

# Improvement Guide



## PEDIATRIC LIVER COLLABORATIVE

**OPTN** *Collaborative Improvement*

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## Preface

This Improvement Guide has been developed in conjunction with the OPTN Pediatric Liver Collaborative. The aim of the collaborative is to increase transplants for pediatric liver patients and reduce the time to transplant. The guide reflects learnings and understandings of key effective practices from several pediatric liver transplant programs. The document is organized into three areas of focus: pre-transplant management, split liver transplantation, and living donor transplantation. While these topics are not the only ones that programs can address to improve and grow their programs, they emerged as areas that may lead to an increased opportunity for patients to receive a transplant.

The Improvement Guide is comprised of three change concepts and specific interventions that support general notions of change. Interventions or changes can be tested using The Model for Improvement, which includes rapid, small-scale tests using Plan-Do-Study-Act, thus resulting in improvements. The accompanying interventions are useful in developing and testing changes leading to improved processes in pediatric liver programs and hopefully increased transplants for this population.

To best utilize the interventions and changes, programs should ...

**1. Examine your pediatric liver transplantation process.** Identify the key roles and responsibilities in your evaluation and listing, managing your waitlist, and the organ offer and acceptance process. Host and facilitate a process mapping session, document your work processes, and validate them with your team.

**2. Identify opportunities for improvement.** Analyze your process map and look for ambiguous or problem areas. Review your baseline data — what information indicates an area for improvement?

**3. Plan small tests of change.** Use the interventions to identify the changes best suited for your center to test. It is best practice to start with small tests of change. For example, draft and test a protocol with one person in one setting. Write down questions you want to answer and collect data through process measures or observation.

**4. Test changes and analyze your results.** What have you learned from testing your intervention? Decide to adapt, adopt, or abandon the change. Continue testing and use your analyses to determine whether the changes or interventions are resulting in improvements within your populations.

**5. Implement improvements.** When you are ready, develop a plan for implementing a tested, proven change within your transplant program. Decide who will be responsible for communicating, tracking, and ensuring sustainability of improvement.

***Disclaimer: Use of this Improvement Guide does not guarantee compliance with OPTN policies, bylaws, or obligations.***

## Improvement Guide Overview

### Change Concept 1: Optimize Pre-Transplant Management

Effective pre-transplant management of patients can greatly benefit referral, evaluation, and listing processes. In addition, comprehensive and efficient waitlist management helps to ensure patient records are up to date and accurate and that candidates are ready for transplant. Addressing processes in these areas can improve evaluation timeframes and listing practices, as well as lead to shorter time on the waitlist and more efficient organ offer and acceptance practices.

### Change Concept 2: Enhance Split Liver Transplantation

Split liver transplantation presents an opportunity to increase the number of liver grafts available for children. It is a complex surgical practice that requires training and opportunities for practice. Pediatric transplant programs should consider their capacity for performing and increasing split liver transplantation. This involves developing standardized approaches to training, donor selection, acceptance criteria, and segment allocation. It also involves fostering relationships with adult programs for shared decision making and maintaining effective communication with OPOs for successful procurement and graft allocation.

### Change Concept 3: Strengthen Living Donor Component

Utilizing living donors is a great way to widen the pool of available organs for transplant and decrease patients' time on the waitlist. Ensuring surgical capabilities as well as a relationship with an adult living donor liver program is integral to exercise this option. Establishing team processes for coordinating and communicating as well as providing awareness and education to patients and their families are keys to making this approach successful.

## Change Concept 1: Optimize Pre-Transplant Management



### *Intervention 1: Establish effective liver team communication and collaboration*

Clear communication between team members through meetings and documentation is critical to ensuring the accurate relay of patient information. Establishing expectations for various staff roles is essential to having efficient processes, as team members have different interactions with potential transplant patients.



