

Briefing Paper

Guidance on Pediatric Transplant Recipient Transition and Transfer

OPTN/UNOS Pediatric Transplantation Committee

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Guidance on Pediatric Transplant Recipient Transition and Transfer

Affected Policies: N/A
Sponsoring Committee: Pediatric Transplantation Committee
Public Comment Period: August 3, 2018 to October 3, 2018
Board of Director's Date: December 3-4, 2018

Executive Summary

Suboptimal transition and transfer processes for pediatric transplant recipients have been associated with increased risk of non-adherence with their plan of care and graft loss. Breakdowns in transition and the transfer to adult medical care may also contribute to “lost to follow-up” designations for pediatric transplant recipients on OPTN data collection forms. The goal of the guidance is to support improvements in transplant outcomes by reducing instances of graft loss from non-adherence, and by providing guidance to transplant hospitals to improve the transition and transfer process for pediatric recipients. A secondary goal of this guidance is to reduce the incidence of lost to follow-up designations for pediatric transplant recipients. By sharing effective practices for recipient transition and transfer from pediatric to adult medical care, transplant outcome data will be more complete and more representative of clinical practices.

This guidance aligns with the goals of the OPTN Strategic Plan to improve waitlisted patient, living donor, and transplant recipient outcomes. Long term post-transplant survival data are vital to understanding outcomes for all pediatric transplant recipients and developing healthcare policy to improve these outcomes.

What problem will this resource address?

Suboptimal transition and transfer of pediatric transplant recipients to adult medical care can have detrimental impact on recipient and graft survival.¹ These can lead to recipients' inconsistent or declining engagement with medical providers over time.² Even worse, these vulnerable recipients may not receive needed out-patient care to promote long term graft and recipient survival. The end result can be graft dysfunction or loss.³

Suboptimal transition and transfer can also create challenges reporting recipients' health information to the Organ Procurement and Transplantation Network (OPTN). This can lead to recipients' designated as "lost to follow-up" OPTN follow-up forms.⁴ As a result, OPTN transplant outcomes data does not include the health status of recipients with this designation. OPTN Policy 18.1: *Data Submission Requirements* requires transplant hospitals to submit Transplant Recipient Follow-up (TRF) forms within either: 1) 30 days after the six month and annual anniversary of the transplant date until the recipient's death or graft failure; or 2) 14 days from notification of the recipient's death or graft failure.⁵ When there are challenges obtaining the recipient's health information, transplant programs can stay in compliance with Policy 18.1 by submitting a TRF form designating the recipient as lost to follow-up.

Adolescent and adult recipients 25 years or younger are more likely to be designated as lost to follow-up within 10 years of transplant than other ages.⁴ Their transplant survival data are vital to understanding outcomes for all pediatric recipients. These data are then used to inform patients and their families of realistic goals regarding transplantation, and to drive healthcare policy decisions.

Why should you support this resource?

This guidance shares effective practices for pediatric transition and transfer from those transplant programs with average or better than average lost to follow-up designations. The Committee hopes sharing these effective practices will improve the transition and transfer process which will in-turn lead to better transplant outcomes by reducing instances of graft loss from non-adherence. Further, rates of lost to follow-up designation will decrease, resulting in more complete data reporting to the OPTN.

How was this resource developed?

In the fall of 2016, the Committee initiated discussions surrounding the concern that lost to follow-up designation be reflective of deficiencies in transition and transfer practices in the transplant community. Central concerns were these deficiencies could impact on recipient and graft survival, and negatively impact the complete understanding of pediatric transplant outcomes. The latter includes critical information for the pediatric transplant community that widely acknowledges the impact of transplantation

¹McDonagh, JE, "Growing up and moving on. Transition from Pediatric to Adult Care", *Pediatric Transplantation* 9 (2005), <https://doi.org/10.1111/j.1399-3046.2004.00287.x>. Accessed June 29, 2018

²Rosen, DS, et al., "Transition to adult health care for adolescents and young adults with chronic conditions: Position paper for the society for adolescent medicine", *Journal of Adolescent Health* 33 (2003), https://www.adolescenthealth.org/SAHM_Main/media/Advocacy/Positions/2003-Transition_from_Child-Centered_to_Adult_Health-Care_Systems_for_Adolescents_with_Chronic_Conditions.pdf. Accessed June 29, 2018

³Butler, JA, Roderick, P, Mullee, M, Mason, JC, Peveler, RC, "Frequency and impact of nonadherence to immunosuppressants after renal transplantation: a systematic review", *Transplantation* no. 77, 5 (2004), pages 769-776, doi: 10.1097/01.TP.0000110408.83054.88. Accessed June 29, 2018.

⁴Unpublished reports to OPTN/UNOS Pediatric Transplantation Committee on October 19, 2016 and March 30, 2017. Based on OPTN data as of August 5, 2016 and February 12, 2016 respectively.

⁵OPTN Policy 18.1, *Data Submission Requirements*, https://optn.transplant.hrsa.gov/media/1200/optn_policies.pdf#nameddest=Policy_18. Accessed June 29, 2018.

for pediatric recipients extends beyond measures of recipient and graft survival.^{6, 7, 8, 9, 10} These data reported to the OPTN by transplant programs drive policy decisions, and are used by providers to communicate realistic goals regarding transplantation to patients and their families or guardians. A subcommittee was formed to explore the problem in greater depth and develop solutions. In forming the subcommittee, a representative of the OPTN/UNOS Minority Affairs Committee (MAC) was also recruited.

The Subcommittee met over several conference calls and meetings to develop the guidance. The early sentiment was guidance on “effective practices” would be more meaningful if linked to OPTN data submission and derived with input from the pediatric transplant community.

Lost to Follow-up Designation

To examine if lost to follow up designation is indeed an issue that impacts TRF submission, the Subcommittee examined lost to follow-up rates for heart, kidney, and liver transplant recipients in the U.S. that were transplanted during 2000 to 2010, and were less than 18 years old at the time of transplant.¹¹ These data showed:

- Recipients are designated as lost to follow-up in each organ, and the overall 10 year rate of lost to follow-up was similar between adolescent (12-17 years old) and adult (18 years and older) recipients.
- The 10 year lost to follow-up rates were the highest in kidney recipients, followed by liver recipients, then heart recipients.
- Lost to follow-up rates were not uniform across different pediatric age groups.
- The lost to follow-up rate in recipients ages 18-25 years old was similar to recipients ages 12-17 years old:

Table 1: Comparison of Lost to Follow-up Rates up to 10 Years Post-Transplant by Age at Transplant^{12, 13}

Organ	Recipients 6-11 years old	Recipients 12-17 year old	Recipients 18-25 years old
Kidney	12.1%	20.8%	21.7%
Liver	6.8%	14.4%	11.7%
Heart	4.8%	6.6%	4.9%

As a result of these data, the Committee focused efforts on identifying effective transition and transfer practices for kidney and liver transplant recipients.

The Subcommittee acknowledged that not all transplant recipients are followed by providers affiliated with a transplant hospital. Literature demonstrates that proximity to a transplant program does impact recipient

⁶ Davis, ID, Chang, P, and Nevins, TE, “Successful Renal Transplantation Accelerates Development in Young Uremic Children”, *Pediatrics* 86 no. 4, (1990), 594-600, <http://pediatrics.aappublications.org.proxy.library.vcu.edu/content/86/4/594>. Accessed June 29, 2018.

⁷ Mendley, SR, et al., "Duration of chronic kidney disease reduces attention and executive function in pediatric patients." *International Society of Nephrology* (2014), doi: 10.1038/ki.2014.323. Accessed June 29, 2018.

⁸ Icard, P, Hooper, SR, Gipson, DS, and de Ferris, ME. "Cognitive Improvement in Children with CKD after Transplant." *Pediatric Transplant* 14 (2010): 887-90, <https://doi.org/10.1111/j.1399-3046.2010.01359.x>, Accessed June 29, 2018.

⁹ Herthelius, M, et al. "Renal transplantation in infants and small children." *Pediatric Nephrology* 27 (2012): 145-150, doi: 0.1007/s00467-011-1962-2. Accessed June 29, 2018.

¹⁰ Organ Procurement and Transplantation Network, “Ethical principles of pediatric organ allocation” (2014), <https://optn.transplant.hrsa.gov/resources/ethics/ethical-principles-of-pediatric-organ-allocation/>. Accessed June 29, 2018

¹¹ Lung transplant recipients were not considered due to low numbers of pediatric lung transplants performed.

¹² Unpublished reports to OPTN/UNOS Pediatric Transplantation Committee on October 19, 2016 and March 30, 2017.

