

A Change Package To Increase Kidney Transplantation

Key Change Ideas for Dialysis
Facilities to Drive Local Action

Updated 2024





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I. Introduction

This change package is intended to support dialysis facilities and End State Renal Disease (ESRD) Networks in increasing the number of patients referred to transplant centers, evaluated for kidney transplantation, and placed on transplant waitlists. The change package includes actionable change ideas, collected from top-performing dialysis facilities related to patients' being placed on transplant waitlists. The change ideas are intended as a menu of interventions from which leaders can choose to implement within their facilities.

The original change package was released by the Centers for Medicare & Medicaid Services (CMS) in 2020 and updated in 2022, 2023, and 2024 after additional interviews were conducted with high-performing facilities.

How to Get Started

Change happens at the local level. Dialysis facility Quality Assessment & Performance Improvement (QAPI) meetings are the perfect place to start. Giving interdisciplinary team (IDT) members this change package for review will allow them to identify and prioritize change ideas that could be implemented to increase the number of patients educated, referred to a transplant center, and waitlisted for a kidney transplant.

The change ideas presented in this change package represent the practices used by high-performing dialysis facilities. They are not meant to serve as the entire universe of approaches to increase the number of patients placed on transplant waitlists. They can, however, serve as “tests of change” that drive performance improvement and quality improvement programs.

About QAPI: QAPI merges quality assessment (QA) and performance improvement (PI) into a comprehensive approach to quality management. QA is the process of meeting standards and ensuring care reaches an acceptable level. PI is the proactive, continuous study of processes with the intent to identify opportunities and test new approaches to fix the underlying causes of persistent, systemic problems. Data-driven QAPI programs may be customized to facility needs. Key steps include:

- Identifying the problem and defining the goal
- Deciding on a measurement to monitor improvement
- Brainstorming solutions based on barriers and root causes
- Planning an intervention
- Using plan-do-study-act (PDSA) to implement the improvement project

Learn more about QAPI: <https://esrdnetworks.org/toolkits/professional-toolkits/qapi-toolkit/>



Contacting ESRD Networks

Dialysis facilities can contact their local ESRD Networks for assistance with PDSA principles and practices, questions about change strategies, and transplant-related resources. A complete listing of ESRD Networks can be found at <https://esrdncc.org/en/ESRD-network-map/>.

II. Change Package Methodology

The ideas presented in this change package were identified through extensive interviews with high-performing dialysis facilities. The facilities were selected utilizing waitlist data as documented in CROWNWeb (now called ESRD Quality Reporting System [EQRS]). During the interviews, systemic themes emerged, which were organized into driver diagrams, visual displays of what drives and contributes to achieving an overall aim.¹ The diagrams include drivers and associated change ideas, which were reviewed by three nationally recognized nephrologists to ensure relevance to a broad range of dialysis facilities. The input of these experts was incorporated into the document.

2022 Update: The 2022 change package revisions were based on 10 additional interviews conducted with high-performing facilities in early 2022, which resulted in the addition and/or modification of change ideas to drive an increase in the number of individuals on transplant waitlists and receiving kidney transplants. The facilities were selected utilizing waitlist data, as documented in EQRS.

2023 Update: The change package was updated in 2023 after 10 additional interviews were conducted with high-performing facilities in late 2022/early 2023. The facilities were selected using waitlist data, as documented in EQRS. Change ideas were modified or added from information gathered from dialysis facility staff during the interviews.

2024 Update: Information was added after 10 additional interviews were conducted with high-performing facilities, based on EQRS data. Change ideas were added (indicated by asterisks) from information gathered from dialysis facility staff during the interviews.



III. Kidney Transplant Drivers

Interviews with high-performing dialysis facilities revealed primary and secondary drivers being used to increase kidney transplantation (Table 1). “Primary drivers are the most important influencers” that “contribute directly to achieving the aim.” Secondary drivers are the actions and interventions that impact the primary drivers.²

The primary and secondary drivers (Tables 1–17), as well as the associated change ideas in the driver diagrams (Tables 2–17), are not in ranked order. They are numbered for easy reference.

Table 1. Primary and Secondary Drivers to Increase Kidney Transplantation

AIM: INCREASE KIDNEY TRANSPLANTS	
PRIMARY DRIVERS	SECONDARY DRIVERS
1. Create a pro-transplant culture	1a: Link the organizational mission to the work 1b: Hire team members who will support a culture of caring 1c: Designate one or two champions to drive transplant efforts 1d: Engage all facility staff in improving transplant referral rates 1e: Engage patients in the transplant referral process
2. Implement continuous quality improvement	2a: Track transplant referrals and progress 2b: Engage physicians and staff in the review of data and the development of interventions 2c: Review transplant information with patients
3. Continually follow up on transplant status	3a: Hold informal discussions about transplant with each patient at every patient clinic visit 3b: Provide patients with knowledge, tools, and support to help them move the process forward 3c: Act as a case manager to facilitate progress 3d: Maintain communications with transplant centers
4. Educate and support patients	4a: Provide education early and regularly on transplants and the transplant process 4b: Offer support throughout the referral process 4c: Facilitate patient-to-patient support
5. Provide staff education	5: Educate staff to maintain their knowledge of transplants and the transplant process



IV. Key Change Ideas

The following driver diagrams (Tables 2–17) expand on the kidney transplant drivers (Table 1) and include specific change ideas for all the secondary drivers identified by high-performing dialysis facilities. The visualizations show the relationships between the primary and secondary drivers and the associated change ideas.

