - Insurance issues – 8.27%
        - Inappropriate substance use – 6.48%
    - Heart
        - Temporarily too sick – 29.56%
        - Temporarily too well – 22.91%
        - Candidate choice – 10.47%
        - Inactivation due to ventricular assist device (VAD) implantation and/or VAD complication – 7.78%
        - COVID-19 precaution – 5.94%
        - Insurance issues – 5.80%
    - Lung
        - Temporarily too sick – 46.24%
        - Temporarily too well – 16.13%
        - Candidate choice – 10.22%
        - COVID-19 precaution – 9.14%
        - Insurance issues – 5.91%
        - Candidate work-up incomplete – 5.38%

Summary of discussion:

A member asked what "not reported" means. Staff said that there are some registrations in the data set that do not have any data in the field for inactive code reason; they have been looking into why that have happened but have not found a clear explanation why some registrations would fall into this "not reported" category instead of having a reason listed.

The Chair said that the count for the number of candidates who are inactive due to work-up incomplete jumped out, since that is a large number of the total number of candidates who are inactive. The Chair also noted that the data presented only covers the median number of days inactive within the year, so it is possible that some of those people have been in inactive status for more than one year. The Chair noted that a large number of people are listed as inactive due to being temporarily too sick, and a smattering of people are inactive due to insurance issues.

A member asked if the default status is to list a candidate as active so that the care team would need to update the registration with one of these codes to convert the candidate to inactive, or if there is a scenario in which someone would be listed with an already inactive status. A member said that candidates are generally listed as active and then made inactive for another reason. A member asked if there are triggers in place to make someone active once whatever was outstanding that led to being placed in inactive status is resolved. Staff said that is managed at the center level and there are not notifications in the system related to inactive codes, but the Committee could potentially look at tools to help transplant programs manage their waitlist as part of this project. Staff suggested that candidates probably should not be inactive due to work-up incomplete for extended periods of time, so it seems

like it might be helpful to provide some sort of notification to transplant programs for them to see what is going on with those candidates. The member agreed with this approach since the concern is that candidates may be falling off the transplant program's radar because they have been placed in inactive status for one of these reasons.

Staff noted that there was a policy change in 2003 that allowed kidney candidates to accrue waiting time while inactive, which impacted listing practices. Around that time, the Kidney Committee was looking at allowing waiting time to start accruing when candidates started dialysis. This raised possible equity concerns if some candidates were not able to accrue waiting time while inactive, but candidates on dialysis, when registered, would receive points for waiting time going back to their dialysis start date, regardless of whether or not they had been inactive during that time. As a result of that policy change, transplant programs recognized that it would benefit their kidney candidates to start accruing waiting time, so they will put the candidates on the list and then place them inactive while they continue working through the work-up or insurance issues.

2. Review literature on inactive codes

The Committee heard an overview of literature related to inactive status. Key findings included:

- There is a tendency to list kidney candidates inactive while completing work-up/insurance issues
- Some kidney candidates do spend extended time in inactive status and are less likely to receive a transplant, though it is unclear if these candidates are not really good candidates for transplant or if more of these candidates can and should be active on the waiting list
- Kidney candidates inactive after work-up is complete are most often "temporarily too sick" for transplant
- Inactive heart & liver candidates are most often "temporarily too sick"
- Particularly for kidney candidates, systematic review of inactive candidates by transplant programs may be beneficial

3. Discussion

The Committee discussed the data and literature presented. The Committee was asked to consider project goals, the solutions they would propose, and if any additional information would be needed to inform proposed solutions.

Summary of discussion:

A member asked if the OPTN is tracking the cause when kidney candidates are made inactive for "temporarily too sick." Staff responded that the OPTN does not collect more specific data on that.

A member asked what needs to happen to make a candidate active when a candidate is made inactive due to "work-up incomplete" and why a candidate would be registered if their work-up was not complete. Staff said they would follow up on this question. A member asked if there is a typical timeline for follow-up tests to be completed for candidates to remain active. Staff responded that there are no OPTN requirements for timelines to complete work-up and it is the responsibility of transplant programs to coordinate with candidates and ensure that any necessary testing is completed.

The Vice Chair asked if transplant centers are held accountable for how long and how big of a population they keep inactive. Staff responded that those data are public and that there are not caps on inactive time. From a system efficiency perspective, it is not necessarily desirable for there to be a disincentive for inactivating candidates who are not suitable for transplant. Staff said that there is opportunity with this project for the Committee to work with the OPTN Transplant Coordinators Committee (TCC) to better understand their challenges with managing active and inactive candidates and explore tools that

would be helpful to make sure transplant programs are not missing opportunities to activate candidates. The Vice Chair suggested that the system should automatically flag every candidate that hits one month, two months, three months, etc. of inactive status for transplant programs to go back and check, particularly to make sure there isn't something administrative that could be a pitfall for a lot of candidates if they don't know to ask their transplant programs those questions. A member agreed and recommended having checks and balances in place in terms of having the transplant center work in tandem with transparency of waiting list status for patients. That way, patients can be more involved with their transplant center in moving forward with their care plan. The Chair agreed, stating that perhaps a candidate knows they are inactive, but that does not seem apparent in the available data. If candidates were informed on a daily basis that they were inactive, it may present an opportunity to put the onus on the patient to get their tests done if that is what is keeping them from being active on the list. The Chair said it is important to figure out how to automate the transparency with the patient so it is not the responsibility of the transplant coordinator to go through the list and make phone calls to lots and lots of patients.

A member noted that candidates can move in and out of inactive and active status. Staff explained that is why they presented snapshot data, since a candidate can be inactive multiple times a year for different reasons. The snapshot data shows the inactive codes that were in use on a certain date.