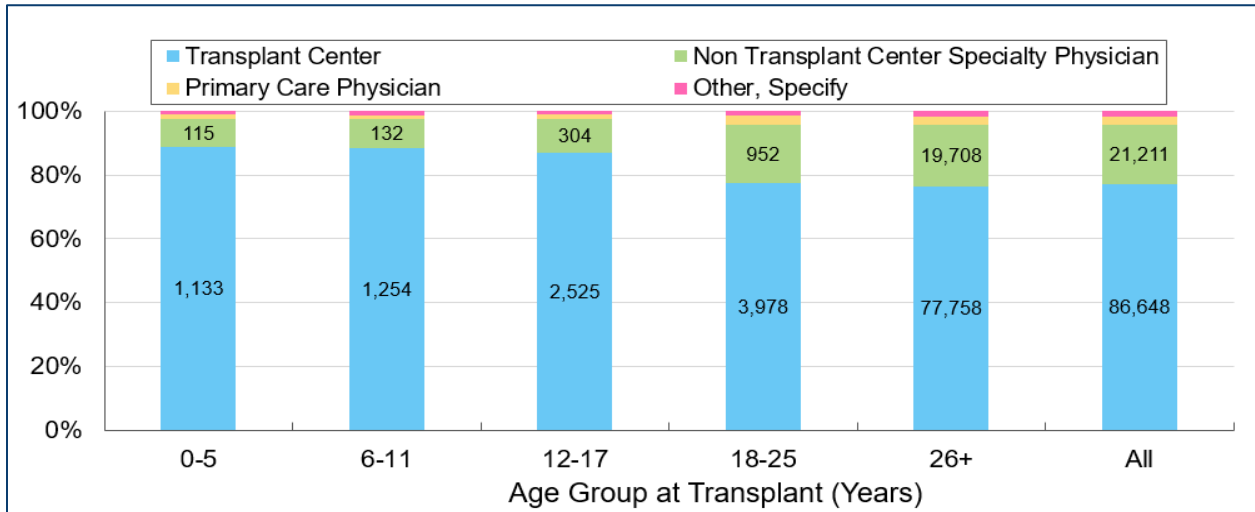
¹³ See Appendix, Figures 2-4.

survival.¹⁴ Subcommittee members agreed there are three common transfer of care scenarios in pediatric transplantation. These include transfer to an adult provider:

1. Within the same transplant hospital
2. At another OPTN transplant hospital, perhaps geographically closer to the recipient
3. Not affiliated with an OPTN transplant hospital, but geographically closer to the recipient

Figure 1 below depicts the types of providers providing follow-up care entered on five year TRF forms for kidney recipients.

Figure 1: Types of Follow-up Provider on Five Year Follow-up Kidney Transplant Recipients 2000-2010



As Figure 1 shows, the majority (~88%) of kidney recipients transplanted from ages 0 to 17 years old were followed by transplant providers five years post-transplant. Approximately 12% of these recipients were followed by non-transplant providers. However, the percentage of kidney recipients ages 18 to 25 years old followed by non-transplant providers increased to approximately 19%.¹⁵ Despite this very large percentage of transplant recipients being followed by transplant providers, pediatric kidney transplant recipients had 32.9% lost to follow-up designation within 10 years of transplant.¹⁶

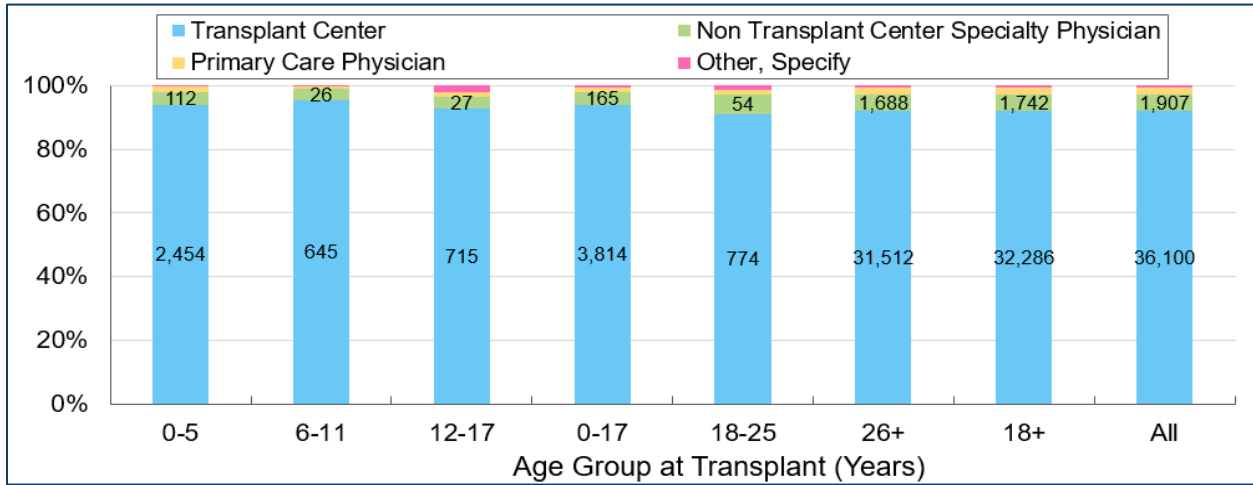
The Committee examined the types of provider entered on five year TRF forms for liver recipients as well. (See **Figure 2**)

¹⁴ Davis, ID, et al., "Successful Renal Transplantation Accelerates Development in Young Uremic Children", *Pediatrics* 86 no. 4, (1990), page 6.

¹⁵ Unpublished reports to OPTN/UNOS Pediatric Transplantation Committee on October 19, 2016.

¹⁶ Unpublished reports to OPTN/UNOS Pediatric Transplantation Committee on October 19, 2016 and March 30, 2017.

Figure 2: Types of Follow-up Provider on Five-Year Follow-up for Liver Transplant Recipients 2000-2010



As Figure 2 shows, the majority (~94%) of liver recipients transplanted from ages 0 to 17 years old were followed by the transplant providers five years post-transplant. Despite this very large percentage of transplant recipients being followed by transplant providers, liver transplant recipients had 14.6% lost to follow-up designation within 10 years of transplant.¹⁷

Based on these data and the prevalent sentiment in the pediatric transplant community about challenges obtaining recipient health information from unaffiliated providers, the Subcommittee felt gaps in outcome data due to lost to follow-up designation could be minimized by sharing effective practices for transition and transfer.

Input from the Pediatric Transplant Community

To engage the pediatric transplant community in the development of this guidance, the Subcommittee created an online survey to help identify effective transition practices. Any kidney or liver programs active as of January 10, 2018, that performed at least one transplant in a recipient younger than 18 years of age between 2012 and 2016 was invited to complete the survey. The survey was sent to programs' transplant administrators and resulted in a 72% response rate.¹⁸ Roughly two thirds of responses came from kidney programs, while the remaining third came from liver programs.¹⁹

To support the identification of effective practices, the survey responses were compared to transplant programs with low lost to follow-up rates on TRF forms.²⁰ The results were stratified over what can be considered small, medium, and large volume transplant programs.²¹ The Subcommittee observed the following themes from the survey results:

1. Transition

- There was a lack of clear understanding of “transition” and “transfer”, and these terms were often used interchangeably.
- Not all transplant programs participating in the survey had formalized transition processes.

¹⁷ Unpublished reports to OPTN/UNOS Pediatric Transplantation Committee on October 19, 2016 and March 30, 2017.

¹⁸ Survey dates January 10, 2018 to February 22, 2018; 206 surveys were sent, 148 responses were received.

¹⁹ Unpublished report to OPTN/UNOS Pediatric Transplantation Committee on April 19, 2018.

²⁰ Transplant program performance on TRF completion: Below Average = program's 5 year lost to follow-up rate was >10%, Average = program's 5 year lost to follow-up date was between 6-10%, Better than Average = program's 5 year lost to follow-up rate was <5%.

²¹ Small Volume = <5 pediatric transplants/year, Medium Volume = 6-9 pediatric transplants/year, Large Volume = at least 10 pediatric transplants/year.

- There was no relationship between a transplant program having a formalized transition process and average or above average lost to follow-up rates.

2. *Transfer*

- While a recipient's age is a determining factor when to transfer to an adult provider, a recipient's developmental milestones were a more important consideration than age.
- Transfer from pediatric to adult providers within the same transplant program has benefits (e.g.: plan of care adherence), and was associated with average or better than average of lost to follow-up rates.
- Low volume transplant programs were frequently in close association with an adult transplant program.
- Reluctance to transfer on the part of the parents was reported more frequently by medium and large volume programs, standalone pediatric transplant programs, and kidney programs with below average lost to follow-up rates.

3. *Program case volume and lost to follow-up designation rates*

- Transplant programs with average or below average lost to follow-up rates were more likely to transfer recipients to providers not affiliated with a transplant program as compared to transplant programs with better than average lost to follow-up rates.
- Large volume transplant programs cited extended distances between recipients and the program as a challenge for transferring recipients.

4. *Staff involved*

- Transplant coordinators were most frequently the individuals responsible for contacting other providers for transfer. These individuals were most frequently registered nurses.
- Large volume transplant programs more frequently utilize social workers, transition specialists, or other staff members in transfer discussions.
- Physicians at small volume transplant programs are more frequently involved in the transfer discussion as compared to medium or large volume programs.

Recommendations

The Subcommittee discussed the survey results and linked these results to transplant programs with average or better than average lost to follow-up rates. They also considered published resources available to the pediatric community on transition and transfer practices.^{22, 23, 24} As mentioned earlier, the highest lost to follow-up rates were observed in kidney and liver transplant recipients. However, the effective practices are not organ specific and could be applied to all pediatric transplant programs. The following responsibilities were proposed for each team:

Pediatric Transplant Team

- Create a written health care transition plan that draws on the multidisciplinary approach to transplant care. Examples of this include cardiology, dermatology, endocrinology, pharmacy, and psychology/ social work.

