

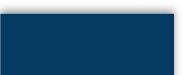
## Role of the Transplant Designee

**UPenn Kidney Transplant Symposium** 

Virna de la Cruz BSN, RN, CNN







# Agenda

- CMS and ESRD Network
- CMS regulations for dialysis facility transplant-related responsibilities
- Role of the dialysis facility (transplant designee in New Jersey)
- Transplant Quality Improvement Activity (QIA)
- "What Matters to You" Concept
- Culturally and Linguistically Appropriate Services (CLAS)



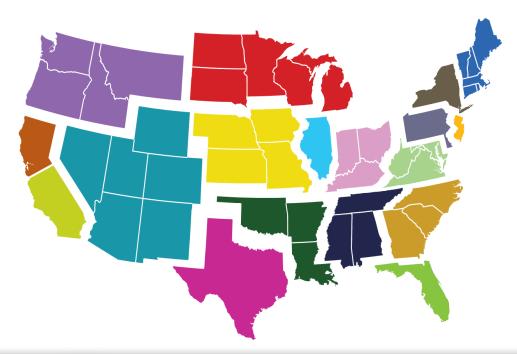
# **ESRD Network Program**

- Contracted with CMS to support national quality improvement goals
- Dedicated to assisting dialysis facilities and kidney transplant centers in their efforts to provide quality care for patients with ESRD.

Source: <a href="https://www.cms.gov/Medicare/End-Stage-Renal-Disease/ESRDNetworkOrganizations">https://www.cms.gov/Medicare/End-Stage-Renal-Disease/ESRDNetworkOrganizations</a>



# **ESRD Network Map**



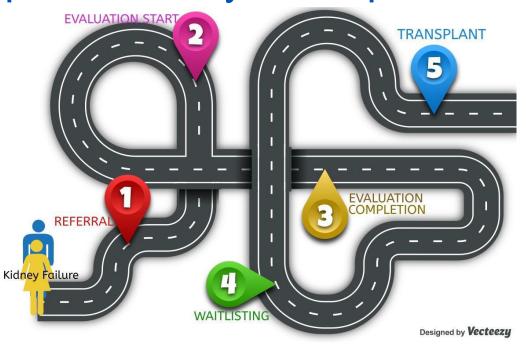
# 18 Network organizations designated geographically by CMS



Network 3 — NJ, PR and USVI Network 4 — PA and DE



# The Steps to Kidney Transplantation



Source: ESRD Forum Kidney Transplant Toolkit



## CMS Regulations on Transplantation

Part 494 Conditions for Coverage for ESRD Facilities



## Federal Regulations V458 and V562

The patient has the right to-

- Be informed about all treatment modalities and settings, including but not limited to, <u>transplantation</u>...
- d) Standard: Patient education and training. ...in home dialysis and self-care, quality of life, rehabilitation, <u>transplantation</u>, and the benefits and risks of various vascular access types



## Federal Regulations V513 (10)

- Evaluation of suitability for a transplantation referral, based on criteria developed by the prospective transplantation center and its surgeon(s).
- If the patient is not suitable for transplantation referral, the basis for nonreferral must be documented in the patient's medical record.



## **Federal Regulations V554**

- Transplantation status. When the patient is a transplant referral candidate, the interdisciplinary team must develop plans for pursuing transplantation. The patient's plan of care must include documentation of the:
  - A. Plan for transplantation
  - B. Patient's decision
  - C. Reason(s) for the patient's nonreferral as a transplantation candidate



## Federal Regulations V561 (c)

Standard: Transplantation referral tracking. The interdisciplinary team must—

- 1) Track the results of each kidney transplant center referral
- 2) Monitor the status of any facility patients who are on the transplant wait list;
- 3) Communicate with the transplant center regarding patient transplant status at least annually, and when there is a change in transplant candidate status



# The Road to Kidney Transplantation



Source: ESRD Forum Kidney Transplant Toolkit



# New Jersey (NJ) State Specific Regulation

- New Jersey State: N.J.A.C. Title 8, Chapter 43A, Standards for Licensure of Ambulatory Care Facilities
  - 8:43A-24.13 Patient care plan, (b) Within one calendar month of initiation of dialysis treatment at the facility, a written plan of care shall be developed for each ambulatory dialysis patient by a multidisciplinary team consisting of at least, a nephrologist, a transplant surgeon or designee, a registered professional nurse, a registered dietitian, and a licensed social worker. The plan of care shall specify observable and measurable goals and expected patient outcomes. The multidisciplinary team shall analyze patient outcomes on a regular basis to assess the patient's progress and evaluate current and future treatment modalities and modify the plan as necessary.



