

# Require Patient Notification for Waitlist Status Changes

*Transplant Coordinators Committee*

# Purpose of Proposal

- Add transparency and empower patients to work with their transplant team to ensure their listing status is accurate
  - Alert patients who are moved to active from inactive status, or inactive from active status
- Standardize patient notification requirements related to waitlist status changes
  - While many programs currently notify their patients of status changes, it has not been an OPTN Policy requirement

# Proposal

- Transplant programs would be responsible for communicating to candidates whenever their waitlist status has changed from inactive to active or active to inactive
- Programs have 10 business days from the status change to send this notification to the candidate
  - Current proposal requires written notification, which is consistent with other notification requirements

# Rationale

- Patients may not be aware of their inactivity on the waitlist
- Empowers patients to work with their transplant team to ensure their listing status is accurate
- Transparency for patients on their status
  - Depending on the organ type, the candidate may not be accruing wait time while inactive
  - Candidates assigned to an inactive status while on the waiting list are ineligible from receiving organ offers during allocation

# Member Actions

- Transplant programs will need to notify candidates within 10 business days of a waiting list status change
- Programs without a status change notification system in place may need to update procedures
- Program-wide notification of this change and training for staff may be needed

# What do you think?

- Is written notification is necessary, or would documentation of notifications, including conversations, be sufficient?
- Is this notification change feasible, or are there concerns about the level of burden?
  - What education or guidance would be helpful for programs to support the implementation of this proposal?
- Do patients & patient families and caregivers support notifying candidates when their waiting list status changes?
  - Any additional information to include in the patient notification, other than waiting list status?
  - What education or guidance would be helpful for patients & patient families and caregivers?
  - Any additional tools, such as patient portal, that would be helpful to engage patients in the future?

# Provide Feedback

Submit public comments on the OPTN website:

- [August 8-Oct 7th, 2025]
- **[optn.transplant.hrsa.gov](https://optn.transplant.hrsa.gov)**