²² American Academy of Pediatrics (2011), Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home, *Pediatrics* 128 (1), 182-200, DOI: 10.1542/peds.2011-0969. Accessed June 29, 2018.

²³ Schwartz, LA, et al. (2014), Measures of Readiness to Transition to Adult Health Care for Youth with Chronic Physical Health Conditions: A Systematic Review and Recommendations for Measurement Testing and Development, *Journal of Pediatric Psychology* 39 (6), 588-601, doi.org/10.1093/jpepsy/jsu028. Accessed June 29, 2018.

²⁴ McManus, M, et al., (2014) Pediatric to Adult Transition: A Quality Improvement Model for Primary Care, *Journal of Adolescent Health*, 56 (1), 73-78, https://doi.org/10.1016/j.jadohealth.2014.08.006. Accessed June 29, 2018.

- Encourage and provide guidance to recipients' family or guardians about how they can promote independence and self-responsibility during the transition process. Emphasize that recipients must advocate for themselves and ask questions when faced with unfamiliar tests, medications, outpatient clinic practices, or if treatment plans are modified.
- Prepare both the recipient and their family members or guardians for transfer to another provider.
- Assess transition readiness, including critical milestones that should be achieved before transferring to adult care.²⁵ Further, transition plans should be flexible and based on the unique needs of each recipient.
- Assess for reluctance to transfer to another provider. This assessment should occur multiple times during the transition process. If the reluctance to transfer continues then the transfer to adult care should be delayed until the cause of reluctance is addressed appropriately.
- Ensure surrogate decision-makers are identified for those recipients with limited decision-making capability. This would include resolution of guardianship or formal legal arrangements, and should be completed before the recipient's 18th birthday. Formal legal arrangements may be necessary to avoid future conflicts, and ensure continuity of a stable support system.
- Develop a formalized policies and procedures for recipient transfers. Tools, such as a transfer checklist, may be helpful to standardize the process.
- Consider transfer to an adult provider within the same institution whenever possible. A multidisciplinary post-transplant transition clinics may be helpful to prepare recipients for transfer to adult providers.
- Partner with adult providers should be established well in advance of transfer.
- Communicate to the OPTN upon each recipient transfer. This will allow accurate assignment of TRF responsibility to the appropriate transplant program. The originating transplant program should communicate to the accepting transplant program when this form reassignment has been performed.
- Provide the transplant recipient with a portable, concise, up-to-date summary of their medical and surgical history, and a detailed list of their medications at the time of transfer. In addition to the normal scope of clinical information, the program should indicate prominently the initial reason for transplant, the type of transplant and whether not they have received more than one transplant, HLA typing, any history of rejection, copies of pathology reports (biopsies), and detailed history of transplant-related complications or comorbidities (post-transplant Diabetes Mellitus (DM), hypertension, rejection episodes & treatment, or post-transplant lymphoproliferative disorder (PTLD)).
- Consider additional resources to effectively obtain recipient health information from outside providers and submit the information to the OPTN.
- Remember that transplant programs that transfer recipients to providers unaffiliated with a transplant program are still responsible for submitting TRF forms for those recipients to the OPTN.²⁶
 - To improve health information sharing, the transplant programs should communicate to the accepting provider the need to be kept informed on the recipient's state of health, information required by the OPTN, and the frequency of data submission requirements prior to and at the time of transfer.
 - The originating transplant program should carefully consider the administrative burden of obtaining health information on these recipients when considering staff responsibilities and work volume.

Accepting Adult Providers:

- Provide staff education regarding childhood and adolescence psychosocial development, and the impact of childhood chronic disease on development.
- Be knowledgeable about congenital conditions that lead to organ failure in childhood and that may rarely be seen in adult patients.
- Develop formalized policies and procedures for recipient transfers.

²⁵ See Appendix, Table 1.

²⁶ OPTN Policy 18.1, Data Submission Requirements, page 4.

- Consider a multidisciplinary post-transplant transition clinics to prepare recipients for transfer to adult providers.
- Recognize that transplant recipients who are transferring into their practice may need time to fully adjust to the more rapid pace of an adult outpatient setting. Programs should consider use of a recipient mentor/coach program to ease the transfer process.
- Maintain ongoing communication with the pediatric transplant programs to improve recipient transfers and provide needed recipient health information for data reporting.

The Subcommittee recognized the value that existing resources have for this discussion. Online resources from other organizations were included in this the guidance to further support to enhancements to institutional policies or procedures on transition and transfer.

The Committee carefully reviewed the guidance. Members verbalized their support for the document and the guidance would meet a need in the transplant community. Members were cognizant that adult transplant programs are critical partners in the transition and transfer process. The Committee asked that adult transplant programs share their feedback to “improve the catch” when accepting a recipient from a pediatric transplant program. Some members shared a concept of a hybrid approach to transferring a recipient to a provider not affiliated with a transplant hospital, perhaps in circumstances when a recipient’s residence was geographically distant from the pediatric transplant hospital. This would entail an agreement for outpatient following between a local provider and another adult transplant program in closer proximity to the recipient. The Committee recommended the guidance document be distributed for the fall 2018 public comment period (18-Yes, 0-No, 0-Abstain)

How well does this resource address the problem statement?

There are numerous manuscripts in peer-reviewed literature that describe the challenges of adolescent development and risk-taking often associated with this population, the impact of clinical non-adherence in patients with chronic illnesses, and the implications of gaps in transition and transfer for transplant recipients.²⁷ To-date, there is no guidance on effective transition or transfer practices from the OPTN. Though not binding to OPTN members, guidance documents developed by the OPTN are valuable resources to the transplant community. Transplant professionals participating in the survey affirmed substantial interest for more information on these topics.

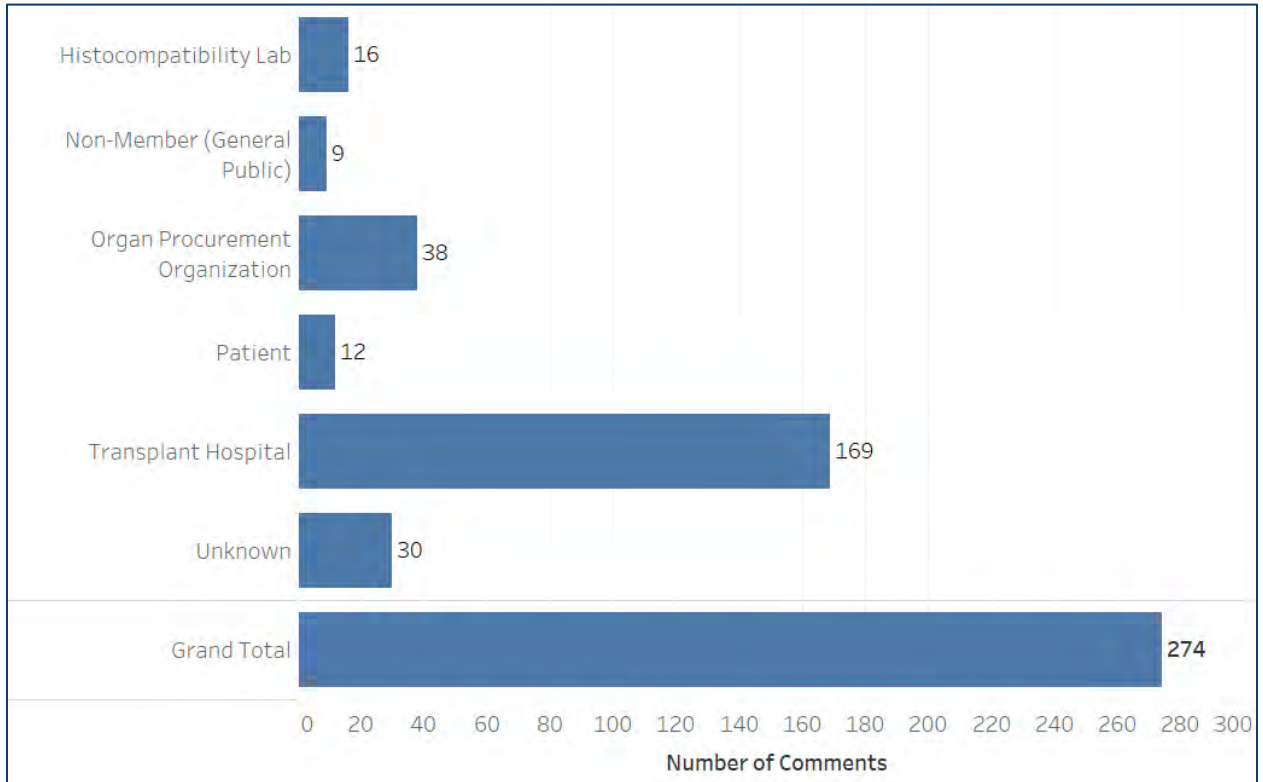
The Committee believes the document carefully conveys the importance of diligently reporting transplant recipient medical information to the OPTN, distinguished between transition and transfer, articulated why these processes occur at challenging for pediatric transplant recipients, clarified OPTN data submission responsibilities, and shared well thought-out recommendations developed in partnership with the pediatric transplant community.