#### **Recommended actions:**

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- 1. Schedule regular meetings to review and discuss patients at all stages of the pre-transplant process; those referred for evaluation, currently being evaluated, ready for selection, or on the waitlist**
- 2. Define a process for documenting and maintaining records of patients' status and needs**
  - a. Identify key elements needed to be captured in patients' records and reinforce clear documentation
  - b. Confirm that all team members, including on-call and ancillary staff, are aware of where and how to access pertinent information
  - c. Ensure the established patient documentation processes are recorded and able to be referenced for on-going staff use and training
- 3. Establish communication standards**
  - a. Standardize the communication plan with referring providers
    - i. Determine appropriate format and timeframes for communication regarding referrals and patient updates
  - b. Standardize the communication plan for patients and patients' families
    - i. Establish appropriate content and format for education regarding the evaluation process; testing and consults as well as follow-up requirements
    - ii. Ensure current contact information is well documented and establish an expectation for frequency of communication between the team and the patients and patients' families



#### **Suggested measures:**

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- Percent compliance with established cadence for patient review meetings, i.e., weekly, monthly.
- Percent compliance with established communication standards to referring providers
- Percent compliance with minimum established communication standards to patients and patients' families

## Change Concept 1: Optimize Pre-Transplant Management



### **Intervention 2: Establish efficient processes from referral to listing**

Teams should have clear expectations regarding each step in the evaluation of a referred patient and there should be reduced variability in how patients are addressed. Teams should also have an established process for offering education to referring providers regarding appropriateness and content of referral.



#### **Recommended actions:**

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- 1. Define processes for each stage of a patient evaluation: referral, intake, appointment scheduling, insurance approval, consults, testing, patient care/coordination, selection, and listing**
- 2. Establish appropriate referral criteria and determine minimum required patient information**
  - a. Provide education to referring providers regarding pertinent information and documents to include with referral
    - i. Develop checklists/tools for providers to ensure completion of information
- 3. Define and communicate expectations for patients and families**
  - a. Provide education to patients and caregivers regarding the evaluation process
  - b. Define what is expected of patients and caregivers; ensure patients/caregivers and team members are aware so everyone is operating consistently
  - c. Identify key team members as primary point of contact for patients/caregivers to avoid confusion
- 4. Set standards for turnaround time or completion of each step in the evaluation process**
- 5. Establish processes for expedited/urgent work-ups**
  - a. Determine clinical triggers that warrant an expedited work-up
  - b. Develop check lists to assist with task completion and process consistency
  - c. Ensure clear communication so that all evaluation components are completed within expedited timeframe and all team members are aware of status



#### **Suggested measures:**

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- Percent of patients evaluated according to established plan
- Compliance with requirements for evaluation components
- Set a target number of education sessions to referring providers and track this effort
- Track the cycle time for a standard referral patient
- Track the cycle time for an expedited patient from referral to active listing

## Change Concept 1: Optimize Pre-Transplant Management

### **Intervention 3: Establish listing criteria**

As pediatric liver transplant patients present with diverse characteristics, establishing specific listing criteria for the different categories can assist the clinical team throughout the evaluation and selection process.



#### **Recommended actions**

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##### **1. Define listing criteria**

- a. Identify specific listing criteria per patient characteristics, such as age, diagnosis, or size

##### **2. Review your program's current listing criteria to ensure relevancy for patients' needs as well as compliance with current policies and practices**

##### **3. Standardize criteria for allocation exception applications and develop a process to aid in consistency**

- a. Review exception applications to ensure appropriate submissions



#### **Suggested measures**

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- Percent compliance with patient selection and listing based on identified criteria
- Percent compliance with submission of allocation exception applications based on defined criteria
- Track dispositions for allocation exception submissions

## Change Concept 1: Optimize Pre-Transplant Management



### **Intervention 4: Standardize waitlist management**

Establishing a process to manage waitlisted patients helps to make certain that patients are addressed in a timely manner and that all team members are aware of each patient's status. Ensuring that clinical data is relevant and that the listing status is current is essential to having patients ready for transplant. Programs can benefit from having re-evaluation protocols that provide a standardized approach to waitlist management.



