

# Case STUDY

 **Learning Systems**  
for Accountable Care Organizations

## Centers for Dialysis Care's Patient Advisory Committees

This case study describes how the Centers for Dialysis Care (CDC) created patient advisory committees to proactively address its patients' concerns and improve the delivery of care. The committees provide a forum for patient and staff representatives to collaboratively address opportunities for improving care within the dialysis units. CDC has made multiple changes to these units as a result of insight gleaned from the committees, such as new dialysis chairs to improve the patients' experience of care and enhanced security for the building entrance. Patients have shared their appreciation for not only the opportunity to raise their concerns with staff during committee discussions but also CDC's responsiveness to these concerns.

### BACKGROUND

#### *Overview of the organization*

The Centers for Dialysis Care (CDC) is a non-profit dialysis organization that treats patients with end-stage renal disease (ESRD) in the Northeast Ohio region. In 2017, CDC joined the Comprehensive ESRD Care (CEC) Model.<sup>1</sup> Participating organizations in the model, known as ESRD Seamless Care Organizations (ESCOs), form partnerships between dialysis units, nephrologists, and other health care providers to improve health outcomes for patients with ESRD at a lower cost.<sup>2</sup> Since joining the model, the number of CDC

dialysis units participating in the ESCO has shifted over time. As of 2019, the ESCO includes 6 of the 15 dialysis units and 21 clinicians who serve approximately 500 ESCO-aligned patients.

#### *Launching the patient advisory committees*

Beginning in 2008, CDC partnered with its dialysis units in order to deepen its engagement with dialysis patients. The goals of this effort were to better understand how the patients experience care and to incorporate their perspective into new initiatives. As of 2019, three units (Euclid ESCO unit, East ESCO unit, and Oakwood unit) had established formal patient advisory committees (PACs) through which patient and staff representatives meet regularly to discuss concerns related to care delivered in the units and opportunities for improvement.<sup>3</sup> These PACs consider a wide array of topics, such as the training and expertise of staff, enhanced security of the building, and availability of patient education resources.

*"We use the patient advisory committees . . . to listen to the voice of the patients and what affects them, to determine what improvements they would like to see, and to get their buy-in to help us implement change."*

—Sharon Thomas, Vice President of Patient Care Services, CDC

CDC views the PACs as an integral approach to improving the delivery of care by incorporating the patient’s voice into the unit-level operations, thereby building the momentum for more PACs to form over time. Approximately 10 years after launching the first patient support group in the Euclid unit, CDC now operates three PACs that meet regularly (see Figure 1 for the timeline). When launching these PACs, CDC leadership collaborated closely with dialysis unit staff and continues to provide ongoing support for the meetings. Key points of contact for the units’ PACs include Sharon Thomas, Vice President of Patient Care Services and Janine Rosenthal, Director of Social Service. Based on CDC’s insight from collaborating with the units and participating in the PACs, the organization intends to establish PACs in all units by the first quarter of 2020.

As additional PACs form, CDC recognizes that the impetus to launch each one differs according to the specific needs and interests of local patients, staff, and leadership. For example, patients at the Euclid unit expressed an interest in forming a social support group and approached a social worker in the unit to request a regular meeting space. In contrast, the East unit took a staff-driven approach, reflected in the social workers’ effort to champion the establishment of a PAC in response to a CMS recommendation that such groups can improve care for ESRD patients.<sup>4</sup> The East unit’s senior management team supported the PAC, noting the importance of collaborating with patient representatives who are interested in improving operations and the process for delivering care in the ESCO. The third unit, Oakwood, initiated a PAC after experiencing a turnover in leadership; its goal was to create an opportunity for patients to raise concerns and ask questions of the management staff.

**OPERATIONALIZING THE PACS**

CDC leadership not only encourages units to launch a PAC to address the needs of their patients and staff but also offers guidance and support to cultivate consistent and effective operations in PACs throughout the organization. This support focuses on staffing, recruiting patient representatives, and operating the meetings.