Was this resource changed in response to public comment?

Yes, the guidance was amended following public comment. The transplant community reviewed the proposal during public comment from August 3, 2018 to October 3, 2018. The proposal received 274 comments.

²⁷ Axelrod, DA, et al., “The Interplay of Socioeconomic Status, Distance to Center, and Interdonor Service Area Travel on Kidney Transplant Access and Outcomes” (2010), page 4.

Figure 3: Public Comment Participation



As shown in Figure 3 above, six percent of the comments were submitted by histocompatibility laboratories, three percent submitted by members of the public, 14% by OPOs, four percent by patients, 62% by transplant hospitals, and 11% by individuals who did not identify their perspective.

Figure 4: Sentiment by Member Type

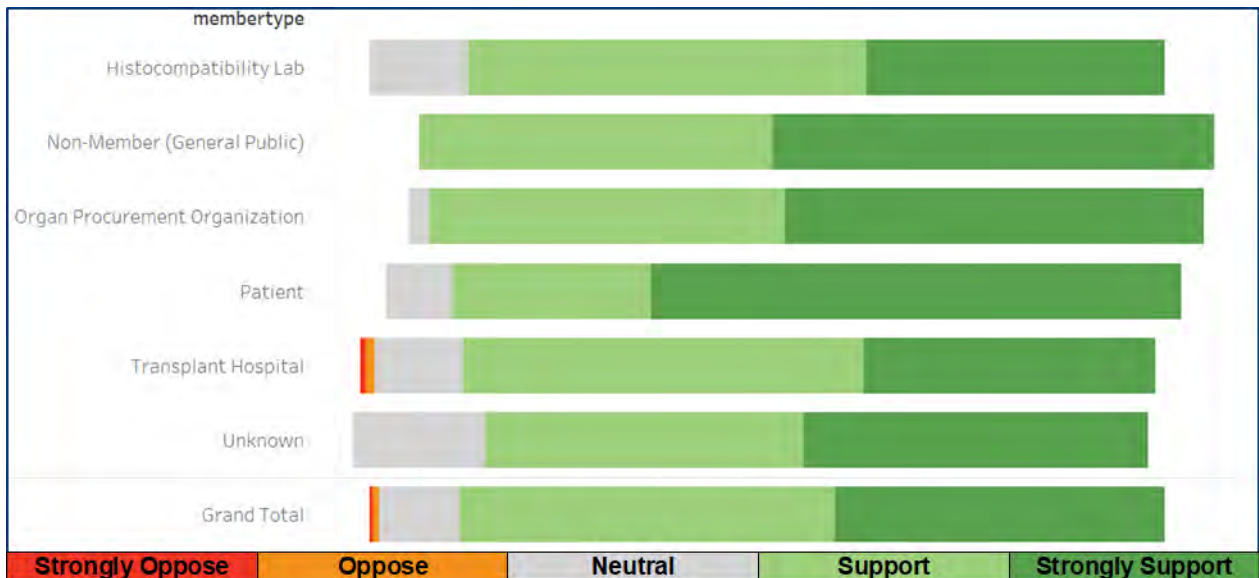


Figure 4 shows support and opposition stratified by member type. This shows support to strong support from most respondents.²⁸

Figure 5: Sentiment by State

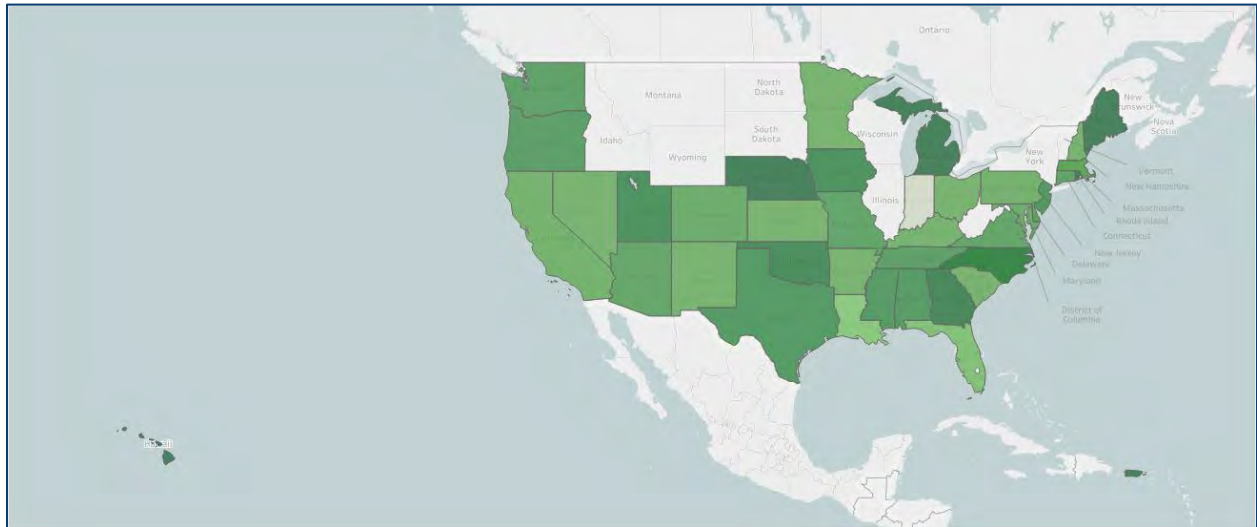


Figure 5 shows support and opposition stratified by geography, with most areas of the U.S. indicating support to strong support for the proposal.²⁹

Recommendations received in public feedback focused on the following two areas:

- Suggestions to enhance recommendations in the guidance document
- Desire for OPTN policy requirement for transplant hospitals policies or procedures on recipient transition and transfer, and benchmark comparison

Suggestions to enhance recommendations in the guidance document

Many of the comments received included recommendations to enhance the document. These included formalizing transition processes at pediatric transplant hospitals and early engagement with the recipient and their family, the need for recipient-focused approach that considered the cultural practices of the family, expanded detail on content for a robust transition care plan and detailed information sharing between programs, and the need for standardization in the transfer process and diligent engagement with involved adult medical care teams. The Committee agreed with many of these recommendations and amended the guidance accordingly.

OPTN Policy Requirement for Transplant Hospitals on Recipient Transition and Transfer, and Benchmark Comparison

The idea of an OPTN policy requirement for transplant hospitals to have policies or procedures on recipient transition and transfer, and the development of benchmarks for lost to follow-up designation were included in several comments. Though outside the scope of this proposal, the Committee feels these ideas are important. Any future policy requirement will need to include mechanisms for objectively evaluating program performance and addressing situations when outlier transplant programs are identified, either through process improvement or a peer-review process. The Committee will have future project discussions with the OPTN/UNOS Membership and Professional Standards Committee (MPSC) on these ideas.

²⁸ Strongly support – 128, Support – 135, Abstain/Neutral – 31, Oppose – 2, Strongly Oppose - 3

²⁹ Some commenters did not identify their state. Therefore, they are not included in Figure 5. Notably, the state was not collected for participants at the Region 10 meeting.

Other Feedback Received

Feedback was also received in the following areas:

- Explore a way to “disincentivize” transplant programs from inappropriately using lost to follow-up designation on TRF forms
- Monitor the impact of the guidance on providers’ existing workloads
- Develop a mechanism between electronic medical record (EMR) platforms and OPTN systems for data submission
- Observed lack of survey engagement with recipients or their families

The Committee appreciated this input, noting that the first three ideas extended outside the scope of this project. The Committee will have future discussions on the concept of a policy requirements for transition and transfer policies and procedures. The first three bullet points above will be important considerations in this potential project.

Regarding the lack of survey engagement with recipients and their families, the Committee affirmed their belief that the primary focus of a transplant teams efforts is to treat a patient with end-stage organ failure and promote the optimal outcome possible. Feedback in support of this guidance was received from transplant recipients, and the OPTN/UNOS Patient Affairs Committee. However, the OPTN’s position is that guidance documents are targeted to transplant professionals as resources to address real time operational challenges. Whether, or the degree to which, a transplant program chooses to use the resource is a decision best left to the individual program and their judgement what may help individual patients. Efforts on patient-centered guidance are best led by other organizations and groups.

After considering the feedback in-total, the Committee unanimously approved the changes and recommended consideration by the OPTN/UNOS Board of Directors at their December 2018 meeting.

Which populations are impacted by this resource?

As mentioned previously, the highest rates of lost to follow-up designation appeared in kidney and liver transplant recipients. In 2017, 646 kidney recipients and 475 liver recipients turned 18 years old.³⁰ Though the data supported the need for guidance targeted to kidney and liver transplant programs, the recommendations in the guidance can be used by all pediatric transplant programs to enhance transition and transfer of recipient to adult care.

How does this resource impact the OPTN Strategic Plan?

1. *Increase the number of transplants:* There is no impact to this goal
2. *Improve equity in access to transplants:* There is no impact to this goal
3. *Improve waitlisted patient, living donor, and transplant recipient outcomes:* Suboptimal transition and transfer of pediatric transplant recipients to adult medical care can have detrimental impact on recipient and graft survival. These can lead to recipients’ inconsistent or declining engagement with medical providers over time. Even worse, these vulnerable recipients may not receive needed out-patient care to promote long term graft and recipient survival. The end result can be graft dysfunction or loss.

