Renal Support Network
RSNhope.org

Over 30 years of service to people who have chronic kidney disease.

December 19, 2025
To: Partnership for Quality Measure
Battelle
901 D Street SW
Suite 900
Washington, DC, 20024
Via: MMSsupport@battelle.org

Re: MUC2025-011: End-Stage Renal Disease Quality Incentive Program, Dialysis Facility Discussion of Patient Life Goals, Person-Centered Care

I am writing as the Founder and President of the Renal Support Network (RSN). RSN empowers People who have kidney disease to take an active role in their care and collaborate with healthcare professionals and other stakeholders to receive the best possible treatment and access to care. Through my personal journey with kidney disease, I have (all treatments) experienced firsthand the challenges and triumphs that come with managing this condition. I have worked with patients from coast to coast for over 30 years and know how patients react to a diagnosis.

RSN advocates for patient-reported outcome measures that are meaningful and effective in enhancing the experience of people who are undergoing dialysis. However, we fail to see how the "Life Goals" measure accomplishes this objective. To pursue life goals, one must first be feel good enough and for some goals possess financial, emotional and housing stability.

We perceive the proposed life goal measure as potentially harmful for people on dialysis. It brings back memories of life-and-death committees from the 60s, where individuals were chosen based on their perceived value to society. The connection can easily be made that someone without life goals may not be deemed valuable.

Those without life goals are likely experiencing poor health or depression. It's hard to make choices when you're in this state of mind. It's well documented that living with a serious chronic illness can lead to anxiety and depression.

The survey asks patients to share their life goals with a member of their dialysis team by checking off boxes representing various goals such as being able to work, spending time with loved ones, pursuing education or independence, watching children/grandchildren grow up, taking care of family responsibilities, engaging in hobbies/activities, feeling like a regular person rather than someone on dialysis, traveling, or specifying other personal goals. The response "feeling like a regular person rather than someone on dialysis" is particularly bothersome and many of our members were uncomfortable with that response.

We reached out to our members who shared additional responses beyond what was included in the survey options:

- Being able to pay bills
- Not burdening family
- Owning a reliable car
- Finding a partner/spouse
- Having safe housing
- Avoiding reliance on public transportation
- Receiving a transplant
- Alleviating depression
- Moving out of parents' home
- Owning a pet

We are deeply concerned about a survey that focuses on measuring the "perceived life goals" of people on dialysis. How will this information be used to improve their care? When will it be asked? What actions will the dialysis staff take based on these survey results? Will there be follow-up to assess if patients achieve their goals? We frequently receive calls and emails from people on dialysis who face major challenges regarding housing, food security, and transportation, seeking assistance. By asking these questions, the dialysis facility may inadvertently raise expectations for potential support, leading to strain in patient-professional relationships.

Additionally, we question what outcomes can be derived from this survey. If a patient has a positive goal, will their treatment be considered successful or changed? How does this survey contribute to improving overall care? Conversely, if someone has a negative goal, how will their treatment be modified?

We know that the goal of this measure is to help people realize their life goals and by knowing them by offer them home therapy options that align with their lifestyle. We agree with that goal of helping patient choose the right treatment for their lifestyle, but do not believe this is the right approach for the reasons mentioned.

Also, RSN remains uncertain about how this information will truly enhance patient care. It is important to consider that patients often experience survey fatigue when they do not receive any feedback.

The primary responsibility of a dialysis facility should be in ensuring a proper treatment. When patients receive a dialysis treatment and subsequently experience reduced fatigue and improved wellbeing, they can then begin contemplating personal life goals. We always hear that it is the patient's fault if a treatment did not go well. We do not think this is validated response and makes the patient feel more depressed. The few patients we know that provide input on their fluid removal or blood flow rate are told "NO: it's the doctor's orders.

As an alternative patient-reported outcome measure approach:

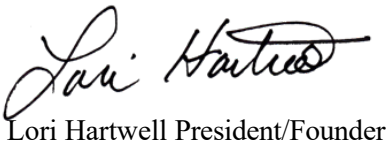
CMS should consider implementing a reporting measure that ensures each patient has a voice during every hemo dialysis treatment session. For instance, after each session, patients could answer a simple question regarding whether they felt (a) not at all bothered; (b) somewhat bothered; (c) moderately bothered; (d) very much bothered; or (e) extremely bothered during the treatment.

If patients indicate any level of botheration or discomfort through the initial question, a series of additional questions could be asked to identify specific difficulties they may have encountered during the treatment, such as access problems, low blood pressure, crashes, cramping, or other relevant indicators. These are problems that can be treated to by the team.

Collecting this information may assist healthcare providers in understanding why patients might not complete their entire treatment or miss sessions altogether. A brief and structured conversation with the patient can also provide valuable insights for physicians, dieticians and facility managers to assess whether the patient is tolerating the treatment well or if adjustments need to be made before a major issue arises. The survey results can also offer guidance on whether an alternative dialysis option would suit a patient better and provide real time information to get their treatment right.

In, conclusion this is a very dangerous measure and a waste of the healthcare professional time. RSN request this measure be permanently removed from consideration in the future and focus on a measure that can have an impact.

Sincerely,



Lori Hartwell President/Founder