Table 2. Link the Organizational Mission to the Work

PRIMARY DRIVER #1: CREATE A PRO-TRANSPLANT CULTURE
Secondary Driver #1a: Link the organizational mission to the work
<p>When an organization promotes transplants as part of its mission, that message filters throughout the organization, guiding staff as they perform their work and generating momentum among staff and with patients for continuous improvement.</p> <p>Change Ideas</p> <ol style="list-style-type: none"> 1. Keep the focus on the mission statement. <ol style="list-style-type: none"> a. Discuss it monthly with staff. b. Share it freely in email communications. c. Lead by example – key leaders (e.g., nephrologist, administrator) live the mission/culture. “This is our whole life. This is what we do.” 2. Constantly talk about transplantation – <ol style="list-style-type: none"> a. “The language of transplant is always there at the core.” b. “From the moment the patient walks in the door, we are talking to them about transplant.”* 3. Assume that every patient is going to get a kidney transplant until proven otherwise. 4. Maintain a culture of teamwork, respect, positivity, empathy, creativity, inclusion, and acceptance.

*Added 2024



Table 3. Hire Team Members Who Will Support a Culture of Caring

PRIMARY DRIVER #1: CREATE A PRO-TRANSPLANT CULTURE
Secondary Driver #1b: Hire team members who will support a culture of caring
<p>Evaluating potential new hires to see if they are a good fit will ensure everyone contributes to a culture of caring.</p> <p>Change Ideas</p> <ol style="list-style-type: none"> 1. Set clear expectations during the interview – staff must be dedicated to the work, treat patients with respect and dignity, and hold a philosophy of <i>patients first</i>. 2. Utilize administrative staff and peers for interviews. 3. Prior to hiring new staff, implement a job shadowing experience (e.g., floor nurse to observe patient education and initiation of dialysis) or share a video that demonstrates “a day in the life of...” a patient care technician or nurse to paint a picture of what the job entails, including promoting and supporting access to transplantation. 4. Determine if the candidate’s core values match the facility’s core values during the interview process. 5. Consider the diversity of staff and patients, when hiring.

Table 4. Designate One or Two Champions to Drive Transplant Efforts

PRIMARY DRIVER #1: CREATE A PRO-TRANSPLANT CULTURE
Secondary Driver #1c: Designate one or two champions to drive transplant efforts
<p>Commonly, facilities with success in referring patients for transplant had one or two persons leading the charge, whether the persons were formally designated as Transplant Designee/Manager, or they grew into that role organically from their passion for transplants. As one staff member said, “I just want them all to get kidneys. I can get another job.”</p> <p>Change Ideas</p> <ol style="list-style-type: none"> 1. Determine who has an interest and passion for promoting transplants. 2. Consider all staff as possible champions, e.g., physician, social worker, and unit secretary. 3. Make the position a formal role. 4. Ensure the champion is educated in general listing criteria for transplant centers, so potential barriers can be discussed with patients. 5. Encourage transplant champions or designees to participate in local transplant center symposia to receive education on transplantation, network with transplant center staff, and gain an understanding of the process for education, referral, evaluation, and transplantation. 6. Engage the medical director, who can set a positive attitude in the facility, spearhead performance, call transplant centers to work through barriers, and talk with hesitant patients directly to resolve concerns about transplantation.



Table 5. Engage All Facility Staff in Improving Transplant Referral Rates

PRIMARY DRIVER #1: CREATE A PRO-TRANSPLANT CULTURE
Secondary Driver #1d: Engage all facility staff in improving transplant referral rates
<p>All facility staff play a role in getting patients on the transplant waitlist. This is especially true of nurses and patient care technicians (PCTs) who have established relationships of trust with patients. These frontline staff can promote transplant, listen to patient concerns, and communicate barriers and questions to the rest of the team.</p> <p>Change Ideas</p> <ol style="list-style-type: none"> 1. Set the expectation for the staff upon hire and during on-boarding that transplant referral is a priority for all patients unless contraindicated. 2. Give each staff member a defined role in the referral process, such as the PCT being responsible for drawing the blood sent to the transplant centers every month. 3. Ensure the staff who receive incoming transplant information (e.g., administrative assistant) know which staff need to be contacted for transplant-related issues. Make this individual a part of the transplant support team for tracking letters, faxes, blood draws, and follow-up activities. 4. Incorporate transplant referrals into weekly staff meetings or emphasize and track referrals during QAPI meetings to include a review of who has not been referred and who has been removed from a waitlist. 5. Keep staff informed of patient goals related to transplant, e.g., through IDT rounds and weekly meetings. 6. Maintain and enhance communication among staff. <ol style="list-style-type: none"> a. Use daily huddles to discuss patient updates. b. Co-locate staff in close proximity to facilitate the exchange of information on a real-time basis. c. Maintain continuous team and physician communication through daily discussions, email, phone, and documentation. 7. Provide a channel of communication for the frontline staff, encouraging them to give feedback and provide recommendations. 8. As a shared success, celebrate patients who receive an offer for a transplant or who have had a transplant. 9. Dedicate an area on a bulletin board to display a star for each patient who receives a transplant each year. 10. Build and maintain staff morale through open communication, addressing issues quickly, fostering trust, and valuing all dialysis disciplines. 11. Provide staff with the flexibility to solve issues and take action.