***Engaging dialysis unit staff to lead the PACs***

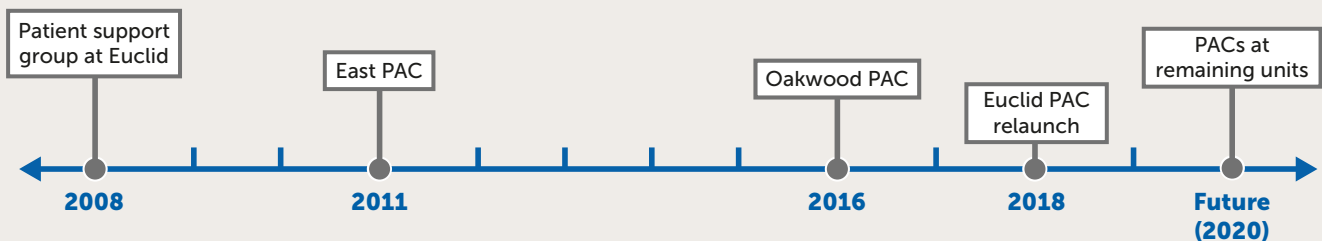
When CDC leaders described the PACs to the dialysis units in the early launch phases, they encountered resistance from staff who would be likely to play a substantial role in the committee meetings. The staff expressed concern that the committee meetings might turn into “free-for-all complaint sessions” and that they did not have time to conduct the meetings alongside their other work. To address these concerns, CDC used CMS’s publicly available tools to describe the value, goals, and structure of the PAC.<sup>5</sup> The tools that CDC found valuable when setting expectations with the unit staff include a manual that outlines the roles and responsibilities of those involved in the PACs, examples of activities and resources that patient representatives can use to engage other patients, and suggested quality improvement initiatives for a dialysis unit.

CDC selected social workers to lead the PAC meetings, given their role as a communication link between patients and clinical staff, and their experience in addressing patients’ social, emotional, and environmental needs. These social workers are responsible for developing agendas, facilitating meetings, and identifying patients who would act as representatives in the PACs. CDC’s Director of Social Service, who oversees the social workers throughout the organization, leads trainings during the quarterly department meetings for social workers who facilitate the PACs. The trainings cover facilitation, conflict management, and motivational interviewing. CDC noted that these skills help social workers to feel prepared to facilitate efficient and effective meetings, and ensure that the staff do not direct the conversation but instead encourage patients to share their most pressing concerns.

CDC recommends that units include a relatively small number of dialysis staff in the PACs to encourage the formation of trusting relationships with the patient representatives, which leads to more honest discussion. Dialysis unit managers or members of the transplant team may attend PAC meetings to get feedback from patient representatives on their care experience and to learn about their other concerns related

**Figure 1**

**PACs launched over time**



to the unit. Pam Kent, Director of Population Health Management, also attended PAC meetings to understand how CDC could revise its education resources to better meet patients' learning needs.

### Recruiting patient representatives

CDC has found that effective patient representatives on PACs are sociable, easy to communicate with, and interested in contributing to the meetings. CDC also recommends that patient representatives should come from a pool of patients who have received dialysis in its units for some time to ensure that they are familiar with the treatment experience and the organization's processes. CDC takes a flexible approach to establishing the requirements for joining a committee by encouraging patient representatives to participate as much or as little as they like based on their interest and availability. Social workers generally recruit patient representatives, though patients occasionally volunteer to join after learning about the committees. The tenure of patient representatives is not limited, but turnover is a common challenge because patients may transfer to another unit, change their dialysis schedule, experience a change in their health, or pass away.

*“As patients, we have so little control of everything that happens in our lives, and it was nice to be able to get to speak up and to be able to try to get things fixed.”*