This guidance shares effective practices for pediatric transition and transfer from those transplant programs with average or better than average lost to follow-up designations. The Committee hopes sharing these effective practices will improve the transition and transfer process which will in-turn lead to better transplant outcomes by reducing instances of graft loss from non-adherence.

³⁰ Based on OPTN Data as of December 31, 2017.

4. *Promote living donor and transplant recipient safety*: There is no impact to this goal
5. *Promote the efficient management of the OPTN*: There is no impact to this goal

How will the OPTN implement this resource?

This guidance document will be posted to the OPTN website, and will not require programming in UNetSM. The OPTN has existing educational resources for the transplant community on transition and transfer in UNOSConnect.³¹ These resources are included in the guidance and will be promoted following Board consideration. The fiscal impact of this proposal among all departments is very small.

How will members implement this resource?

OPO and Histocompatibility Laboratories

This guidance will have no operational or fiscal impact on OPOs or histocompatibility laboratories.

Hospital

If a transplant program implements the practices contained in this guidance, they may need to:

- Enhance or refine their transition practices to be recipient-driven.
- Develop and maintain relationships with providers that accept pediatric recipients for on-going medical care.
- Develop internal policies or procedures to ensure accepting providers receive the information needed for transfer and help these providers “perfect the catch” on the receiving end.
- Allocate additional resources to obtain recipient health information from outside providers. This may take the shape of additional staff time to contact outside providers and report the information to the OPTN.

There may be some small administrative work for pediatric and adult transplant programs to implement this guidance, and it may take one to six months.

Ongoing costs for a pediatric transplant program would be low, potentially \$1,500-\$2,000 per recipient. This cost would be on a per-occurrence basis and variable based on the degree to which a transplant program implements the recommendations. There would be no further costs associated with a recipient after transfer. The receiving transplant program’s costs would be driven by their internal policies and procedures for post-transplant medical care and likely be covered by payers.

Will this resource require members to submit additional data?

No, this resource does not require members to submit additional data submission.

How will members be evaluated for compliance with this resource?

Guidance from the OPTN does not carry the weight of policies or bylaws. Therefore, members will not be evaluated for compliance with this document.

³¹ Organ Procurement and Transplantation Network – UNOSConnect: *Special Considerations and Challenges in Management of Children and Adolescents Presenting to Adult Transplant Centers, and Smoothing the Path to Adulthood: A Transition Clinic for Kidney Transplant Recipients.*

How will the sponsoring Committee evaluate whether this resource was successful post implementation?

It will be challenging to establish causation of a decrease in lost to follow-up designation based on this guidance document and corresponding education/outreach. In order to assess if the guidance and related education/outreach may have contributed to a decrease lost to follow-up designation, the Committee will monitor the lost to follow-up rates for liver and kidney transplants, with a focus on those recipients transplanted at less than 18 years old. The OPTN will report this information to the Committee annually for two years following approval by the Board.

Guidance Document

All the language in the white paper below is proposed new language; underlines have been omitted for easier reading.

Guidance on Pediatric Transplant Recipient Transition and Transfer

Summary and Goals

Suboptimal transition and transfer processes for pediatric transplant recipients have been associated with increased risk of non-adherence with their plan of care and graft loss. The goal of the guidance is to support improvements in transplant outcomes by reducing instances of graft loss from non-adherence, and by providing guidance to transplant hospitals to improve the transition and transfer process for pediatric recipients.

Breakdowns in transition and the transfer to adult medical care may also contribute to “lost to follow-up” designations for pediatric transplant recipients on OPTN data collection forms. A secondary goal of this guidance is to reduce the incidence of lost to follow-up designations for pediatric transplant recipients. These data are used to help the transplant community develop healthcare policy (e.g.: in organ allocation) and guides their clinical decision making (e.g.: in determining acceptable travel distance and cold ischemic times for organ recovery). Additionally, transplant professionals use these data when counseling patients’ families and guardians regarding expected outcomes and to set realistic goals regarding transplantation.

By sharing effective practices for recipient transition and transfer from pediatric to adult medical care, transplant outcome data will be more complete and more representative of clinical practices.

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33 Guidance on Pediatric Transplant Recipient Transition 34 and Transfer

35 Background

36 Suboptimal transition and transfer processes for pediatric transplant recipients have been associated with
37 increased risk of non-adherence with their plan of care and graft loss. Breakdowns in transition and the
38 transfer to adult medical care may contribute to instances of non-adherence, and also contribute to “lost
39 to follow-up” designations on OPTN data collection forms. The OPTN/UNOS Pediatric Transplantation
40 Committee (Committee) uses these data to examine long-term outcomes in pediatric organ
41 transplantation. Transplant professionals use these data when counseling patients’ families or guardians
42 regarding expected outcomes and to set realistic goals regarding transplantation.

43
44 The Committee recognized there are gaps in data reported to the OPTN that may influence their
45 analyses. The “lost to follow-up” designation is available for a transplant program to enter on Transplant
46 Recipient Follow-up (TRF) forms if the program is unable to obtain the recipient’s health information. This
47 may be due to losing contact with the recipient, the recipient relocating, or being referred to another
48 healthcare provider for post-transplant medical care.

49
50 By identifying and promoting effective transfer and transition practices, the Committee hopes to support
51 improvements in transplant outcomes by reducing instances of graft loss from non-adherence to a
52 recipient’s treatment plan. A secondary goal of this guidance is to decrease the number of pediatric
53 recipients lost to follow-up after they transition to adult care, which will in turn increase the accuracy and
54 transparency of the recipient data available to the OPTN, the transplant community, and the public.

56 Transition

57 Transition ideally begins in late childhood and early adolescence and involves many stakeholders. This
58 occurs during a challenging stage of development, the complexities of which are well documented in
59 medical literature.^{1, 2, 3, 4, 5, 6, 7} This is even more challenging in children with complex medical conditions,
60 which would include transplant recipients.⁸ Further complicating this progression to autonomous care is

¹Park, MJ, et al., “The health status of young adults in the United States, *Journal of Adolescent Health* 39 (2006), <https://doi.org/10.1016/j.jadohealth.2006.04.017>. Accessed June 27, 2018.

² Keith, D, Cantarovich, M, Paraskevas, S, Tchervenkov, J, “Recipient age and risk of chronic allograft nephropathy in primary deceased kidney transplant”, *Transplant International* 19 (2006), <https://doi.org/10.1111/j.1432-2277.2006.00333.x>. Accessed June 27, 2018.

³ U.S. Government Accountability Office, *End-stage renal disease: Characteristics of kidney transplant recipients, frequency of transplant failures, and cost to Medicare* (2007), <https://www.gao.gov/assets/270/267345.pdf>. Accessed June 27, 2018.

⁴ Dobbels, F, Van Damme-Lombaert, R, Vanhaecke, J, De Geest, S, “Growing pains: non-adherence with immunosuppressive regimen in adolescent transplant recipients”, *Pediatric Transplantation* 9 (2005), doi10.1111/j.1399-3046.2005.00356.x. Accessed June 27, 2018.

⁵ Hazen, E, Schlozman, S., Beresin, E, “Adolescent psychological development: A review”, *Pediatrics in Review* 29 (2008), DOI: 10.1542/pir.29-5-161. Accessed June 27, 2018.

⁶ Giedd, J, “The teen brain: insights from neuroimaging”, *Journal of Adolescent Health* 42, (2008), <https://doi.org/10.1016/j.jadohealth.2008.01.007>. Accessed June 27, 2018.

⁷ Steinberg, L, “A social neuroscience perspective on adolescent risk-taking”, *Developmental Review* 28 (2008), <https://doi.org/10.1016/j.dr.2007.08.002>. Accessed June 27, 2018.

⁸ Andreoni, KA, Forbes, R., and Andreoni, RM, “Age-Related Kidney Transplant Outcomes Health Disparities Amplified in Adolescence”, *JAMA Internal Medicine* 16 (2013), doi:10.1001/jamainternmed.2013.8495. Accessed June 29, 2018.