Table 6. Engage Patients in the Transplant Referral Process

PRIMARY DRIVER #1: CREATE A PRO-TRANSPLANT CULTURE
<p>Secondary Driver #1e: Engage patients in the transplant referral process</p>
<p>Engaging patients in their own care enhances their understanding of the transplant process and provides them with opportunities to share their questions and concerns about transplants. Patients can then make fully informed decisions about whether or not they want a transplant.</p> <p>Change Ideas</p> <ol style="list-style-type: none"> 1. Work with nephrologists to refer patients to transplant centers before patients start dialysis. 2. Refer all eligible patients for transplant evaluation within the first 90 days of starting dialysis. 3. Create a facility culture that encourages trust between patients and staff. <ol style="list-style-type: none"> a. Treat patients as whole individuals from the minute they walk in the facility door. b. Connect patients with staff members with whom they relate, e.g., speak their language or share their culture. c. Provide empathetic care to patients; treat them as a family member would be treated. d. Foster a trusting environment through open communication with patients. e. Meet patients where they are. 4. Support patients who have not had a positive experience navigating the healthcare system. Listen. Empathize. Reinforce education. Be willing to answer questions with as much detail as patients need to feel comfortable. 5. Introduce transplant during the first meeting with the social worker or facility staff; then, follow up timely (e.g., in a week or at 30- and 90-day assessments, depending on the patient’s readiness to discuss transplant) and regularly during clinic visits. <ol style="list-style-type: none"> a. During initiation of dialysis, approach the patient with the message, “Dialysis is used as a bridge to transplant.” Emphasize the temporary nature of dialysis by including the message monthly. b. Determine the patient’s readiness to discuss transplantation and his/her knowledge base. c. Discuss the patient’s family support, transplant options, living donors, transplant centers, and requirements. 6. Ask the medical director to discuss high Kidney Donor Profile Index (KDPI) kidney transplants. 7. Recognize that building rapport takes time. Demonstrate to patients that they are important by knowing them as persons, e.g., knowing the name of the spouse. Touch base frequently. 8. “Don’t let ‘no’ be a ‘no.’” Follow up with patients who initially decline to be referred for a transplant (e.g., in six months) to provide re-education. 9. Explore the real “why” patients are not interested in transplant by establishing relationships, building trust, and using open dialogue, which can lead to identification of issues (e.g., unable to pay rent) that patients might need help resolving to pursue transplant. 10. Discuss patient concerns or fears related to transplant, e.g., being too old. 11. Ask the medical director to encourage reluctant patients to continue with the referral meeting, learn more about the process, and then reconsider their interest in receiving a kidney transplant. 12. Involve the family and support system in education.



PRIMARY DRIVER #1: CREATE A PRO-TRANSPLANT CULTURE

Secondary Driver #1e: Engage patients in the transplant referral process

13. Encourage patients to attend kidney symposiums to hear speakers on transplant or a patient education session on transplant. Ask patients to bring a friend or family member.
14. Find out reasons patients could be motivated to get a transplant (e.g., family, travel, lifestyle) and incorporate the motivators into discussions. Ask patients “what matters most?” (e.g., 50 years of marriage, grandchildren) to determine motivation and goals and frame the benefits of transplantation. Focus on improved quality of life after transplant.
15. Incorporate transplant information into other modality education, e.g., discuss transplant during home dialysis training.
16. Re-visit transplant when patients are better able to receive the information, e.g., after uremia is resolved.
17. Discuss transplant during yearly psychosocial evaluations, if patients have indicated they do not want a transplant.
18. Share an educational video with in-center patients on transplant, including deceased and living donor options and living donor champions.
19. Let patients know they can get the evaluation and make the final decision about the transplant later.
20. Share transplant successes of other patients. Invite patients with transplants to visit the facility and speak with patients.
21. Implement grassroots efforts to educate on and encourage transplantation for patients in underserved communities or who are impacted by social determinants of health, e.g., literacy, transportation, nutrition.
 - a. Engage cultural community leaders, healthcare professionals, and younger family members from underserved populations, e.g., Native American, Hmong.
 - b. Invite them to the dialysis facility, educate them on the process and benefits of transplantation, and ask for their support to overcome barriers.
22. Identify cultural barriers related to social acceptance of a transplant. Work with patients and families to overcome them.
23. Suggest patients obtain copies of their tests/reports, e.g., stress test or colonoscopy, for them to give to the transplant centers, if they are applying at multiple centers.*
24. Encourage patients to bring a notebook and start writing down questions prior to the transplant center appointment. Also, empower them to make sure all their questions get answered.*