### **Recommended actions**

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- 1. Establish clinical parameters for addressing waitlisted patients; how often seen in clinic, lab work completed, etc.**
- 2. Establish a process for managing patient caseloads**
  - a. Clarify coordinator roles and responsibilities
  - b. Communication between team members
- 3. Regularly review inactive patients and develop a team plan to address any identified needs**
- 4. Create re-evaluation protocols**



### **Suggested measures**

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- Percent compliance with waitlist management protocols
- Percent of completed re-evaluations within established timeframes



## Change Concept 1: Optimize Pre-Transplant Management



### **Intervention 5: Establish effective organ/offer acceptance processes**

Teams should have a clear and defined process for evaluating an organ offer. Team roles and documentation standards should be set. As broader sharing occurs, programs should continuously collaborate with OPOs to maintain effective relationships and establish standards to facilitate the evaluation of an organ offer.



#### **Recommended actions:**

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##### **1. Develop and/or define internal organ offer processes**

- a. Define roles and ensure all parties are aware of responsibilities (third party, on-call coordinator, surgeon, nephrologist, etc.)
- b. Identify required and preferred information on offers and create checklists or other tools to aid in consistency of information gathering and sharing
- c. Establish a decision tree/flow for review of organ offers

##### **2. Foster collaborative relationships with OPOs and discuss acceptable baseline standards for evaluation, such as images, labs, etc.**

##### **3. Establish a process for retrospective reviews of declined offers to aid in future decision making and foster consistency among decision makers**



#### **Suggested measures:**

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- Number of complete/incomplete checklists
- Track offers that require multiple requests for information

## Change Concept 2: Enhance Split Liver Transplantation



### *Intervention 1: Enhance capacity & technical ability for split liver transplantation*

Transplant centers need to evaluate their program capacity and surgical capability for split liver procurement and transplantation. Fostering partnerships with both individuals and programs who have expertise in split liver transplantation is essential in developing necessary skill sets and processes.



#### Recommended actions:

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- 1. Evaluate current state of split liver surgical technical capabilities**
  - a. Improve current capabilities and training framework
  - b. Increase number of split liver transplantation opportunities
- 2. Develop collaborations with partner hospitals for surgical support and training**
- 3. Develop effective coordination between procuring and transplanting surgeons**



#### Suggested measures:

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- Number of complete/incomplete checklists
- Track offers that require multiple requests for information

## Change Concept 2: Enhance Split Liver Transplantation



### *Intervention 2: Promote effective relationships with organ procurement organizations*

Any improvement in pediatric liver transplantation will necessitate effective communication and coordination with OPOs. This is especially important when it comes to split liver transplantation, given the added complexities in procurement, surgical retrieval, and allocation. Regular sharing of data and analysis of current and past practices help to identify gaps in practice that need improvement.

Engaging OPOs other than your local OPO is also of equal importance in this age of broader organ sharing. A mutual understanding regarding each other's needs and desires can enhance partnerships and collaboration in organ allocation and procurement.



#### **Recommended actions:**

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- 1. Establish a regular cadence of meetings with OPOs for review of split liver transplantation**
  - a. Joint identification of gaps in practice as targets of future improvement
  - b. Retrospective review of practices for identification of under-performance
- 2. Define and standardize preferred donor acceptance criteria**
- 3. Promote collective understanding of allocation policies**
- 4. Improve communication with OPO leadership**
  - a. Improve communication and participation with local OPO medical advisory boards
  - b. Increase educational touch points between OPO advisory boards and your team
- 5. Identify and engage non-local OPOs with high interaction with your center for mutual education and collaboration**



#### **Suggested measures:**

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- Compliance with established meetings with OPOs of retrospective reviews

## Change Concept 2: Enhance Split Liver Transplantation



### **Intervention 3: Promote effective partnerships with adult programs**

Split liver transplantation necessitates partnership with adult programs for identification of livers that can be potentially split, retrieval of hepatic segments, and coordination of the allocation process. There may be further opportunities to enhance your surgical team's training and knowledge of technical variance by engaging with professional societies and other such organizations on a regular cadence.