61 the transfer to an adult medical provider when the recipient reaches early adulthood. Clear plans for
 62 transition have been identified as an effective practice across many disciplines in pediatric health care.^{9, 10}
 63

64 As pediatric transplant recipients reach this vulnerable age, health professionals often find it challenging
 65 to effectively transition the recipients from pediatric to adult care. There are broadly acknowledged facts
 66 that may negatively impact transition:

- 67 • Lack of optimization in the transition process
- 68 • Many youth are ill-equipped to receive care in the adult system
- 69 • Adult providers may lack knowledge and skills to care for young adults with childhood-onset
 70 chronic conditions
- 71 • Inadequate health insurance and transition services funding^{11, 12, 13, 14, 15}

72
 73 Acknowledging the linkages between less than effective transition, the challenges associated with
 74 recipient transfer during a challenging developmental time, and the impact of these on recipient data
 75 submission, the Pediatric Committee examined lost to follow-up rates for heart, kidney, and liver
 76 transplant recipients in the U.S. who were transplanted during the period 2000 to 2010, and were less
 77 than 18 years old at the time of transplant. The data showed diverse lost to follow-up rates across all
 78 organs, with the highest for kidney recipients, than liver recipients.¹⁶
 79

80 Transfer

81 There are three common models of transfer of care to an adult provider:

- 82 • Transfer to an adult transplant physician within the same transplant program
- 83 • Transfer to an adult transplant physician at another transplant program, usually geographically
 84 closer to the recipient
- 85 • Transfer to an adult provider who is not associated with a transplant program, but geographically
 86 closer to the recipient

87 Responsibility for completion of the TRF forms will differ, depending on the model of transfer used. For
 88 those recipients transferred to adult providers at another transplant program, the responsibility for
 89 completion of the TRF forms will follow them to the new transplant center following an official handoff of
 90 this responsibility. For those recipients transferred to an adult provider not associated with a transplant
 91 program, the responsibility for completion of the TRF forms will continue to reside with the transplanting
 92 program.¹⁷
 93

⁹ American Academy of Pediatrics, Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home, *Pediatrics* 128 (2011), 182-200, DOI: 10.1542/peds.2011-0969. Accessed June 29, 2018.

¹⁰ Schwartz, L.A., et al., Measures of Readiness to Transition to Adult Health Care for Youth with Chronic Physical Health Conditions: A Systematic Review and Recommendations for Measurement Testing and Development, *Journal of Pediatric Psychology* 39 (2014), 588-601, doi.org/10.1093/jpepsy/jsu028. Accessed June 29, 2018.

¹¹ Unpublished reports to OPTN/UNOS Pediatric Transplantation Committee on October 19, 2016.

¹² McDonagh, JE, "Growing up and moving on. Transition from Pediatric to Adult Care", *Pediatric Transplantation* 9 (2005), <https://doi.org/10.1111/j.1399-3046.2004.00287.x>. Accessed June 29, 2018.

¹³ Rosen, DS, et al., "Transition to adult health care for adolescents and young adults with chronic conditions: Position paper for the society for adolescent medicine", *Journal of Adolescent Health* 33 (2003), https://www.adolescenthealth.org/SAHM_Main/media/Advocacy/Positions/2003-Transition_from_Child-Centered_to_Adult_Health-Care_Systems_for_Adolescents_with_Chronic_Conditions.pdf. Accessed June 29, 2018.

¹⁴ Watson, AR, "Noncompliance and transfer from paediatric to adult transplant unit", *Pediatric Nephrology* 14 (2000), <https://doi.org/10.1007/s004670050794>. Accessed June 29, 2018.

¹⁵ Knauth, A, Verstappen, A, Reiss, J, and Webb GD, "Transition and transfer from pediatric to adult care of the young adult with complex congenital heart disease", *Cardiology Clinics* 24 (2006), <https://doi.org/10.1016/j.ccl.2006.08.010>. Accessed June 29, 2018.

¹⁶ Unpublished reports to OPTN/UNOS Pediatric Transplantation Committee on October 19, 2016 and March 30, 2017. Based on OPTN data as of August 5, 2016 and February 12, 2016 respectively.

¹⁷ OPTN Policies 18.1 *Data Submission Requirements*, and 18.2 *Timely Collection of Data*, https://optn.transplant.hrsa.gov/media/1200/optn_policies.pdf#nameddest=Policy_18. Accessed June 29, 2018.

94 Identification of Effective Practices

95 The Committee created and administered an on-line survey of transition and transfer practices. They
 96 compared survey responses to transplant programs with low, average, or better than average lost to
 97 follow-up rates on TRF forms identified in OPTN data.¹⁸ The results were stratified over what can be
 98 considered small, medium and large volume transplant programs.¹⁹ This comparison highlighted those
 99 effective practices that may promote average or better than average lost to follow-up rates.

100
 101 The Committee observed the following themes from the survey results:

- 102 • A defined transfer age varied among transplant programs. Such a practice may not be in the best
 103 interest of long-term follow up. In general, the younger the recipient at transfer, the worse the lost
 104 to follow-up rate. Instead, a recipient's developmental milestones and maturity should be strongly
 105 considered to determine when to begin the transition process and when to transfer a recipient to
 106 an adult provider.
- 107 • The absence of a formalized transition process was noted at small volume transplant programs,
 108 but was not associated with higher lost to follow-up rates.²⁰ The lower case volume at these
 109 programs may inherently allow staff to focus more on recipient-centric indicators for transition and
 110 transfer readiness, and focus less on transition processes.
- 111 • Low volume centers were frequently in close association with an adult center. The transfer of care
 112 to an adult transplant physician within the same program likely contributes to the low lost to follow
 113 up rates observed at low volume centers.
- 114 • Transfer to adult providers within the same transplant program has its benefits and is associated
 115 with lower rates of lost to follow-up designation.
- 116 • Transplant programs should commit resources to diligent follow-up of those recipients who reside
 117 extended distances from the transplant program and to report these data to the OPTN.
- 118 • Transplant programs with average or below average lost to follow-up rates were more likely to
 119 transfer recipients to unaffiliated providers compared to transplant programs with better than
 120 average lost to follow-up rates.
- 121 • Physicians at small volume transplant programs are more frequently involved in the transfer
 122 discussion as compared to medium or large volume programs.
- 123 • Large volume transplant programs more frequently utilize social workers, transition specialists, or
 124 other staff members in transfer discussions.
- 125 • Reluctance to transfer care on the part of the parents was reported more frequently by medium
 126 and large volume programs, standalone pediatric transplant programs, and kidney programs with
 127 below average lost to follow-up rates.
- 128 • Large volume transplant programs cited geographic location as a challenge for transferring
 129 recipients. This may reflect pre-transplant referrals from a wide geographic area, or programs that
 130 operate outreach care clinics.
- 131 • Transplant coordinators were most frequently the individuals responsible for contacting other
 132 providers for transfer. These individuals were most frequently registered nurses.

133

134 Recommendations

135 Successful transition and transfer practices must balance the needs of the recipients and
 136 families/guardians, regulatory requirements, payer factors, hospital policies, transplant program
 137 resources, and OPTN member obligations. Though the highest lost to follow-up rates were observed in
 138 kidney and liver transplant recipients, the practices outlined can be applied to all types of transplant
 139 programs.

¹⁸ Transplant program performance on TRF completion: Below Average = program's 5 year lost to follow-up rate was >10%, Average = program's 5 year lost to follow-up date was between 6-10%, Better than Average = program's 5 year lost to follow-up rate was <5%.

¹⁹ Small Volume = <5 pediatric transplants/year, Medium Volume = 6-9 pediatric transplants/year, Large Volume = at least 10 pediatric transplants/year.

²⁰ See Appendix, Figure 1.

140
141 The following are the responsibilities proposed for each team:
142

143 **Pediatric Transplant Team:**

- 144 • Create a written health care transition plan that draws on the multidisciplinary approach to
145 transplant care. Examples of this include cardiology, dermatology, endocrinology, pharmacy, and
146 psychology/social work. Encourage and provide guidance to recipients' family/guardians about
147 how they can promote independence and self-responsibility during the transition process.
148 Emphasize that recipients must advocate for themselves and ask questions when faced with
149 unfamiliar tests, medications, outpatient clinic practices, or if treatment plans are modified.
- 150 • Prepare both the recipient and their family members/guardians for transfer to another provider.
- 151 • Assess transition readiness to include:
 - 152 ○ A recipient's general preparedness for independent care
 - 153 ○ Knowledge and practice gaps
 - 154 ○ Potential threats to graft health and recipient wellness (including emotional/behavioral
155 health), and a mechanism for addressing deficiencies
 - 156 ○ Critical milestones that should be achieved before transferring to adult care²¹

157
158 Transition plans should be flexible and based on the unique needs associated with each
159 recipient, and cultural considerations to the recipient and their family.

- 160 • Stand-alone pediatric transplant programs should carefully assess if the transplant recipient is
161 reluctant to transfer to another provider. This assessment should occur multiple times during the
162 transition process. If the reluctance to transfer continues then the transfer to adult care should be
163 delayed until the cause of reluctance is addressed appropriately.
- 164 • Ensure surrogate decision-makers are identified for those recipients with limited decision-making
165 capability. This would include resolution of guardianship or formal legal arrangements, and should
166 be completed before the recipient's 18th birthday. Formal legal arrangements may be necessary
167 to avoid future conflicts, and ensure continuity of a stable support system.
- 168 • Should have a formalized policies and procedures for recipient transfers. Tools, such as a
169 transfer checklist, may be helpful to standardize the process. Collaborate with adult providers on
170 tools to have linkage/overlap to prevent communication gaps.
- 171 • Consider transfer to an adult provider within the same institution whenever possible. A
172 multidisciplinary post-transplant transition clinics may be helpful to prepare recipients for transfer
173 to adult providers.
- 174 • Partnerships with adult providers should be established well in advance of transfer.
175 Multidisciplinary post-transplant transition clinics jointly staffed with by pediatric and adult teams
176 may be considered in preparing recipients for transfer to adult providers.
- 177 • Consider payer requirements earlier in the transition period to prevent lapses in coverage that
178 can lead to recipient noncompliance.
- 179 • Communicate each recipient transfer to the OPTN. This will allow accurate assignment of TRF
180 responsibility to the appropriate transplant program. Guidance and frequently asked questions
181 can be found on the TransplantPro website.²²
- 182 • Provide the transplant recipient with a portable, concise, up-to-date summary of their medical and
183 surgical history, and detailed list of their medications. In addition to the normal scope of clinical
184 information, the program should indicate prominently the initial reason for transplant, the type of
185 transplant and whether not they have received more than one transplant, HLA typing, any history
186 of rejection, copies of pathology reports (biopsies), detailed history of transplant-related
187 complications or comorbidities (post-transplant DM, hypertension, rejection episodes & treatment,
188 or PTLD).