* Added 2024



Table 7. Track Transplant Referrals and Progress

PRIMARY DRIVER #2: IMPLEMENT CONTINUOUS QUALITY IMPROVEMENT
Secondary Driver #2a: Track transplant referrals and progress
<p>Quality improvement cannot occur without measurement. Facilities that are successful in referring patients for transplant track transplant metrics as well as each patient’s progress with the referral process.</p> <p>Change Ideas</p> <ol style="list-style-type: none"> 1. Collect data on metrics, including the number of patients referred to transplant centers, the number of patients who are active, and the number of patients who have been removed from waitlists. Include these as elements of the QAPI plan. 2. Review metrics, e.g., waitlist percentage, during monthly QAPI meetings. Conduct root cause analyses for dips in percentages from month to month. 3. Access patient portals in hospital systems or through health information exchanges (HIEs) to check the patient’s transplant status and appointments as well as to access test results. 4. Use electronic tools or maintain a log, accessible to staff, to assign tasks for patient care activities, communicate, and track each patient’s waitlist/transplant status, including patients who are on hold, inactive, and newly listed. Review monthly. <ol style="list-style-type: none"> a. Document details in each patient’s electronic health record (EHR). Use the EHR to track the patient’s progress through the transplant referral process and to trigger follow-up activities by the social worker or transplant champion. b. Use dialysis-specific software or a webtool with reminders. c. As a supplement to the EHR, if needed, track patient information in an Excel spreadsheet. d. Use the facility health record to determine which patients are inactive. Determine the reason patients are inactive, e.g., medical delay due to needing cardiac clearance. 5. Use reminders in electronic tools to trigger follow-up conversations with patients. 6. Maintain transplant binders. Examples include: <ol style="list-style-type: none"> a. A transplant referral binder, tabbed by patient name, with all correspondence to and from the transplant centers, such as waitlist status and notices of upcoming appointments. b. A binder with information on all patients on active waitlists. c. A binder of information on patients who are not on waitlists, so the staff can re-visit later. 7. Create individual sheets to track all patient appointments and other visits throughout the referral and evaluation process. Maintain the tracking sheets as living documents in the patients’ medical records. 8. Ask physicians to include transplant status in their notes from weekly rounds. Remind physicians that Transplant Status and Plan is one of the components of the Monthly Comprehensive Plan. 9. Document transplantation in psychosocial evaluation and progress notes, including transplant status, monthly updates, tests needed, and questions to ask the patient at the next visit.



PRIMARY DRIVER #2: IMPLEMENT CONTINUOUS QUALITY IMPROVEMENT

Secondary Driver #2a: Track transplant referrals and progress

10. Conduct a review of each patient every week; track barriers, discuss actions taken and next steps. Institute a deep dive for patients with new issues (e.g., patient was inactivated on the waitlist) and create a plan of action, assign tasks and due dates, and follow up.
11. Obtain lists of patients on waitlists from transplant centers.
12. Refer to closest transplant center and if denied then create a widening circle of possible programs that meet the patients characteristics or needs, i.e., high BMI, or HIV.*
13. Review all reasons a patient is declined for transplant and (1) re-refer them to a transplant center with different criteria more suitable to the patient and/or (2) assist patient with changes needed to meet the specific criteria (e.g., BMI reduction through dietary changes, improved cardiac status through increasing dialysis sessions 4 times per week.) *
14. Refer patients to one transplant program at a time to avoid confusion and overwhelming the patient.*

*Added 2024



Table 8. Engage Physicians and Staff in the Review of Data/Development of Interventions

PRIMARY DRIVER #2: IMPLEMENT CONTINUOUS QUALITY IMPROVEMENT
Secondary Driver #2b: Engage physicians and staff in the review of data and the development of interventions
<p>Including physicians and staff in the review of data allows for robust root cause analyses, brings real-world perspectives to the development of interventions, and reinforces the philosophy that “We are all in this together.”</p> <p>Change Ideas</p> <ol style="list-style-type: none">1. Commit to quality improvement.2. Set a goal for improving the percentage of patients on waitlists with a specific time frame, e.g., monthly or quarterly.3. Incorporate transplant metrics and discussions into every monthly QAPI meeting.4. Include frontline staff in QAPI meetings, rotating different staff each month.5. Hold a brief huddle after each QAPI meeting to review highlights of the QAPI meeting with staff who did not attend.6. Determine the root causes if metrics were not met and develop interventions to improve performance.7. Include a review of transplant data weekly in staff meetings and monthly with nephrologists.8. Review the transplant log to identify barriers to maintaining waitlist status, such as missed appointments, monthly.9. Review reports from transplant centers to verify waitlist status monthly. Develop interventions, e.g., if the patient is inactivated due to weight gain, the dietitian would help the patient develop a weight loss plan.10. Identify interventions to facilitate patients being added back onto a waitlist, such as referring a patient dropped from one list for age to a different transplant center that accepts older patients.11. Ask the medical director to reach out to his/her network of contacts to resolve issues that affect multiple patients, which could result in new collaborations, e.g., a university program providing dental care for patients planning to get transplants.



Table 9. Review Transplant Information with Patients

PRIMARY DRIVER #2: IMPLEMENT CONTINUOUS QUALITY IMPROVEMENT
Secondary Driver #2c: Review transplant information with patients
<p>Sharing lab results and other data with patients deepens their engagement in their own care, reinforces the importance of continual vigilance to stay healthy and transplant-ready, and gives them the information they need to actively participate in maintaining active status on the waitlist.</p> <p>Change Ideas</p> <ol style="list-style-type: none"> 1. Review patient lab results each month, discuss how the results affect transplant suitability, and make adjustments as needed to ensure patients are transplant ready. 2. Share details from the transplant log monthly and discuss next steps to ensure patients clearly understand where they are in the process of evaluation and/or listing. 3. Review communications from the transplant center with patients, including pending diagnostic tests (e.g., colonoscopy) and appointments.