#### **Recommended actions:**

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- 1. Build relationships with adult programs to facilitate organ sharing**
- 2. Establish periodic meetings with adult programs to conduct retrospective reviews**
  - a. Outcomes of livers that were split
  - b. Livers that were not split but could have been
- 3. Build relationships with partner programs to facilitate split liver transplantation training and practice**
- 4. Explore further educational opportunities with surgical societies and other professional organizations**



#### **Suggested measures:**

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- Compliance with standardized cadence of meetings with partner adult programs
- Track outcomes of split liver transplants
- Track split liver offers to provide trends and education

## Change Concept 3: Strengthen Living Donor Component



### **Intervention 1: Evaluate and optimize current living donor program/pathway**

The living donor component should be functioning under a solid team approach. This includes ensuring that roles are clear and well defined, and that all team members are aware of their own responsibilities as well as the responsibilities of others. There should also be clear communication within and between adult and pediatric team members at each level of the referral, evaluation, and selection process.



### **Recommended actions:**

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#### **1. Review current LD program structure to ensure clear roles and responsibilities**

#### **2. If partnering with an adult program, review pathways and strengthen communication**

- a. Establish a joint adult/pediatric team to develop and review processes between programs to ensure a cohesive approach
- b. Determine who is communicating, what information is being communicated, and when information is being communicated to the potential donor and the recipient
- c. Determine who is responsible for providing education to the potential donor and recipient
  - i. As education to donors and recipients is often conducted by different teams, it is important to coordinate efforts and ensure consistency and clarity of information
- d. Identify external liaisons when appropriate to ensure timely and effective communication



### **Suggested measures:**

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- Compliance with established meeting cadence between programs
- Compliance with established internal and external communication plans

## Change Concept 3: Strengthen Living Donor Component



### Intervention 2: Improve living donor referral and evaluation process

To ensure that each potential donor is appropriately considered, programs should have clear processes for referrals and evaluations. Defined donor standards and transparent education at the forefront help provide focus on appropriate and interested donors and prevent time lost evaluating unsuitable donors.



#### Recommended actions:

##### 1. Establish a referral process and determine referral standards

- a. Define minimum donor criteria to aid in ruling in and/or ruling out potential donors
- b. Develop education for potential donors to help them understand what to expect
  - i. Provide information on the entire process (referral, evaluation, surgery, follow-up)
  - ii. Provide basic information on what it takes to become a donor (minimal health criteria)
- c. Develop a system to aid in the referral and screening process
  - i. Develop screening tool(s) for donors to complete
    1. Web based questionnaire
      - a. Automated screening to assess donor suitability
      - b. Quick response to interested donor if not suitable
      - c. Automated alert to living donor team of potential suitable donors to follow-up
    2. General screening questionnaires

##### 2. Define the evaluation process and set parameters

- a. Decide how many potential donors will be evaluated for one recipient at a time
- b. Develop education for potential donors to help them understand the evaluation and surgical processes (insurance, consults, testing, timeframes, surgical procedure, post-care, follow-up)
- c. Establish a list of evaluation components and decide timeframes for each stage
- d. Determine process for directed vs non-directed donors
  - i. Establish standards for allocation of non-directed donors
- e. Establish a clear and consistent donor selection and prioritization process

##### 3. Establish pathways to resolve common barriers to donation

- a. Cultivate resources to help patients navigate common socioeconomic barriers (i.e., insurance, childcare, time off, loss of wages, etc.)
- b. Provide education to staff regarding common religious or cultural needs surrounding living donation



#### Suggested measures:

- Track time from donor referral to selection and various identified points in between
- Track number of donors actually evaluated over number of donors appropriate to move forward from initial screening criteria
- Track number of donors approved to donate over number of donors evaluated

## Change Concept 3: Strengthen Living Donor Component



### **Intervention 3: Improve outreach and education on living donation**

Ensuring that your patients and the community are aware of the possibility of living donation is vital to the growth of any living donor program.



#### **Recommended actions:**

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- 1. Provide outreach and education to referring providers about the option of living donation**
- 2. Once patients are referred for transplant evaluation, provide education to the family regarding living donation**
- 3. Develop or optimize a living donor marketing campaign for your program**
  - a. Provide education to patients surrounding effective social media utilization in searching for potential living donors
  - b. Consider utilizing multiple platforms for education and outreach (i.e., computer-based learning, videos, LD educator/coaching sessions, printed materials, donation testimonials)



#### **Suggested measures:**

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- Track donor referral growth percentage