# Transplant Designee Role and Responsibilities Document



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### Transplant Designee Role and Responsibilities

Objective: To assure the evaluation for medical suitability of all patients for transplant referral at the initiation of treatment for ESRD and at least annually thereafter. There are no strict criteria for referral, but most patients with stage 4-5 CKD are appropriate for referral.

### Recommendations for Dialysis Facilities

- · Review the following role and responsibilities of the transplant designee.
- Facilities shall have policies to ensure that staff functioning as the transplant designee is
  appropriately educated to function in the role.
- Appropriate education would be obtained from a transplant focused educational program.
   See Network 3 guidelines for transplant designee programs.

#### Role of Designee

- Educates dialysis patients regarding transplant options within 28 days of initiation of chronic dialysis and at minimum annually
- Reviews and documents patient suitability for referral to a transplant program in the interdisciplinary care plan
- · Facilitates patient referrals for transplant evaluation
- Serves as a liaison between patients and transplant centers from referral through transplant wait-listing.

### Recommendations for Professional Staff Acting as Transplant Designee

- Licensed registered nurse and licensed social worker.
- · Immediate dialysis experience of at least one year in direct clinical ESRD practice
- Satisfactory completion of an annual educational program for transplant designees is recommended.

### Responsibilities

- Determine each newly diagnosed CKD Stage 5 (or ESRD) patient's <u>interest</u> for transplant.
- Examine each newly diagnosed patient record for transplant suitability according to written criteria provided by transplant center and document review in patient's medical record
- If medical record does not contain requisite information on which to base evaluation, additional information should be obtained from the patient's other health care providers.
- Documentation should state whether patient is or is not a candidate for transplant referral, reasons for determination and if patient accepts or refuses the referral



# Practical Guidance for Transplant Designee

## **Practical Guidance for Transplant Designee**



#### Patient Related Tasks

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- Educate dialysis patients regarding transplant options within 30 days or 13 treatments from admission and annually at a minimum.<sup>1</sup>
- Identify patients' interest for transplant.
- Provide a list of transplant centers for patients to choose from. Keep in mind that centers' criteria may vary. Patients not a candidate at one place may be a candidate for another.
- Refer patients to their chosen transplant center by:
  - Provide the patient the center's contact information.
  - Assist patient with the transplant center referral process:
- Provide pre-transplant education and assist with transplant evaluation requirements, such as, forms and records requests.
- Remind patients of their transplant visit appointments.
- Track and document patients' transplant status.
- Ensure that monthly blood specimen for transplant waitlisted patient is obtained, labeled and sent out per transplant center specifications by staff.
- Establish and maintain working relationship with transplant centers.
  - Obtain waitlisting status of patients routinely.
- Remind patients to update the dialysis unit and the transplant center of any change in patient information.
- Communicate to the transplant center any update in patient information such as:
  - Change in address
  - Change in phone contact number
  - Change in alternate contact person
  - Change in insurance coverage or loss of insurance coverage
  - Changes in medical condition, dialysis modality or death
  - If deemed not a candidate at a center due to medical/compliance issue and that issue is resolved, may re-refer for reconsideration.
  - Transfer into or out of the dialvsis facility
  - Issues with compliance that could impact post-transplant care.

### Facility Related Tasks

- Participate and discuss transplant in patient's plan of care meetings<sup>2</sup>.
- Discuss the patients' transplant status in QAPI.
- Communicate to the transplant center any change in facility transplant designee/s contact.



## Transplant Designee - Network 4 (PA and DE)

- No state regulation
- Anyone in the facility can be assigned to this role.
  - Transplant champion, point person, designee and etc.



## Transplant Quality Improvement Activity (QIA)

- Improve Education and Access to Empower Patient Choice of Transplant
  - Nationwide effort to improve kidney care
  - In 2019, the U.S. Department of Health and Human Services launched the Advancing American Kidney Health Initiative (AAKH)
  - AAKH has goal of 80% of new patients in 2025 begin dialysis at home or receive a pre-emptive kidney transplant





## Goal (1)

 Increase the number of patients <u>added to a</u> kidney transplant waiting list

## Facility activities that can influence achievement of this goal:

- Educate and identify patients
- Refer interested patients to transplant center
- Facilitate evaluation
- Assist in addressing barriers
- Track referrals
- Communicate with transplant center/s



## Goal (2)



 Increase in the number of patients <u>receiving</u> <u>a kidney transplant</u>

## Facility activities that can influence achievement of this goal:

- Keep actively waitlisted patients healthy
- Obtain monthly required bloodwork, label and ship timely
- Ensure patient contact information updated
- Ensure transfer of any transplant information with new patients, if any
- Identify reasons for inactivation and help address modifiable barriers
- Educate on High Kidney Donor Profile Index (KDPI) kidneys
- Promote living donation
- Communicate with transplant center/s