Table 10. Hold Informal Discussions with Each Patient at Every Patient Clinic Visit

PRIMARY DRIVER #3: CONTINUALLY FOLLOW UP ON TRANSPLANT STATUS
Secondary Driver #3a: Hold informal discussions about transplant with each patient at every patient clinic visit
<p>Weaving transplant discussions into care processes provides an efficient means for staff to obtain updates from patients on transplant status (e.g., waiting for Medicare coverage), answer questions (e.g., what should be done next?), and collaborate with patients on solutions to challenges they may be experiencing (e.g., delays in evaluation by the transplant center).</p> <p>Change Ideas</p> <ol style="list-style-type: none"> 1. Have a conversation with each patient about transplant and waitlist progress during all aspects of care, including physician rounds, patient care by nurses and PCTs, and meetings with social workers. <ol style="list-style-type: none"> a. Determine the frequency of the transplant discussion, e.g., a discussion will occur monthly with the physician. b. Use open-ended, conversational questions, such as, “Where are you with your transplant?” and “How’s the transplant evaluation going?” 2. Encourage patients to have the transplant evaluation early in the process, so they can be the best version of themselves. 3. Identify obstacles to maintaining waitlist status or completing a transplant evaluation. 4. Ask physicians to check with patients at each visit on where they are in the transplant process.



Table 11. Provide Patients with Knowledge, Tools, and Support

PRIMARY DRIVER #3: CONTINUALLY FOLLOW UP ON TRANSPLANT STATUS
<p>Secondary Driver #3b: Provide patients with knowledge, tools, and support to help them move the process forward</p>
<p>When patients know what to expect and what they can do related to the transplant process, whether completing referral forms or connecting with transplant center coordinators, they take a more active role. Actively engaged patients can speed up the referral and evaluation processes, identify challenges early, and maintain their waitlist status.</p> <p>Change Ideas</p> <ol style="list-style-type: none"> 1. Give patients transplant educational materials, beginning with the first visit. 2. Assess insurance status and advise patients to apply for Medicare, as applicable. 3. Refer patients to the financial coordinators at transplant centers to discuss insurance and out-of-pocket expenses. 4. Use the Scientific Registry of Transplant Recipients (SRTR) website to find the average wait time for kidney transplants for each transplant hospital and share with patients to help them with decision-making for both in-state and out-of-state transplant programs. 5. Elicit feedback from patients about their experiences with different transplant centers. Share the information with nephrologists and the IDT to potentially expand the recommended list of transplant centers for patient referrals. 6. Share information on the requirements of the referral process, so patients can prepare, e.g., line up transportation and schedule a dental exam or mammogram. Check with the ESRD Network to see if it has a patient guide to the referral process. 7. Give patients information about the transplant referral process as well as what will happen after transplant, so they have a realistic view of what to expect, e.g., list of tests that have to be completed prior to being on the waitlist and medications needed after transplant. 8. Explain why the screening tests are needed, e.g., dental exams to ensure there are no potential infections that may negatively impact transplantation. 9. Inform patients in writing when they have been referred to a transplant center. 10. Share an educational video with in-center patients on navigating the transplant process. 11. Share the transplant center contact information with patients. To avoid missed calls, help them to program the transplant center number into their phones, if needed. 12. Educate patients on the bloodwork needed by the transplant center, so patients can remind the dialysis facility staff to fill the appropriate tubes for the transplant team. 13. Encourage patients to contact their transplant coordinator regularly by phone, text, or application, if available. Help patients find out who the coordinator is. 14. Provide patients with a referral form that has a list of criteria for each transplant center. To avoid duplication of effort, contact the ESRD Network to determine if it has compiled a list of criteria by transplant center. 15. Support patients with the completion of paper-based and online referral forms and other patient responsibilities, e.g., bringing lab tubes to the clinic if the transplant facility mails them to the patient. 16. Encourage patients not to wait for the transplant team but to call and ask, “What do I need to do next?”



PRIMARY DRIVER #3: CONTINUALLY FOLLOW UP ON TRANSPLANT STATUS

Secondary Driver #3b: Provide patients with knowledge, tools, and support to help them move the process forward

17. Teach patients how to stay healthy (e.g., not smoking) to maintain active status on the waitlist.
18. Use analogies to connect with patients, e.g., “play the best odds” for “a transplant will improve your chances of survival” or “keep the car running” for “you have to stay healthy while waiting for a kidney.”
19. Refer patients to clinical and support services, so they can take an active part in removing modifiable barriers to transplant, e.g., working with a dietitian on weight loss or a social worker on getting treatment for mental health issues.
20. Have bilingual/multi-lingual staff members translate information.
21. Coordinate language translation services via telephone or tablet for patients that speak a language that cannot be supported by the staff.
 - a. Provide staff with a card with the contact number and the language type, so that patients can identify their language.
 - b. Use a cordless phone or tablet on the treatment floor to call the translation service.
 - c. Use a speakerphone if patients are in a private space, such as a conference room.
 - d. Use a visual translation service for patients who have hearing loss, so the patients and the sign language translators can see each other.
22. Involve families to help resolve language barriers, such as dialects or slang terms.
23. Facilitate patients listing with more than one transplant center:
 - a. Create a “book of transplant centers” that includes the requirements/criteria, patients referred, and patient status.
 - b. Share transplant center requirements with patients.
 - c. Provide the links to transplant centers’ websites and the SRTR website.
24. Reach out to inactive patients individually to find out the reason they are not on a waitlist and develop plan, e.g., for patients that need to lose weight, loop in the dietitian, refer for weight loss surgery, or refer to a transplant center that accepts patients with a higher BMI.*

