



Service to those affected by chronic kidney disease

Lori Hartwell
Founder/President

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Wendy Rodgers, M.Ed, MPH
Chairman of the Board

To: The Honorable Xavier Becerra
Director of Department of Health and Human Services

Lana Kacherova, RN
Treasurer

To: The Honorable Chiquita Brooks-LaSure
Administrator Department of Health and Human Services

Joanna Galeas Lee
Secretary

Re: CMS–5535–P: Alternative Payment Model Updates and the Increasing Organ Transplant Access (IOTA) Model

Dear Secretary Becerra and Administrator Brooks-LaSure,

Board Members:

Lubna Akbany, RD
Kathleen Baldwin, PhD
Kristen Cisneros, RN
Marlene De Vera, RN
Joanna Galeas Lee
Lori Hartwell
Dean Hartwell, JD
Jill Heydorff
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Wendy Rodgers, M.Ed, MPH
David Trujillo
Rafael Villicana, MD
Susan Vogel, MHA, RN,
CNN

Renal Support Network (RSN) empowers people who have kidney disease to become proactive in their care, and to work with healthcare professionals and all stakeholders to get the best care and health outcomes possible. I have been dealing with kidney disease since age two (1968), and spent 13 years on dialysis, with ten years on successful home dialysis, both hemodialysis and peritoneal dialysis and currently have a successful kidney transplant. I founded RSN in 1993 to provide hope to my peers and advocate for the best care. RSN reaches hundreds of thousands of people who have kidney disease and their families through our many patient engagement, education and peer support programs.

On behalf of Renal Support Network, I would like to express our gratitude for reading our comments and develop and implement of a policy that can improve the care for people who have kidney failure and need a lifesaving transplant.

People who need a transplant encounter many barriers and we have learned a lot over the years through our own experiences and from the patient audience we serve.

We commend CMS for recognizing the barriers that people with kidney failure encounter when trying to access a life-saving kidney transplant. Equitable access to a kidney transplant is important to secure the trust of the public and be fair to those in need.

Equitable Access

There are several factors that hinder fair access to kidney transplants, including socioeconomic barriers, disparities in healthcare access, and systemic biases within the healthcare system.

One of the main obstacles to fair access to kidney transplants is the socioeconomic disparities among people who are seeking a transplant. This is often due to financial constraints, such as lack of insurance coverage, lack of caregiver to help post-transplant, transportation or lack of

An illness is too demanding when you don't have hope!
– Lori Hartwell, RSN Founder and President

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information etc. There has been more than one occasion that we have been told a story where the patient was inactive due to no one being able to transport them to and from their visits post op. We have heard some centers require two caregivers. We have also been told the patient can't afford the parking or the gas to get to the transplant center. We understand that it's important requirement from the transplants center. Sadly, this is one of the largest barriers. Additionally, people from disadvantaged backgrounds may encounter obstacles in accessing transplant centers or receiving proper pre- and post-transplant care.

ASK: This area needs to be explored on ways to meet this barrier. Lack of financial and caregiver support are the biggest barriers. Satellite clinics and initial visits via telemedicine to go over the steps needed to start the process will help people have more access. Innovative resources should be rewarded to meet this need.

Status of Patient on the Waitlist

There is a great need to improve communication with people who have been approved for the transplant list. It is crucial that those on the transplant list are promptly notified on their status through modern technologies such as text messaging or other current communication platforms. This would ensure that patients receive timely updates and relevant information regarding their status and potential transplant opportunities. We were surprised to learn that over 40 percent of people on the kidney transplant list are **inactive**. We have not found a study that explains the cause of this large percentage of people who are inactive. Is the patient too sick, needs a test/visit or the transplant hospital. Lack of insurance, lack of caregiver or transportation, non-adherent or they didn't receive the necessary blood work etc.? How long has a patient been inactive?

It is essential for patients to have access to this important information and adequate time to complete medical tests promptly to remain active on the list. Those who do not have a printer or cannot view the information on their phone should be able to easily request a hard copy by clicking a button and confirming their address.

This will help to keep all the necessary reports to emphasize their well-being are up to date from other medical providers. Additionally, regular updates can alleviate stress, uncertainty, and the feeling of being forgotten, offering reassurance that their needs are being acknowledged and prioritized.

ASK: Transplant Centers need to develop a standardized approach to communication, and this is an area where they should be rewarded. By establishing systematic communication channels, individuals on the waitlist have enough time to see the specialist and address any concerns, so patients are not left inactive while waiting for their specialist appointment.

