



30 years of service to those affected by chronic kidney disease.

Lori Hartwell
Founder/President

June 22, 2023

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

The Honorable Chiquita Brooks-LaSure
Administrator of Centers for Medicare & Medicaid Services
7500 Security Boulevard, Baltimore, MD 21244

Lana Kacherova, RN
Treasurer

From: Lori Hartwell, Founder/President of Renal Support Network

Joanna Galeas Lee
Secretary

Re: CMS-3742-P: ESRD Dialysis Patient Life Goals Survey (PaLS)

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I am writing as the Founder and President of the Renal Support Network (RSN). 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 to live the life they were meant to live. I have been living with kidney disease since age two (1968) and spent 13 years on dialysis.

RSN supports patient reported outcomes measure that are meaningful and have the capacity to address and improve their dialysis treatment experience. We fail to see how “Life Goals” measure accomplishes this. To pursue life goals, one must feel well enough to do so and have the financial and emotional stability to do so.

We see the proposed life goal measure as dangerous to people on dialysis. The first thing that came to mind is the life and death committees in the 60s. People were chosen based on their value to society. One can easily make the connection to someone with no life goals to not being all that valuable. If a person has no life goals, they most likely don't feel well or are depressed. Living with any chronic illness can cause anxiety and depression.

The survey asks for the patient to tell one dialysis team members their life goal and the patient self-reports by filling out the survey with the following questions. Check off the box of all life goals you have.

- Being able to work
- Spending time with family and friends
- Going to school or college
- To have my independence
- Watching my children or grandchildren grow-up
- To take care of family

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

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- Spending time on hobbies and other activities
- To feel like a regular person, not a person on dialysis
- To travel
- Other _____

We asked some of our members and these are some additional answers that came up. Many were offended by the term “to feel like a regular person, not a person on dialysis.”

- Be able to pay my bills.
- Not to be a burden to my family.
- To be able to have a car that is dependable.
- To find a partner and get married.
- To have a secure place to live.
- Not have to take the bus.
- To get a transplant.
- To not be so depressed.
- Move out of my parent’s home.
- To have a dog.

We are very concerned about a survey that is constructed to measure the “perceived life goals” of people living on dialysis. How will this information be applied and utilized to improve their care? What does the dialysis staff do with this survey information? Will there be follow up to see if the patient reached their goal? We get so many calls/emails that people who are on dialysis have major housing, food insecurity and transportation issues and are seeking help. By the dialysis facility asking these questions it may appear to the patient they may be able to get assistance. This could cause stress on the patient/professional relationship.

Also, What will the results of the survey yield? If a person has a “positive” goal, will their treatment be deemed a success or changed? How will the survey improve their care? Conversely, if a person has a “negative” goal, how will their treatment be modified?

We heard that the goal of this measure was to help people realize their life goals and, in many instances, they will be offered a home therapy that will fit their lifestyle. Has this been verified as working? RSN is still unclear how this information will be used to improve care. In addition, patients suffer from survey fatigue. Especially when they don’t get any feedback.

The only thing the dialysis facility should be responsible for is getting the treatment right. If the dialysis treatment is right the patient has less fatigue and starts to feel better and can then begin to think about what goals they have.

Alternative PRO measure:

CMS should consider adopting a reporting measure to ensure that the patient has a voice during every dialysis treatment. For example, after each treatment, patients could be asked a simple question, such as whether they were (a) not at all bothered, (b) somewhat bothered, (c) moderately bothered, (d) very much bothered, or (e) extremely bothered during a treatment.

If the patient is bothered, a series of additional questions could be asked to qualify their response based on the common difficulties of patients’ experience, such as access problems, low blood pressure, crashing, cramping, or other pertinent indicators.

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Collecting this information might help providers understand why patients do not stay for the entire treatment or why they miss treatments. A brief, structured conversation with the patient can also provide the physician and the nurse manager with insights on whether a patient is tolerating treatment or not, and on the potential need for adjustments before a major problem emerges. The survey results can also offer insight if a patient may do better on another option of dialysis.

Here is an outline of the measure that we created.

Access Problems

Not at all bothered, Somewhat bothered, Moderately bothered, Very much bothered, Extremely bothered

Cold

Not at all bothered, Somewhat bothered, Moderately bothered, Very much bothered, Extremely bothered

Cramps

Not at all bothered, Somewhat bothered, Moderately bothered, Very much bothered, Extremely bothered

Dizziness [KDQOL-36 combines Faintness and Dizziness]

Not at all bothered, Somewhat bothered, Moderately bothered, Very much bothered, Extremely bothered

Dry Mouth

Not at all bothered, Somewhat bothered, Moderately bothered, Very much bothered, Extremely bothered

Headache

Not at all bothered, Somewhat bothered, Moderately bothered, Very much bothered, Extremely bothered

Itchy skin

Not at all bothered, Somewhat bothered, Moderately bothered, Very much bothered, Extremely bothered

Low Blood Pressure

Not at all bothered, Somewhat bothered, Moderately bothered, Very much bothered, Extremely bothered

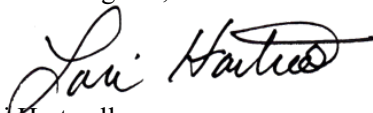
Nausea [KDQOL-36 combines Nausea or Upset stomach]

Not at all bothered, Somewhat bothered, Moderately bothered, Very much bothered, Extremely bothered

Restless Legs

Not at all bothered, Somewhat bothered, Moderately bothered, Very much bothered, Extremely bothered

Warmest Regards,



Lori Hartwell
President/Founder