# **New Feature**: End Stage Renal Disease (ESRD) Quality Reporting System (EQRS) Transplant Dashboard for Dialysis Facilities

Figure 1: Transplant Waitlist Dashboard for Dialysis Facilities

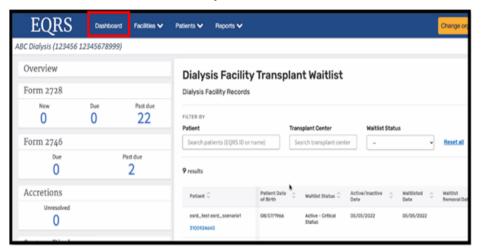
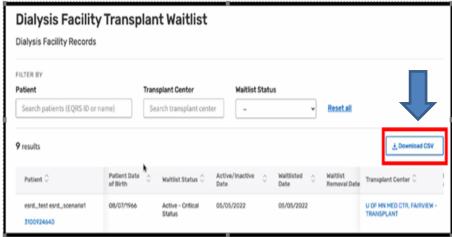


Figure 2: Download CSV Button





# Putting "What Matters to You?" Into Practice to Improve Patient Experience and Equity

- Asking patients "What matters to you?" (WMTY) was pioneered by Dr.
   <u>Michael Barry and Susan Edgman-Levitan</u>\* to flip the traditional "What's the matter with you?" focus of many shared decision-making conversations to make them more patient-centered.
- Learning what matters to patients and what motivates them to make progress allows us to provide individualized and coordinated care.



<sup>\*</sup>N Engl J Med 2012; 366:780-781 DOI: 10.1056/NEJMp1109283

Source: What Matters To You <u>resources from around the world</u>, <u>goShadow</u>, the <u>Montefiore Hudson-Valley Collaborative</u>, and the Institute for Healthcare Improvement.



## Top Tips For a WMTY Conversation

Asking What Matters is for everyone. Build a culture that supports curiosity, person-centeredness, and action. Work across roles and teams to bring patients' requests to life.

Be vulnerable and approach the patient with curiosity and give it a go; ask even 1 patient "What matters to you right now?"

The expectation is not to fix anything. Most requests are achievable.

Ask questions that spark conversation. Use open-ended questions that make the patient feel safe to give feedback and ideas to solve pain points.

Be present and authentic by actively listening and practicing empathy. Ask question(s) with patients and let them guide the conversation. Patients recognize authenticity when reflecting on their experience.

Show that you are listening; Make an action plan. Incorporate your patients' feedback into their plan of care. If you are unable to act on the request, explain why.

Close the loop. Share with the patient the action that you and the team are taking. Demonstrate that they are part of the decision-making team and when to expect action.

Learn and iterate. Reflect with the care team to learn if knowing What Matters changed the way that they delivered care. Are there common themes that patients report matter most? How might we anticipate patient needs and address them before?

Propriation takes from:



# Strategies to Improve to Patient Education for ESRD Patients Pursuing Kidney Transplant

- Tailor education for individual patients
- Make education understandable for patients
- Provide culturally competent education
- Help patients navigate the healthcare process

Source: Skelton SL, Waterman AD, Davis LA, Peipert JD, Fish AF. Applying best practices to designing patient education for patients with end-stage renal disease pursuing kidney transplant. Prog Transplant. 2015 Mar;25(1):77-84. doi: 10.7182/pit2015415. PMID: 25758805; PMCID: PMC4489708.



## https://www.qualityinsights.org/qirn3/ongoing-projects/transplant-qia

### **Encuesta de Trasplante para Pacientes**



Esta encuesta identificara sus conocimientos, preocupaciones, pensamientos, y comprensión sobre la

## **Transplant Patient Survey**



lante de riñón.

We would like to know your beliefs, concerns,	thoughts and understanding about kidney
transplantation. Please answer every	question as it applies to you best.

Na	ame	
1.	Write three words that first come to your mind when you think of getting a kidney transplant.	
2.	Has your kidney doctor talked to you about kidney transplant?	ante de riñón?
	□ Yes □ No	
3.	Do you believe that kidney transplant is safe?  Yes No, why?	nédica?
4.	What do you believe is the age limit to be considered as a kidney transplant candidate?	en diálisis?
Do you believe that you are not a candidate for transplant due to an illness? Pes, what is that condition or illness?  No		en dialisis:
	3 10	nación en vida)?
6.	Do you believe that life is more complicated after kidney transplant than life on dialysis?	
	□ Yes, why?	un riñón.
7.	Would you be willing to ask family and/or friends to donate a kidney (a living donor) for you?	lonación en vida.
	☐ Yes ☐ No, why? Please choose from the choices below.	
	<ul> <li>I do not think my family or friends will donate for me.</li> <li>I would not want to put their health at risk.</li> </ul>	ecibir la información?