—Patient in Oakwood PAC

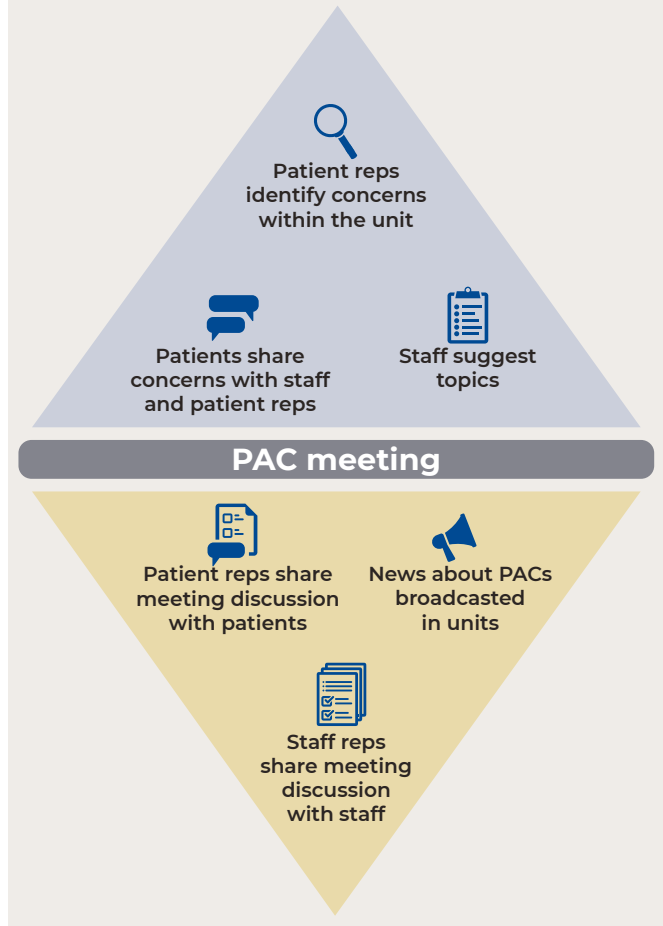
Committee size varies across units. Most PACs have 3 or 4 patient representatives, though the Oakwood PAC included 12 at one time. Some units have found that having a few, highly engaged representatives is more important than the size of the committee. Other units have found that larger committees lead to more dynamic conversations as a result of the additional voices and opinions.

CDC noted the importance of building trust between the patient and the staff representatives in order to establish a stable, productive committee. When first launching a PAC, Ms. Rosenthal observed that patients may be reluctant to voice concerns, perhaps fearing retaliation. CDC addressed this challenge by (1) recognizing that a patient's motivation to participate is a desire to improve the care experience of other patients, (2) keeping the committees small and therefore intimate, and (3) reiterating that the goal of a PAC is to establish a forum for open and honest communication.

### Operating the committee meetings

Social workers in the units help coordinate agendas for the PACs, which are typically convened monthly or quarterly depending on the patients' availability. The agendas vary and have included items such as improving the unit's physical

**Figure 2**  
**PAC meeting development and results**



plant and materials, addressing transportation needs, and educating patients about their treatment options. Patients who do not participate in the PACs provide most agenda items directly to the patient or staff representatives; in some units, they submit suggestions to comment boxes distributed in the unit. Patient representatives also suggest topics based on their own observations or on feedback from other patients and their caregivers. Additionally, CDC staff suggest discussion topics and may ask to attend meetings as a guest to hear how patients feel about a particular issue. Figure 2 highlights the mechanisms for obtaining topics for the PAC meeting agendas.

CDC emphasizes the importance of sharing insights from the PAC meetings with patients and dialysis unit staff in order to illustrate its commitment to encouraging and responding to the patients' feedback. Communications about the PACs' role in improving the patients' care experience consist of flyers distributed in treatment rooms or posted on bulletin boards, and articles in the organization's bimonthly patient newsletter. In addition, CDC's CEO and president discusses the PACs' recommendations in the newsletter both to highlight the organization's appreciation for the patients' feedback and to explain what the organization plans to do in response.

The PAC participants look to informal communication channels to share their insight from meetings with other patients and staff. Patient representatives often discuss the meetings with other patients during dialysis in order to identify new concerns for the committee agendas. Staff representatives also share information that surfaces during the meetings with colleagues during staff meetings. Figure 2 illustrates how information from the PAC meetings is shared with others in the organization.

## FINDINGS

CDC collects anecdotal feedback from staff and patients to assess whether the PACs have meaningfully and positively influenced the experience of care. Over the years, patients have expressed appreciation for the opportunity to engage directly with unit management, and they value the timely changes made as a result of PAC recommendations. For example, one patient representative observed that a change in staff training, like providing education about monitoring dialysis access placement, made patients feel more comfortable when interacting with their dialysis technicians. In addition, one PAC focused on the need to welcome patients new to dialysis, so the committee crafted a program to greet and orient these patients.