*Added 2024



Table 12. Act as a Case Manager to Facilitate Progress

PRIMARY DRIVER #3: CONTINUALLY FOLLOW UP ON TRANSPLANT STATUS
Secondary Driver #3c: Act as a case manager to facilitate progress
<p>Staff at successful facilities take on a role resembling case manager to assist patients and caregivers in navigating the complicated transplant process.</p> <p>Change Ideas</p> <ol style="list-style-type: none">1. Collaborate with nephrologists to identify transplant centers that would best meet patients' needs (e.g., high body mass index [BMI], age, or specific type of insurance or request for a modified protocol) or that accept patients who do not qualify elsewhere, e.g., a patient with Sickle Cell Disease.2. Call the social worker (transplant champion) if patients indicate they have not been referred or evaluated and to help resolve barriers.3. Refer patients to clinical and support services, as needed, to address modifiable challenges, such as smoking.4. Determine why patients have been deferred or removed from a waitlist and identify possible solutions.5. Intervene on the patient's behalf to resolve barriers, e.g., "The transplant team won't call me back."6. Confirm patients have transportation to appointments and help solve transportation problems by exploring options, e.g., neighbors, church members, ride sharing, and government assistance programs.7. Extend problem-solving to include family when issues may impact the patient's comfort level with being on a waitlist or receiving a transplant, e.g., identify social services support for a family member who would be left alone during the transplant procedure.8. Work with transplant centers to set up virtual appointments. Assist patients in planning for the appointments (e.g., talking through how to set up their laptop).9. Serve as a "link or facilitator" between patients, primary care providers, and transplant centers to ensure any medical clearance appointments are scheduled.10. Remind patients about appointments (e.g., for colonoscopy). Provide support with scheduling appointments, if needed.11. Communicate information received from transplant centers, e.g., letters faxed or emailed to the dialysis clinic with transplant evaluation appointments scheduled for patients.12. Check with patients to see if they have received and read all letters mailed from the transplant center.13. Make every effort to accommodate patients' schedules, especially for those who are working, to ensure patients are able to complete the transplant evaluation process and go to all appointments, e.g., coordinate with the transplant center for appointments after normal business hours or adjust treatment schedules by moving patients to another shift or having patients dialyze at a local "sister" facility.14. Facilitate the completion of Family and Medical Leave Act (FMLA) forms to ensure patients get time off from work to complete the transplant evaluation and work-up.



Table 13. Maintain Communications with Transplant Centers

PRIMARY DRIVER #3: CONTINUALLY FOLLOW UP ON TRANSPLANT STATUS
Secondary Driver #3d: Maintain communications with transplant centers
<p>Open, continuous communication between dialysis facilities and transplant centers supports collaborative efforts to get patients onto waitlists.</p> <p>Change Ideas</p> <ol style="list-style-type: none">1. Establish relationships with transplant center coordinators and actively collaborate with them.<ol style="list-style-type: none">a. Call to introduce the staff and the facility.b. Exchange cell phone numbers and email addresses to expedite communication.c. Schedule quarterly transplant center staff visits to the dialysis facility.2. Contact transplant centers to determine requirements for lab tests.3. Utilize an electronic system to digitally send referral applications and clinical documents to transplant centers.4. Communicate patient updates via secure email and phone among IDT members and transplant coordinators to stay current on the status of patients.5. Request monthly reports from transplant centers to show where patients are in the transplant process and which tests are pending. Provide feedback on changes in patients' conditions, as requested, e.g., recent hospitalization, changes in weight/BMI.6. Schedule individual monthly calls between the dialysis facility and each transplant facility to review the status of each patient on the waitlist.<ol style="list-style-type: none">a. Reach out to the transplant center coordinator to explore holding monthly calls.b. Emphasize the advantages of the calls, e.g., resolving transplant center concerns, which will decrease the transplant coordinator's workload.c. Once established, review each patient on the transplant center's waitlist each month to identify patient barriers and transplant center concerns, e.g., low patient health literacy, lack of dental clearance, and inability to reach a patient.7. Share social worker and renal dietitian notes, as appropriate, with transplant centers to facilitate timely evaluation and prevent gaps in care.8. Collaborate with transplant centers to improve patient access (e.g., reduce travel time) and ease of evaluation, such as satellite clinics for transplant workups and drawing blood for lab tests at the dialysis facility or physician office.9. Intervene on the patient's behalf, e.g., have the patient put on hold instead of being removed from the waitlist and see what can be done to speed up the waitlist process.10. Make sure transplant centers have accurate patient phone numbers and other information when changes occur in patient contact information or after quarterly updates to patient demographics.11. Use a referral form to share information (e.g., lab results, medications, comorbidities, hospitalizations, social worker assessments) with transplant centers.12. Facilitate communication between transplant centers and patients when transplant centers cannot reach patients.13. Contact transplant centers directly upon receipt of denial letters or if updates have not been received in one to two months.