I probably would not be able to find a match for living donor.

8. If you are interested to learn about kidney transplant, how would you like to receive information?

o Group discussion (i.e. transplant center staff, peer mentors, with care partners)

o Printed materials such as brochures, handouts

 With a transplanted patient With a dialysis center staff

Video or online resources

Individual or one on one discussion

Network 3



## THINGS TO CONSIDER WHEN CHOOSING A TRANSPLANT CENTER





#### INSURANCE

Many insurance companies offer coverage for transplant costs. But, terms and benefits of different insurance policies can vary widely. Your insurance company may tell you to go to a specific transplant center.



#### LOCATION. TIME AND ACCESS

The distance and time it takes you to get to the transplant center is important. You will be traveling to the center when you are undergoing evaluation, waiting for a kidney, receiving a transplant and following up after your transplant. Ask if housing is available near the transplant center. Some transplant centers are in large cities where parking can be expensive. Find out if free or discounted parking is available.



#### **COMPARING PROGRAMS**

The best transplant center for you will depend on your situation. The Scientific Registry of Transplant Recipients (SRTR) can provide you with information to help make an informed decision. Visit www.srtr.org to learn about the average wait time and survival rates for each transplant center.



#### LIVING DONOR TRANSPLANT

Ask the transplant center about living donor transplant. If you have a living donor, the center needs to be the right place for both you and for your donor.



#### LANGUAGE ACCOMMODATIONS

If you do not speak English, find out if your transplant center can provide someone to translate for you. You should always feel understood and informed throughout your treatment.



#### POST-TRANSPLANT CARE

Ask your transplant center about the short-term care available immediately after your transplant. After you get released and your local doctor takes over your care, ask how your doctor will continue to communicate with the transplant center.

Don't be afraid to ask questions. The more you know, the better your experience will be. Bring a family member or another person to support you. They may ask questions you did not think to ask. Remember - it is your choice whether or not to have a transplant and which transplant center is right for you.



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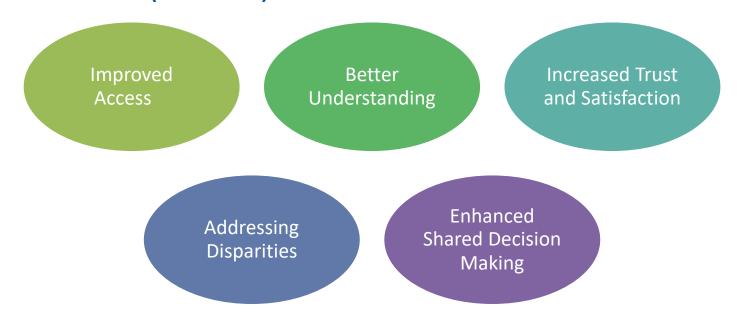
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# What is Culturally and Linguistically Appropriate Services (CLAS)?

- is a way to improve the quality of services provided to all individuals
- is about respect and responsiveness
- is one strategy to help bring about positive health outcomes for diverse populations



# Why Culturally and Linguistically Appropriate Services (CLAS)?







## Do you have CLAS?

Delivering culturally and linguistically appropriate services (CLAS) is as important to patients' mortality, morbidity, and quality of life as clinical interventions and treatments. Learn more by watching the two video-based microlearns below. Each video is less than 6 minutes and has Spanish subtitles available.



Using Culturally and Linguistically Appropriate Services to Improve Delivery of Care



What are Culturally and Linguistically Appropriate Services?

To access Quality Insights CLAS videos, visit: <a href="https://www.qualityinsights.org/qirn3/health-equity/training-and-education">https://www.qualityinsights.org/qirn3/health-equity/training-and-education</a> or contact your Network representative.

To learn more about CLAS, visit: <a href="https://thinkculturalhealth.hhs.gov/clas/what-is-clas">https://thinkculturalhealth.hhs.gov/clas/what-is-clas</a>



## Transplant Network Contacts

- QIRN3 (NJ, PR, USVI)
  - https://www.qirn3.org/Ongoing-Projects/Improving-Transplant-Listing-QIA.aspx
  - Virna de la Cruz vdelacruz@qualityinsights.org
- QIRN4 (PA, DE)
  - https://www.qirn4.org/Ongoing-Projects/Improving-Transplant-Waitlists-QIA.aspx
  - Kou Kha Moua kkhamoua@qualityinsights.org



# Thank you!