A member said that this is a great project, and that they have been asked to serve on the TCC as a patient representative starting on July 1st, so they will be able to help facilitate collaboration between the two committees on this project.

Staff noted that a similar project had been taken up by TCC several years ago and the proposed solution was a hard copy letter, which was unpopular in public comment. As a result, the project never went to the OPTN Board of Directors. Around 2016-2017, the Patient Affairs Committee picked up this topic again and reviewed lessons learned from the TCC project and discussed the concept of a patient portal or some sort of application that candidates could log into and get a sense of "where they are" in the pool of candidates. At the time, there was not a lot of appetite in the community to explore something like that. However, staff said that the Committee has a lot of ideas in terms of automation that could go a long way with the community. Additionally, staff noted that if the Committee is looking for system-level impact, then policy changes would be one of the best ways to do that, since the system is programmed according to policy, which establishes the rules.

A member asked why the letter was unpopular in public comment. Staff said they would have to look back at the public comments to confirm but they thought the concern was administrative burden. The member said that would be helpful to know because it seems like a letter to notify patients would be very informative and it was not clear why that would be unpopular. Staff said it may also have been founded on concerns that transplant programs are already giving candidates huge packets of information so another sheet of paper could get lost, but communication approaches for health care providers have gotten more sophisticated since then, so it could be as easy as providing language for a template that transplant programs could deploy via their electronic health records. Staff noted that policy language could just require a "communication" and it could be left to the transplant centers to decide the best channels to reach their candidates, or the policy language could be more prescriptive and specify a mode of communication. Another staff member added that one of the concerns with the former proposal was that it would have required transplant programs to send out 30,000 letters, and transplant programs said they were already notifying their candidates and didn't necessarily want a new requirement for this in policy. However, the Committee could explore putting a requirement in policy and could look for opportunities to automate this work as members recommended. Another way that the Committee could potentially reduce the burden and unnecessary communications would be to work

with TCC to identify the inactive codes where they would really expect there to be a need for follow-up. For example, it may make more sense to require different notifications for candidates who are inactive for long periods of time due to work-up incomplete or insurance issues, whereas for candidates who are temporarily too sick – particularly heart, lung, and liver candidates – those candidates are probably hospitalized and more closely monitored by the transplant center.

A member agreed that candidates waiting for a heart, lung, or liver tend to be critically ill and not necessarily in a situation where they are waiting for long periods of time for an organ like a kidney, for which a candidate may wait years. Kidney candidates are more likely to be at home and on dialysis, so the member recommended that the Committee focus on kidney candidates for making improvements. The member said maybe there should be an inactive policy requiring transplant centers to have open lines of communication, and if patients are inactive for years at a time due to insurance issues or reasons like that, then those issues need to be identified and resolved, and the patients need to be notified so they have an accurate understanding of their waiting list status.

A member asked it would be possible to get more information on kidney candidates in terms of the length of time the candidates are spending in inactive status and the reasons for inactive status to get the whole picture of what is going on, instead of just the snapshot data. Staff said that is possible, it just was not in scope for this effort in terms of providing the Committee some initial data to review.

A member asked if a candidate will only have one reason listed at a time for inactive status. Staff confirmed that only one inactive reason can be selected at a time.

A member asked if there is an association between time on dialysis and candidates inactive due to "temporarily too sick." Staff said they could see if there is an existing analysis on that or if that is something the Committee could dig into more.

The Vice Chair agreed that it would be good to know what happened to those candidates who were too sick. The Vice Chair also agreed with focusing on kidney, not because the other organs aren't important, but because kidney candidates make up the largest proportion of the population, so that gives a richer data set to help uncover more powerful insights that may also be useful for other organs. The Vice Chair said they would like to dig into the raw data and would be particularly interested in looking at the data through the lens of possible racial and gender disparities. The Vice Chair noted that they had provided a list of various other data they would like to see. Staff said they will provide reports to the Committee based on data requests but that there is also a mechanism to request OPTN data if members want to evaluate it more on their own. Staff said they can also have a conversation with the Committee on a future meeting to make sure they are providing targeted analysis to inform whatever solutions the Committee wants to develop. Staff noted that the data request process is intended to be collaborative to work through the questions that the Committee wants to answer and which data will be most helpful to answer those questions, so that it is focused on the issue that the Committee wants to solve.

Next steps:

The Committee requested more information on what is happening in the kidney transplant process between when candidates are registered and the time at which work-up is considered complete. The Committee agreed to focus on kidney for this project and would also like to better understand if there are disparities in terms of who is inactive and who is not. The Committee said it would be helpful for a representative from a kidney transplant program to come to a future meeting and share some insights on waitlist management.

Upcoming Meetings

- May 16, 2023
- June 20, 2023

Attendance

- **Committee Members**
  - Garrett Erdle, Chair
  - Molly McCarthy, Vice Chair
  - Calvin Henry
  - Dana Hong
  - Eric Tanis
  - Julie Spear
  - Justin Wilkerson
  - Justine van der Pool
  - Kenny Laferriere
  - Kristen Ramsay
  - Lorrinda Gray-Davis
  - Steve Weitzen
  - Tonya Gomez
- **HRSA Representatives**
  - Arjun Naik
  - Megan Hayden
  - Mesmin Germain
- **SRTR Staff**
  - Katie Audette
- **UNOS Staff**
  - Alex Carmack
  - Bridgette Huff
  - Jesse Howell
  - Julia Foutz
  - Kaitlin Swanner
  - Kim Uccellini
  - Laura Schmitt
  - Roger Brown
- **Other Attendees**
  - Andreas Price
  - Antoinette McNair