

MEMO



TO: CMS
FROM: Ketchum
DATE: December 20, 2016
SUBJECT: Executive Summary of the December 13 DFC-ESRD QIP Patient Listening Session at the CMS Quality Conference

On Tuesday, December 13, Ketchum attended and supported the “Measuring Patient Outcomes: The Patients’ Perspective on Improving Care” listening session hosted by CMS’ Dialysis Facility Compare (DFC) and End-Stage Renal Disease (ESRD) Quality Incentive Program (QIP) teams at the CMS Quality Conference in Baltimore, Md. The following is an executive summary of the session, including feedback from patient advocates and recommended next steps.

Overview

Representatives from across the renal community attended the session, including:

- People living with chronic kidney disease;
- Healthcare providers specializing in chronic kidney disease;
- Staff from patient advocacy groups and medical professional societies; and
- Members of the [National Forum of ESRD Networks](#), a not-for-profit organization under contract to the Centers for Medicare & Medicaid Services (CMS), which advocates for the organizations that monitor the quality of chronic kidney disease, dialysis and kidney transplant care in the United States.

DFC Technical Lead Elena Balovlenkov, RN, MS, CHN, welcomed attendees and provided an overview of DFC and ESRD QIP. Elena then introduced five patient advocates who shared their respective experiences with chronic kidney disease, dialysis, and kidney transplant care. They also offered their perspectives on:

- CMS’ current work in measuring quality patient outcomes for dialysis care;
- How CMS can educate patients about CMS programs that can help inform their decisions about where to receive dialysis.

In addition, the patient advocates shared their feedback on CMS’ future work in renal care.

Patient Advocates

The patient advocates were:

- Alex Berlin, kidney transplant representative from ESRD Network 6
- Paul Conway, kidney transplant recipient and president of the American Association of Kidney Patients (AAKP)
- Jim Dinnen, kidney transplant representative from ESRD Network 9
- Virna Elly, kidney transplant recipient
- Cynthia Franklin, kidney transplant representative from ESRD Network 6

Patient Advocates' Feedback

Elena guided the conversation by asking the patient advocates questions, which are outlined below along with their answers.

Q: Where did you get information about your diagnosis? How did you decide where to receive care?

A:

- Nephrologist – Which led to the patient's decision to get a preemptive transplant.
- Emergency care after kidneys "crashed" – However, the healthcare providers did not spend time educating the patient on her options for care—they handed her a piece of paper and told her to show up at a specific dialysis center at a certain time and start treatment. Frustrated, the patient took it upon herself to learn more about her diagnosis and educate herself about her care options—she spoke with other patients sitting next to her during dialysis and searched online for reputable information, including from CMS.
- Self – The patient emphasized the importance of empowering patients to educate themselves and become their own advocates. Informed patients could then empower other patients to become their own advocates.
- Pre-dialysis orientation at dialysis center.
- Healthcare provider – Most patients don't know they have options where to get dialysis and they just go where their healthcare provider tells them to go.

Q: How can CMS educate patients about DFC and ESRD QIP?

A:

- Simplify existing materials; make them plain language.
- Look at patient referral networks, including online platforms and social media.
- Patients want information when they need it, and this differs per patient; however, other patients are the biggest source of information (i.e., patients sitting next to them during dialysis).
- Healthcare providers need to share their final treatment goals with patients, their plan to reach those goals, and progress towards those goals; they need to involve their patients in their treatment plans and get continuous feedback from patients.
- Healthcare providers also need to explain paperwork to patients, including any materials about DFC and ESRD QIP.

Q: What types of educational materials would be useful to help patients learn about their options for care?

A:

- Videos – Most dialysis centers have a television in their reception and/or treatment areas; CMS could develop informational and/or testimonial videos and partner with dialysis centers to broadcast them on their televisions.
- Caregiver materials – Caregivers play an important role in renal care and should have resources available to them that address their specific questions and concerns; the materials must demonstrate that CMS understands the impact of kidney disease on caregivers.
- Data-focused materials – Patients need reliable data to base their decisions on.
- Overall, it's important to improve communication between healthcare providers, patients and caregivers.

Q: Should DFC and ESRD QIP incorporate the Patient Activation Measure (PAM)?

A:

- PAM is difficult to get off of the ground, but stakeholders were interested in incorporating it; CMS should consider tracking the need for adding the measure, adding it in a phased approach and identifying who would pay for training facilities on the measure.
- CMS should conduct plan-of-care reviews with patients to determine whether to incorporate PAM.
- If CMS decides to incorporate the measure, it must educate patients on it.
- CMS should also consider measures related to autonomy support, mental health (depression and chemical dependency) and patients' physical and cognitive function.

Next Steps

CMS/NORC/Ketchum will discuss the patient advocates' feedback during an upcoming check-in call, and decide on next steps for additional patient engagement sessions (particularly with AAKP). Ketchum will also work with CMS and NORC to develop patient educational materials.