PRIMARY DRIVER #3: CONTINUALLY FOLLOW UP ON TRANSPLANT STATUS**Secondary Driver #3d: Maintain communications with transplant centers**

14. Engage the medical director to establish and maintain relationships with transplant centers and surgeons, negotiate for patients on exclusion criteria (e.g., BMI or marijuana use), and collaborate on solutions to psycho-social barriers.
15. Call the transplant center's medical director, if necessary, to resolve issues.
16. Update each transplant center's contact information every six months.
17. Facilitate sharing of laboratory and diagnostic test results among the transplant facilities where patients are listed.



Table 14. Provide Education Early and Regularly on Transplants/Transplant Process

PRIMARY DRIVER #4: EDUCATE AND SUPPORT PATIENTS
Secondary Driver #4a: Provide education early and regularly on transplants and the transplant process
<p>Patients who understand what a transplant is and what to expect during the referral process and after transplant will be able to make informed decisions about whether to have a transplant. They will also be better prepared to complete all of the requirements of the referral process.</p>
<p>Change Ideas</p> <ol style="list-style-type: none">1. Educate pre-dialysis patients about modalities, including transplant.2. Provide education to all patients on the transplant process, including listing with more than one transplant facility, within the first 90 days of starting dialysis.3. Give patients easy-to-read and easy-to-understand transplant educational materials, beginning with the first visit, e.g., transplant booklet from a provider.4. Conduct formal education sessions, e.g., Kidney Smart classes every month.5. Meet with patients individually to answer questions.6. Avoid using medical jargon.7. Be innovative to meet the learning needs of every patient, e.g., for patients with low reading levels, use a whiteboard to draw a picture of an abdominal cavity with the two kidneys and the transplanted kidney to explain where the new kidney would be placed.8. Encourage patients to ask questions until they understand the information that is being presented.9. Assess patients' understanding after education is provided. Use the teach-back method to ensure patients understand the information. Repeat education as needed.10. Spend additional time with patients who are reluctant to have a transplant to address misunderstandings about transplants and discuss the benefits, including improved quality of life and survival rates.11. Ask the medical director to provide one-on-one education to address apprehensions, e.g., uneasiness with the process.12. Incorporate education into discussions with patients, such as what will happen next in the transplant process and what they can expect after transplantation.13. Put up a bulletin board/education station in the lobby with transplant information to promote questions and interest.14. Use alerts in the EHR to let staff know when follow-up education is due.15. Provide additional formal education semi-annually.16. Share transplant center educational materials with patients.17. Obtain language services via phone or sign language interpreters via video translation services as needed to ensure patients and families understand what is being communicated.18. Tailor education and materials based on patients' needs related to culture, health literacy, language, and physical abilities, e.g., ability to see.



Table 15. Offer Support Throughout the Referral Process

PRIMARY DRIVER #4: EDUCATE AND SUPPORT PATIENTS
Secondary Driver #4b: Offer support throughout the referral process
<p>The transplant waitlist process can be overwhelming to patients and members of their support systems. Providing support helps patients stay on track, resolve barriers, and maintain active waitlist status.</p> <p>Change Ideas</p> <ol style="list-style-type: none">1. Use an IDT approach throughout the referral process, e.g., dietitian to advise patients on diet related to needed weight loss.2. Let patients know “We are your family”: Build trust every day. Show sincerity. Maintain open communications. Follow up with patients and follow through to show that a transplant is important.3. Communicate through team members with whom patients feel most connected, e.g., PCT or nurse or dietitian.4. Help patients to identify members of their support system not previously considered, e.g., neighbors, friends, and church members.5. Offer support to families or members of the support system.6. Give patients access to nurses, social workers, and dietitians by phone to help them stay medically stable and troubleshoot barriers.7. Partner with transplant centers to conduct pre-transplant patient support groups.8. Use a tool, such as a distress thermometer, to identify the patient’s level of anxiety and what is causing the stress.9. Provide patients with an emotionally safe environment to share concerns, so that staff members are aware of issues and can assist in resolving them.10. Communicate with and encourage patients throughout the transplant process, which can extend over years, to help them stay focused on the goal of transplant.11. Identify community and transplant center resources to address barriers, such as lack of access to dental care or lack of transportation.12. Engage professional networks for resources and support for patients with barriers to transplantation by calling colleagues, posting questions to nursing association listservs and social worker groups, and reaching out to ESRD Networks.



