

## Dialysis Facility Compare Patient Engagement Session Debrief 4/15/17

Dialysis Facility Compare is the official Centers for Medicare and Medicaid Services (CMS) source for information about the quality of dialysis centers. The website publishes data on thousands of Medicare-certified dialysis centers across the country. In an effort to meet the needs of individuals with kidney disease and their caregivers through Dialysis Facility Compare (DFC), the Centers for Medicare and Medicaid Services asked NORC at the University of Chicago to bring together a group of kidney patients to provide candid feedback about this website.

On April 3, 2017, NORC, with support from the American Association of Kidney Patients, conducted a five-hour discussion with end-stage renal disease (ESRD) patients. CMS provided NORC with contacts at five national organizations that represent the interests of ESRD patients and each of these organizations agreed to help identify patients to participate. We asked each organization to identify approximately four patients<sup>1</sup>. Twelve patients participated in the meeting. This is the first time DFC was able to leverage relationships with the patient advocacy organizations in the kidney community to receive broad patient input on both the website itself and opportunities for engaging patients.

The original strategy was to recruit patients who were currently undergoing in-center hemodialysis dialysis, or had past experience with in-center hemodialysis dialysis in the past. However, as responses came in from individuals with other backgrounds (e.g., peritoneal dialysis or a caregiver) we saw the value in opening up the discussion to others to inform a broader view of ESRD and CMS agreed to include some of these individuals.

Besides NORC facilitators and support staff, and several CMS staff members who attended either in person or via telephone to listen to the meeting, two members of the American Association of Kidney Patients Board members also attended the meeting to listen but did not participate in the discussion.

### Key-Takeaways and Potential Next Steps

- 1. Patients want and seek out resources specific to their current stage of disease and health status.**  
Framing content and communication efforts to meet the specific information needs of patients at different stages of diagnosis and treatment, (e.g., various stages of chronic kidney disease, undergoing different dialysis modalities, and post-transplant) is more likely to resonate with patients. Dialysis Facility Compare, though focused on the quality of dialysis centers, can address this feedback through some minor reorganization and reframing of content to ensure the site is talking to people at different stages of kidney disease more than it currently does.

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<sup>1</sup> The exception was Rogosin Institute/ New York- Presbyterian who we asked to identify two patients since they are a smaller organization.

2. **Current depictions of ESRD and ESRD patients do not always represent the range of patient experiences, and many feel they are too negative.** Participants described the isolating and terrifying impact of an ESRD diagnosis, but noted that there are many examples of individuals who lead a full life while coping with the disease and want to share the ability to feel empowered despite having the diagnosis. They expressed the need for education and awareness building for patients, as well as the public, about the fact that dialysis is a lifestyle, not a death sentence. Additionally, participants shared their aversion to the framing of kidney disease requiring dialysis as “end-stage” since it carries such negative connotations. Patients also noted that dialysis patients can be any age or race, and depictions of patients both on the DFC website and outreach materials (e.g., social media posts) should reflect that diversity.
3. **Information about treatment options and quality is important enough that it should be proactively provided directly into the hands of patients who might not otherwise seek it out.** The patients who might most need information on treatment options and quality of facilities, are also the ones who might be less motivated or empowered to search for it, (unlike the participants in this meeting who are generally very engaged in their care and the ESRD community). Investigating how dialysis centers or other mechanisms may deliver this information to patients directly is one option. Additionally, conducting further research to understand how different segments of the DFC audience, and ESRD patients, prefer information may be an important next step. Though several participants in this meeting preferred a more mobile friendly version of DFC, this may not be the best option to connect with already less engaged patients who are less likely to seek out information regarding their care themselves through any mechanism (including visiting a website).
4. **Medicare is a trusted source of information.** Particularly for ESRD patients, for whom Medicare is the predominant payer for treatment, CMS is the primary and most trusted sources of information about ESRD and quality. DFC should leverage this trust and ensure that it highlights the Medicare brand in outreach to patients regarding ESRD.

## Next Steps

1. Share learnings about patient engagement and shared decision-making in website design across programs to inform future efforts.
2. Address “quick wins” to incorporate feedback into the DFC website. For example, reframing or reorganizing existing content to meet different stages of kidney disease and addressing sensitivities of patients with regarding to terminology and depictions of patients can take place in the immediate future.
3. Leverage feedback, particularly patient desire to have more tailored content, into ongoing audience segmentation and communications efforts.
4. Consider feedback in the bigger picture of future development of DFC (and future addition of new quality measures). Should the site only focus on in-center hemodialysis or can it be a resource for the broader kidney disease community for quality information (e.g. regarding home-hemodialysis or transplant)?
5. Consider a future meeting with less engaged patients to understand their perspectives and how DFC can help them engage in their kidney care.
6. Hold a follow-on meetings with the leadership (e.g., board president or board members and association staff) of each of the organizations who worked to identify participants. Objectives:
  - a. Share findings from the 4/3/17 meeting with patients
  - b. Identify next steps (and opportunities for ongoing patient engagement)
  - c. Discuss resources DFC could be leveraging