CDC also assesses the impact of the PACs by tracking changes that resulted from committee recommendations, including the following:

- One unit installed additional security for the building entrance and held active-shooter trainings in response to the patients' worries about safety.
- To address concerns about the potential for disruption caused by turnover in unit leadership and staff, CDC improved retention by investing in staff development and engagement.
- CDC prioritized the replacement of older dialysis chairs with new ones that allow for more thorough cleaning between uses and are more comfortable for patients.
- To address the wait time experienced by some patients for their dialysis shift, CDC streamlined the intake process so that treatment can begin soon after the patient arrives.

## LESSONS LEARNED

As CDC continues not only to operate the three PACs but also to consider ways to expand the patient engagement strategy to additional units, the organization has identified the lessons it learned while implementing and operating the PACs. These lessons, listed below, may be helpful for organizations that are considering a similar initiative:

**Aim for consistent, efficient meetings.** CDC encourages units to hold regularly scheduled meetings in order to maximize attendance and ensure a timely response to patient feedback. Units post the meeting time publicly so that all patients, even

those who are not designated patient representatives, know when the meeting will occur and how to submit suggestions for the agenda. In addition, CDC encourages unit social workers to prepare for each meeting by setting the agenda, including the patients' suggestions, which helps to keep the discussion on track and makes efficient use of the participants' time.

### **Interact frequently with patients to identify potential**

**PAC action items.** CDC recommends that staff and patients interact continually as a way to encourage open lines of communication about opportunities for improvement, which can be further discussed in the PAC meetings. Staff members visit with patients "chairside" while they receive dialysis, and some CDC units have comment boxes in which patients can share their concerns or ideas anonymously. Patient representatives are also in a position to hear concerns that surface outside of regularly scheduled meetings, and they discuss these concerns with other patients when they see each other at the unit.

**Keep the atmosphere at meetings positive.** CDC encourages staff representatives to use the PAC meetings as a learning experience through which they can respond to patients' concerns in a solution-oriented way. This positive approach makes patient representatives feel more at ease and motivated to speak their mind.

*"The patient advisory committee is a strategy . . . and the focus now is on how do we build and sustain this. It is an evolving process and we learn as we go along."*

—Pam Kent, Director of Population Health Management, CDC

## NEXT STEPS

CDC intends to establish PACs in all units, which reflects the organization's commitment to enhancing the patients' experience. Building on what it has learned thus far, CDC has begun to engage with staff in its dialysis units that do not yet have PACs in order to both cultivate their buy-in and identify leaders for launching and operating new committees. In this early planning phase, CDC will share the PACs' successes, educate unit managers about the role of the committees, and determine how patient representatives currently involved in PACs can support and mentor new PAC participants. At the same time, CDC will explore new strategies for further engaging patients in the existing three PACs, such as identifying additional channels through which it can solicit input from patients who have not yet contributed to the committees. The organization remains committed to creating opportunities for all patients to feel comfortable voicing both their needs and their ideas for improving care for themselves and others.

## ENDNOTES

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<sup>1</sup> See more information about the CEC Model on the CMS website: <https://innovation.cms.gov/initiatives/comprehensive-ESRD-care/>.

<sup>2</sup> Additional information about the Northeast Ohio Renal Alliance ESCO is on the CDC website: <http://www.cdcare.org/news/cdc-access-care/>.

<sup>3</sup> For the CEC Model, CMS also requires either a patient or an independent consumer advocate to serve on the ESCO board.

The local PACs, however, focus on unit-level changes and therefore do not fulfill this specific ESCO requirement.

<sup>4</sup> The CMS ESRD Network recommends that patient support groups both engage patients in their health care and open a channel of communication between patient and staff representatives. See <https://esrd.ipro.org/>.

<sup>5</sup> See more information about the expectations and roles for PAC members on the CMS ESRD Network website: <https://network9.esrd.ipro.org/home/patient-portal/getting-involved/ohiorivervalleypac/>.

### About the ACO Learning Systems project

This case study was prepared on behalf of CMS's Innovation Center by Meg Maxwell, Neni Osuoha, and Kate D'Anello of Mathematica under the Learning Systems for ACOs contract (HHSM-500-2014-00034I/HHSM-500-T0006). CMS released this case study October 2019. We are tremendously grateful to Pam Kent and Sharon Thomas of Centers for Dialysis Care for participating in this case study.

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