Table 16. Facilitate Patient-to-Patient Support

PRIMARY DRIVER #4: EDUCATE AND SUPPORT PATIENTS
Secondary Driver #4c: Facilitate patient-to-patient support
<p>Patients who have received a transplant serve as powerful and trusted advocates of transplants. They can allay other patients’ fears and answer questions. Patient representatives who are receiving dialysis can also offer peer support to other patients.</p> <p>Change Ideas</p> <ol style="list-style-type: none">1. Ask patients with transplants to act as mentors to encourage and empower others by inviting them to speak with patients or to join lobby days. “Hearing from someone who has walked in their shoes makes all the difference.”2. Share information about patient support groups and educational meetings that highlight transplantation topics and testimonies about patient success.3. Engage patients who are receiving dialysis to act as facility patient representatives to educate other patients about transplants and provide peer support.4. Provide patients with dialysis organizations’ phone apps that help them find support calls with other patients.5. Hold virtual coffee breaks with patients on the waitlist and their families and caregivers.6. Identify a patient advocate on each shift to provide peer-to-peer support on transplantation and share educational materials.7. Coordinate community meetings, where a panel of patients can share their stories and successes with other patients. Invite radiologists, vascular surgeons, and transplant surgeons and staff to answer questions and clear up misconceptions; facility staff to bring stories back to other patients; and transplant coordinators to talk with patients and schedule initial appointments for self-referrals.8. Celebrate patients receiving a transplant with a video chat while the patient is recovering and invite them back to the dialysis clinic to ring the “transplant bell” to honor the patient and the gift of life received.*

*Added 2024



Table 17. Educate Staff to Maintain Their Knowledge

PRIMARY DRIVER #5: PROVIDE STAFF EDUCATION
Secondary Driver #5: Educate staff to maintain their knowledge of transplants and the transplant process
<p>Staff who are knowledgeable about transplants will be able to answer patients' questions, promote transplants, and educate peers.</p> <p>Change Ideas</p> <ol style="list-style-type: none">1. Introduce education on modalities to all newly hired staff during initial training, including the basic principles of receiving a kidney transplant (referral, evaluation, and waitlisting processes as well as how patients stay active on the list).2. Provide cultural sensitivity training each year (annual company training), so that the staff meet the needs of each patient.3. Utilize the transplant champion (e.g., facility administrator) to educate staff.4. Hold brief huddles or on-the-spot conversations during teachable moments to convey information timely and efficiently.5. Conduct educational webinars and in-services regularly with staff.6. Share literature with staff about new technologies.7. Provide resources that address religious differences, e.g., how staff should address patients who for religious reasons may be hesitant to “accept other people’s body parts as their own.”8. Invite patients who have received a transplant to speak with staff about their experiences.9. Collaborate with transplant centers on education.<ol style="list-style-type: none">a. Invite transplant centers to conduct in-services with facility staff or hold lobby days where facility staff can interact with transplant center staff.b. Have staff join the patient on the first work-up day at the transplant center.10. Encourage professional certification, e.g., Certified Hemodialysis Technician (CHT) and Certified Nephrology Nurse (CNN).11. Have staff attend conferences (e.g., American Nephrology Nurses Association [ANNA]) and share information with colleagues.12. Implement a transplant Question & Answer system for staff within the facility, corporation, or region to support colleagues and provide help from peers, e.g., asking questions, such as, “How do I complete the transplant assessment?” or “How many transplant referrals can be made for each patient?”13. Train staff to recognize learning deficits and share concerns with the social worker and staff, so training needs can be met, e.g., a PCT may recognize that a patient cannot read very well and can ask staff to use verbal instruction and low literacy materials.14. Implement scenario-based education for facility staff to learn about social risk drivers, how it impacts care, and how to interact with and support patients (e.g., patient with food insecurity bringing affordable fast-food meals to treatment are supported with referrals to food banks for healthier, kidney-friendly foods).*

*Added 2024



V. Conclusion and Next Steps

Increasing kidney transplantation is a national priority. Dialysis facilities play a central role in helping more patients with ESRD understand their treatment options with a hope of a higher quality of life. A concerted effort is needed among all kidney care stakeholders to meet the bold goals set by the HHS Advancing American Kidney Health Initiative.³ The ideas presented in this change package are being implemented in high-performing dialysis facilities across the United States. These ideas can be tailored and adapted to fit the needs of dialysis facilities and the patients with ESRD that they serve across the country.

As with any change, a best practice is to start small and build improvement toward systemic change. Facilities can start with one test of change and do it well. This will relieve the burden on staff and encourage buy-in when change begins. Measuring and monitoring performance improvement will ensure the facility stays on track with goals. Celebrating every success with staff, patients, families, and community partners at every change will be contagious. Above all, the best time to start performance improvement is now. With this change package in hand, program leaders, administrators, and staff should ask themselves, “What can I do by next Tuesday to get this started?”

VI. References

1. Institute for Healthcare Improvement. *QI Essential Toolkit* [ebook]. 2017; pp. 7–8. Available at: http://www.ihl.org/resources/Pages/Tools/Quality-Improvement-Essentials-Toolkit.aspx?utm_campaign=QI-Toolkit-Promotion&utm_medium=Whiteboard-Video&utm_source=ihl. Accessed February 5, 2020.
2. Institute for Healthcare Improvement. *QI Essential Toolkit* [ebook]. 2017; pp. 7–8. Available at: http://www.ihl.org/resources/Pages/Tools/Quality-Improvement-Essentials-Toolkit.aspx?utm_campaign=QI-Toolkit-Promotion&utm_medium=Whiteboard-Video&utm_source=ihl. Accessed February 5, 2020.
3. U.S. Department of Health and Human Services. Advancing American Kidney Health. Available at: <https://aspe.hhs.gov/system/files/pdf/262046/AdvancingAmericanKidneyHealth.pdf>.

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