Validate Existing Waitlisted Patients Contact Info and Improve Data Management

There is great concern regarding the validity of contact information for people on the current transplant platform. It has been stated that 20% of individuals could not be reached due to incorrect contact details. Steps should be taken to ensure the accuracy of data to reach patients. It is suggested that authentication measures be implemented to verify that patients are receiving the necessary communication, such as text messages or the modern forms of communication. This is a common practice, as most individuals have cellphones that can access their medical records portals. Incorrect data entry or clerical errors leads to loss of deceased lifesaving organs and loss of lives.

One of the goals is to provide patients on the transplant waitlists about the number of organs declined on their behalf. We are concerned about this because it could potentially hinder the patient-doctor relationship, as patients may not understand why an organ was declined and could create their own misconceptions. They

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may second guess the doctor's decision. It is crucial that the any data presented is meaningful and easily comprehensible to patients and families, but not so much information that it puts a barrier between the patient and transplant team.

ASK: Help support and drive technology that communicates effectively and validates contact information with the people who are waitlisted and is easy to navigate. Reconsider providing the number organs denied on a patient's behalf.

Patient Activation Measure

Patient activation measures, which refer to a person's level of knowledge, skills, and confidence in managing their own health and healthcare, can have both positive and negative effects on people seeking a kidney transplant. Benefits can include improved health outcomes, better adherence to treatment regimens, and enhanced communication with healthcare providers. However, potential drawbacks include feelings of anxiety and overwhelm, as well as barriers such as lack of resources, embarrassed to answer the questions truthfully. People who are seeking a transplant may have been newly diagnosed and not understanding all the questions listed. For instance, some of the problematic questions.

1. "Do you feel confident asking the questions the doctor's do not ask?"
2. "I am confident that I can tell whether I need to go to the doctor or whether I can take care of a health problem myself?"
3. "I know how to prevent problems with my health."

"These questions are extremely challenging for even the most experienced advocate and can impede health equity," a group of patients who have undergone the transplant process stated during a call. They also mentioned that patients may answer in a way they believe the provider wants in order to avoid being denied a transplant based on their responses. Healthcare providers should aim to support and empower their patients in their care, as surveys can sometimes introduce bias and act as a hindrance. We are concerned about this approach, especially considering it is being tested in a CMMI pilot program. Perhaps implementing motivational interviewing techniques or finding ways to help patients better understand the purpose of the survey could be beneficial. Patients may feel stigmatized or marginalized when asked to complete the PAM survey, perceiving it as a judgment on their intelligence or abilities, potentially leading to feelings of shame or inadequacy.

ASK: A comprehensive evaluation of this measure is necessary to determine its effectiveness in helping people diagnosed with kidney failure, particularly those who may struggle to comprehend the various acronyms and complexities associated with the kidney failure. We are uncertain of its validity in improving outcomes for all patients and are concerned that it could perpetuate healthcare disparities and bias by allowing those who are able to provide the answers they want and not address any obstacles the patient may face simply because they checked off the wrong box. While the concept of a Patient Activation Measure is a useful tool for assessing a patient's knowledge, skills, and confidence in managing their health, it is important to consider the unintended consequences when using the PAM in patients, so they are free from bias and promotes collaboration and empowerment rather than stigmatization.

Incentives

We support transplant centers to be incentivized to meet transplant goals and to recognize that people who have social economic challenges may require more time. We support surveys if they are meaningful and help improve patient care and experience. Surveys should never take the place of getting to know the patient.

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Patients suffer from survey fatigue and the reality is patients need more facetime with their healthcare team. That is what should be the goal. We ask that you recognize “time” is so precious with our healthcare provider and they need resources to allow the time to facilitate the needed discussion.

In addition, a novel idea is recognizing the patients who do put the effort in to partner and manage their own care? Perhaps they could receive a discount on their premiums?

Finally, we believe that this program should be optional rather than mandatory because we are unsure if the target volumes are realistic. We are concerned that making the program mandatory could backfire on patients, potentially causing transplant centers to become more selective in choosing who is eligible for a transplant. This could have the opposite effect of what was intended and lead to greater health inequity.

Thank you for considering our suggestions. We believe that by incorporating these changes, we can significantly enhance the transplantation process and ultimately improve patient outcomes and let them live the life they were meant to live.

Please let me know if you have any questions or need additional information.

Warmest Regards,



Lori Hartwell,
President & Founder