²¹ See Appendix, Table 2.

²² <https://transplantpro.org/news/tiedi-enhancements-allow-for-self-service-on-recipient-follow-up-forms/>. Accessed June 29, 2018.

- 189 • If a recipient relocates or a payer requires transfer of a recipient, additional resources may be
190 needed to effectively obtain recipient health information and submit the information to the OPTN.
- 191 • Remember that transplant programs that transfer recipients to providers unaffiliated with a
192 transplant program are still responsible for submitting TRF forms for those recipients to the
193 OPTN.²³
 - 194 ○ To improve health information sharing, the transplant programs should communicate to the
195 accepting provider the need to be kept informed on the recipient's state of health, information
196 required by the OPTN, and the frequency of data submission requirements prior to and at the
197 time of transfer.
 - 198 ○ The originating transplant program should carefully consider the administrative burden of
199 obtaining health information on these recipients when considering staff responsibilities and
200 work volume.

201 **Accepting Adult Providers:**

- 202 • Provide staff education regarding childhood and adolescence psychosocial development and the
203 impact of childhood chronic disease on development.
- 204 • Be knowledgeable about congenital conditions that lead to organ failure in childhood and that
205 may rarely be seen in adult patients.
- 206 • Should have a formalized policies and procedures for recipient transfers.
- 207 • Multidisciplinary post-transplant transition clinics jointly staffed with by pediatric and adult teams
208 may be considered in preparing recipients for transfer to adult providers
- 209 • Recognize that transplant recipients who are transferring into their practice may need time to fully
210 adjust to the more rapid pace of an adult clinic, and a recipient's transition to assuming more
211 responsibility for self-care does not stop after the transfer event.
- 212 • Collaborate with pediatric transplant programs on tools to have linkage/overlap in order to prevent
213 communication gaps.
- 214 • Programs should consider use of a recipient mentor/coach program to ease the transfer process.
- 215 • Maintain ongoing communication with the pediatric transplant programs to improve recipient
216 transfers and provide needed recipient health information for data reporting.

218 **Additional Resources**

219 Additional resources for the recipient's transplant team are available below:

- 220 • American Academy of Pediatrics – *Guidance on adolescents transitioning to adult care*²⁴
- 221 • New England Journal of Medicine – *Operational Standard for Transitioning Pediatric Patients to*
222 *Adult Medicine*²⁵
- 223 • Organ Procurement and Transplantation Network –
 - 224 ○ UNOSConnect: *Special Considerations and Challenges in Management of Children and*
225 *Adolescents Presenting to Adult Transplant Centers, and Smoothing the Path to*
226 *Adulthood: A Transition Clinic for Kidney Transplant Recipients*²⁶
 - 227 ○ *What Every Parent Needs to Know*²⁷

228 In addition to this guidance for transplant hospitals from the OPTN, transition guidance specifically for
229 transplant recipients can be found on the AST Pediatric Transition Portal.²⁸

²³ OPTN Policies 18.1: *Data Submission Requirements*, and 18.2: *Timely Collection of Data*.

²⁴ <https://www.aap.org/en-us/about-the-aap/aap-press-room/pages/Helping-Adolescents-Transition-to-Adult-Health-Care.aspx>. Accessed June 29, 2018.

²⁵ <https://catalyst.nejm.org/operational-standard-pediatric-transition-adult/>. Accessed June 29, 2018.

²⁶ <https://unosconnect.unos.org/UI/LandingPage.aspx>. Accessed June 29, 2018.

²⁷ https://optn.transplant.hrsa.gov/media/2464/weparentntk_optn.pdf. Accessed June 29, 2018.

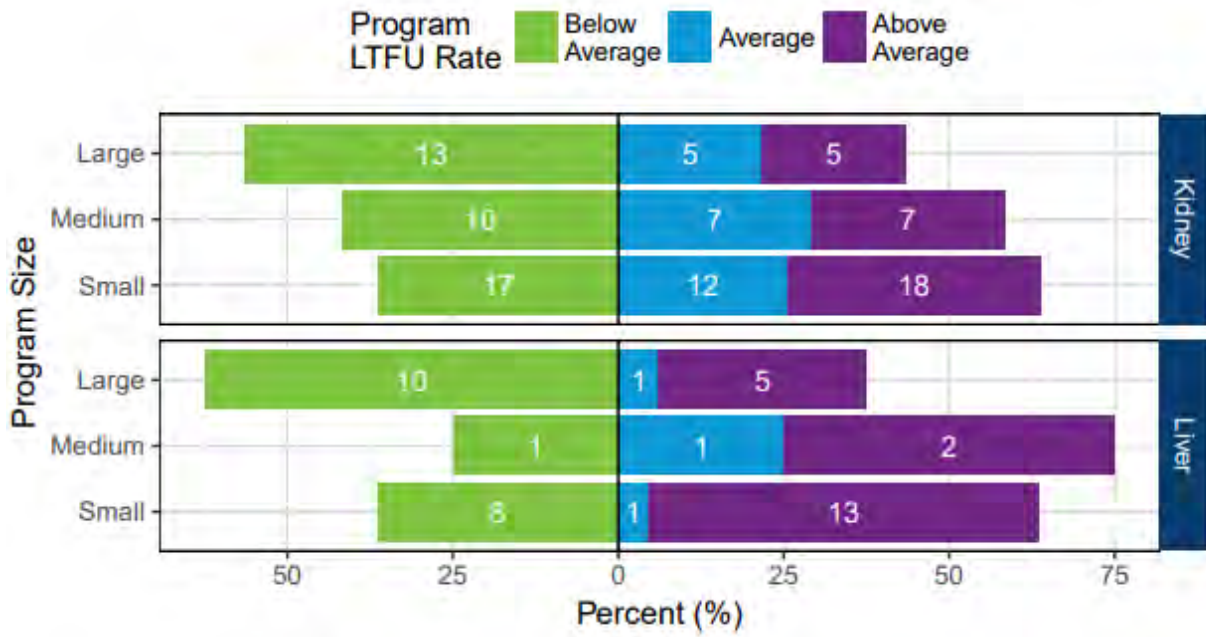
²⁸ <https://www.myast.org/education/specialty-resources/peds-transition>. Accessed June 29, 2018.

233 **Conclusion**

234 By sharing effective practices for transition and transfer of pediatric transplant recipients, this guidance
235 will hopefully support improvements in transplant outcomes, and reduce the incidence of lost to follow-up
236 designations for pediatric transplant recipients.
237

238 **Appendix**

239 **Figure 1: Survey Responses by Organ Type, Program Size, and Program Lost to Follow-up Rate²⁹**

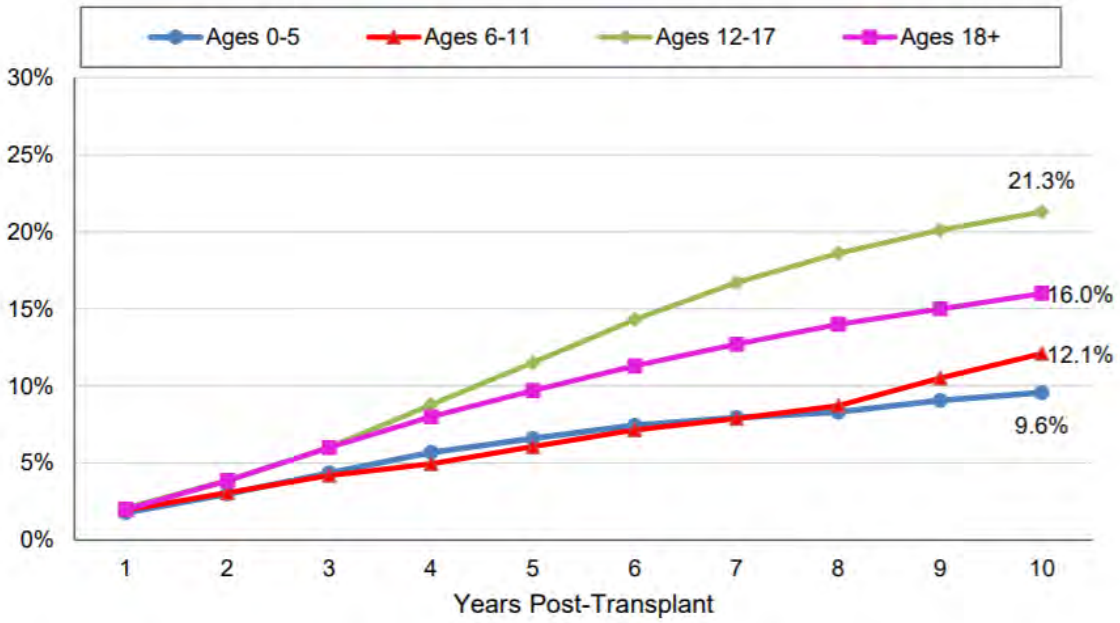


240

²⁹ Based on OPTN Data as of March 16, 2018.

241
242

Figure 2: Lost to Follow-up Rates at 1 through 10 Years after Transplant for Kidney Transplants Performed during 2000 - 2010 by Age at Transplant³⁰



243
244

Figure 3: Lost to Follow-up at 1 through 10 Years after Transplant for Liver Transplants Performed during 2000 - 2010 by Age at Transplant²⁹

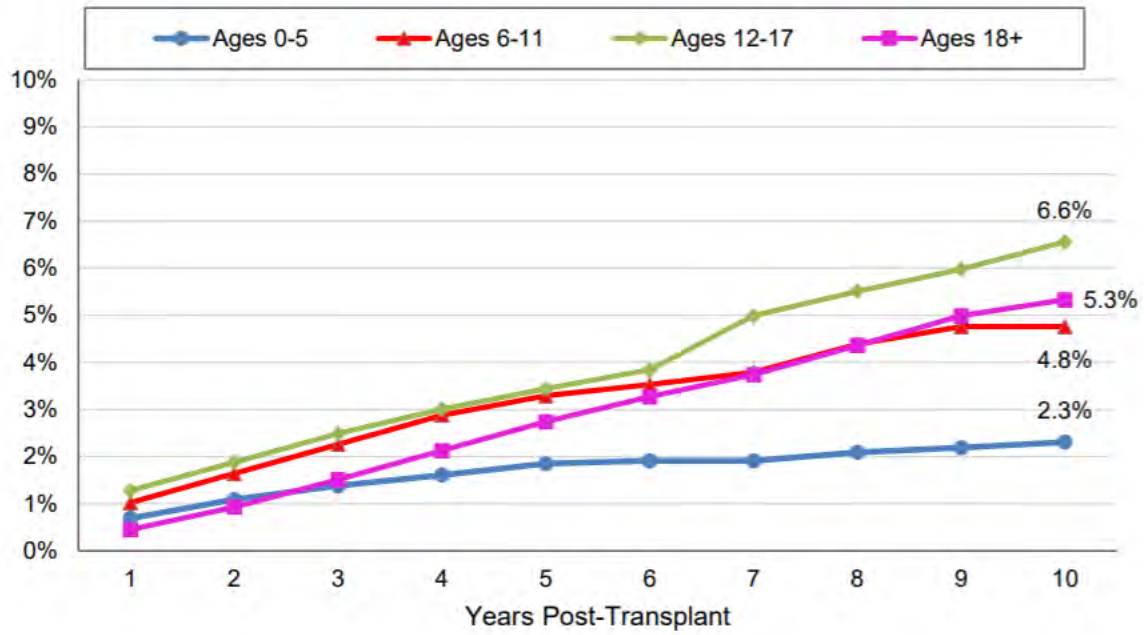


245
246

³⁰ Unpublished reports to OPTN/UNOS Pediatric Transplantation Committee on October 19, 2016 and March 30, 2017.

247
248

Figure 4: Lost to Follow-up at 1 through 10 Years after Transplant for Heart Transplants Performed during 2000 - 2010 by Age at Transplant²⁹



249

Figure 5: Critical Milestones for Patients to Achieve Prior to Transfer to Adult Care³¹

- Understanding of and ability to describe the original cause of their organ failure, need for transplantation
 - Initial education may have been primarily provided to their parents; repetition is necessary to ensure they understand their condition
- Awareness of the long and short term implications of the transplant condition on their overall health and other aspects of their life (e.g. infection prevention, cancer surveillance, academic and vocational aspirations)
- Comprehension of the impact of their illness on their sexuality and reproductive health, including
 - the impact of pregnancy on their own wellbeing
 - the effect of their medications on fertility
 - Any potential teratogenicity of their medications
 - The role of genetic counselling, and genetic risk of their disease recurrence in future offspring, if pertinent to their condition
 - their own increased susceptibility for sexually transmitted disease
- Demonstration of a sense of responsibility for their own healthcare
 - Knowledge of the names, (and shapes/colors), indications and dosages of their transplant and ancillary medications (or carry that information in wallet/purse)
 - Call for their own prescription refills and renewals
 - Prepare their own medication dose boxes, if not done by their pharmacist
 - Independently communicate their health care needs to their providers
 - Know when and how to seek urgent medical attention, including health emergency telephone number(s)
 - Ability to make, keep a calendar of, and follow through with their own health care appointments
 - Understanding of their medical insurance coverage and eligibility requirements
- Capacity to provide most self-care independently
- An expressed readiness to move into adulthood
- Ownership of their medical information in a concise portable accessible summary

³¹ Bell, L.E., et al., (2008) Adolescent Transition to Adult Care in Solid Organ Transplantation: A Consensus Conference Report, page 9.

Table 1: Developmental Stages/Milestones of Adolescence and Young Adulthood, and Suggested Clinic Visit Developmental Subjects³²

	Early adolescence ages ~10-13 years*	Mid adolescence ages ~ 14-16 years*	Late adolescence ages ~ 17-21 years and beyond*
Cognitive, affective & moral	<ul style="list-style-type: none"> • Concrete thinking • Beginning development of abstract thought in some • Inability to grasp long-term outcome of current decisions • Heightened emotional arousability • Sensation seeking • Early exploratory behaviors (e.g. smoking, violence) • Reward oriented • Development of early moral concepts 	<ul style="list-style-type: none"> • Increased intellectual functioning and abstract thinking • May revert to concrete thinking in confusing or stressful situations • May begin to perceive future consequences of actions but not utilize in decision making • Sense of omnipotence and invincibility • Heightened vulnerability to risk taking • May have difficulty regulating affect and behavior • Questioning of moral conventions • Development of personal code of ethics • Emergent fervent ideology 	<ul style="list-style-type: none"> • Complex abstract thinking (some may never fully achieve) • More future oriented: can act on long-term plans, delay gratification, set limits • Greater emotional stability • Idealism but sometimes absolutism, with intolerance of opposing views • May be swayed by religious and political ideology that promise answers to complex questions
Self- concept/identity formation	<ul style="list-style-type: none"> • Fantasy and present-oriented • Self-conscious about appearance, body image and attractiveness 	<ul style="list-style-type: none"> • Increased introspection • May question meaning of life and have intense feelings of inner turmoil and misery • Concern with attractiveness 	<ul style="list-style-type: none"> • Progression of personal identity • More stable body image; attractiveness may remain important
Family and peers	<ul style="list-style-type: none"> • Beginning of emotional separation from parents and early effort toward independence • Need for privacy • Beginning of strong same gender peer identification and affiliation 	<ul style="list-style-type: none"> • Further emotional separation from parents and family • Struggles and conflicts over autonomy • Strong peer identification and involvement 	<ul style="list-style-type: none"> • Separation from family emotionally and physically • Peer group / peer values begin to diminish in importance • Formation of stable relationships with increasing involvement of love and commitment

³² Bell, L.E., et al., (2008) Adolescent Transition to Adult Care in Solid Organ Transplantation: A Consensus Conference Report, *American Journal of Transplantation* (8) 11, 2230-2242, <https://doi.org/10.1111/j.1600-6143.2008.02415.x>. Accessed June 29, 2018.

	Early adolescence ages ~10-13 years*	Mid adolescence ages ~ 14-16 years*	Late adolescence ages ~ 17-21 years and beyond*
<i>Sexual</i>	<ul style="list-style-type: none"> • Examination of own sexual feelings • Progression of sexual identity development & orientation 	<ul style="list-style-type: none"> • Questions of sexual orientation • Initiation of sexual relationships (often superficial) • Sexual experimentation • Aware of risks of pregnancy and sexually transmitted diseases, but may not consistently act upon the knowledge 	<ul style="list-style-type: none"> • Consolidation of sexual identity
<i>Relationship to society</i>	<ul style="list-style-type: none"> • Adaptation to middle/early secondary school years 	<ul style="list-style-type: none"> • Assessment of skills and opportunities • Early educational and/or vocational plans • Realistic role models critically important 	<ul style="list-style-type: none"> • Career decisions central • University/college/vocational experience with increased self-responsibility • Progression of workforce capability and financial independence
<i>Suggested subjects to explore and discuss at clinic visits discuss</i>	<ul style="list-style-type: none"> • Introduce concept of private confidential visits to parents and patient • Simple directed interactive questions to patient • Straightforward interactive counselling • Discuss healthy lifestyle choices 	<ul style="list-style-type: none"> • Enquire about friends, free time activities, home life, school • Ask in non-threatening, non-judgmental manner about experimentation with drugs, alcohol or sexual activity, and about any trouble with the law • Discuss healthy living 	<ul style="list-style-type: none"> • Discuss healthy living habits and personal interventions for improving overall wellness • Identify unhealthy living habits and their consequences • Build upon questions from earlier age ranges (left of table)

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255

#