



END STAGE RENAL DISEASE NETWORK OF TEXAS

Patient Engagement Learning and Action Network

September 2 and 3, 2015

Webinar Sessions

Meeting Minutes

ATTENDANCE

Network 14 Staff: Rachelle DuBose Caruthers, Debbie O'Daniel, and Kathleen Prewitt

Patient and Family SMEs: 84 facilities included 6 patient SMEs (452506, 452742, 452797, 452883, 672573, 672573, 672662) and 7+ FPRs. 15.4% (13/84) of participating facilities included patients in the webinar.

Facilities Present: 138 staff members from 84 facilities (84/123) = 68.3% facility participation rate. Facilities included 452506, 452513, 452522, 452528, 452532, 452541, 452552, 452557, 452560, 452561, 452575, 452576, 452605, 452611, 452635, 452648, 452663, 452667, 452668, 452675, 452676, 452679, 452682, 452692, 452693, 452694, 452696, 452699, 452719, 452727, 452732, 452735, 452737, 452742, 452755, 452761, 452776, 452777, 452797, 452820, 452823, 452831, 452840, 452851, 452857, 452858, 452866, 452868, 452873, 452883, 452893, 452895, 452899, 453502, , 672501, 672515, 672525, 672531, 672536, 672537, 672542, 672549, 672555, 672559, 672561, 672573, 672578, 672584, 672590, 672593, 672600, 672604, 672605, 672627, 672629, 672637, 672654, 672662, 672667, 672675, 672688, 672700, 672703, 672734.

Facility Staff: The cross-functional PE LAN team included facility staff from multiple disciplines, including Clinic Managers/Facility Administrators (40), RNs (6), SWs (52), RD (24), PCTs (2), and AAs/other (14).

MEETING MINUTES

Members of the PE LAN convened in one of two Learning Session 5 meetings: Wednesday, September 2, at 10:05 a.m., and Thursday, September 3, at 2:02 p.m. Both Learning Session 5 meetings featured the following content.

Welcome and Introduction

Rachelle DuBose Caruthers opened the meetings by welcoming all participants, introducing the Network 14 staff, and recognizing PE LAN member facilities and patients. Ms. Caruthers polled the participants to identify the roles of the members present. Ms. Caruthers explained that this final Learning Session would serve to respond to any questions and to wrap up the project. She reviewed the meeting objectives and project timeline.

QIA Knowledge-sharing

Ms. Caruthers shared the QIA outcomes to-date with the PE LAN members. She then invited participants to share knowledge and lessons learned during the QIA, which required all facilities to recruit and train Facility Patient Representatives (FPRs). Staff and patients were asked to complete polling questions regarding the number of trained FPRs at each facility. 84 facilities responded with a total of 108 trained FPRs, 50 of whom speak Spanish=49.3%.

4040 McEwen Road, Suite 350, Dallas, Texas 75244

Phone: 972-503-3215 | Fax: 972-503-3219 | info@nw14.esrd.net | www.esrdnetwork.org

Supporting Quality Care



END STAGE RENAL DISEASE NETWORK OF TEXAS

Ms. Caruthers then asked all participants to use the Chat box and opened the phone lines for PE LAN members to respond to the question, “*What is the best advice you can give patients and staff that are starting an FPR program?*” One patient responded that she was approached by the staff in a very positive way and that the time the staff spent with her one-on-one to educate her about the program inspired her to become an FPR. Another patient said that he was approached because of his age (younger than average) and that the staff felt that patients would be more responsive to information coming from him than from staff. He serves as a peer mentor in his facility and feels that he is a successful FPR. A third patient stated that he started dialysis with a very negative attitude and that it was only through repetition and reeducation by staff that he eventually turned his life around and became active as an FPR. It is his goal to help other resistant patients become more compliant.

CHAT: What is the best advice you can give patients and staff that are starting an FPR program? (A sample of the responses is shown below. For complete list of responses submitted in Chat, see attachment *2015 PE LAN Lessons Learned LS5*.)

- Focus on patient's strengths to engage them in participating with clinic.
- I would recommend seeking out pts w/ positive attitudes. Those that see need for improvement, but are willing to help change. Both of our FPRs are good resources for new pts because of their pos. attitude - they can be very motivational.
- Be excited about it yourself when you talk to patients. Reach out in an encouraging way.
- Asking our FPRs for their input on what would best affect outcomes with patients at our facility. For example, we are creating an education program for our pts that better explain clinic outcomes with treatment times, fluid gains, procedures, mechanics of the machine, etc.
- Choose patients that are interested in being an advocate for the other patients, as well as any patient who encourages other patients help facility to improve their processes.

Campaign 1 Knowledge-sharing

Ms. Caruthers shared Campaign 1 outcomes to-date and asked all members to continue encouraging patients to complete modules. She asked patients and staff to complete polling and Chat questions and opened up discussion. One patient shared that she found the workbook activity on converting pounds to kilos very helpful and is now better able to manage her fluid intake and weight. Another patient stated that he felt the information was appropriate for the patients at his facility and that he would like to see facilities hold classes to help patients better understand fluid management. He explained that visual aids such as the size of a water bottle marked with the amount of fluid would have been helpful when he was a new patient.

Poll: How effective was Campaign 1: Fluid Management Workbook in educating patients at your facility?

- Very effective: 12/78 respondents=15.4%
- Somewhat effective: 54/78 respondents=69.2%
- Somewhat ineffective: 11/78 respondents=14.1%
- Very ineffective: 0/78 respondents=0.0%
- Unknown, we have not started Campaign 1: 1/78 respondents=1.3%
- No response: 36/114=31.6% of participants

4040 McEwen Road, Suite 350, Dallas, Texas 75244
Phone: 972-503-3215 | Fax: 972-503-3219 | info@nw14.esrd.net | www.esrdnetwork.org

Supporting Quality Care



END STAGE RENAL DISEASE NETWORK OF TEXAS

CHAT: How has Campaign 1 impacted patients at your facility? (A sample of the responses is shown below. For complete list of responses submitted in Chat, see attachment *2015 PE LAN Lessons Learned LS5*.)

- Those patients who were invested in change, it was very effective. At least one patient is still weighing each morning, logging his weights & seeing improvement with IDWGs. Most patients seemed to understand and answer questions at approp level.
- Patients were very receptive to the fluid management workbook; it gave the RD and MSW some new ways to communicate the effect of fluid on the patients' health.
- Patients started asking questions to nurses about their dry weights.
- We went from 43% to 32% we talk with the pts and mail them some inform home to encourage them.
- I was just speaking with a patient today who was sharing with me about her s/s she did tell me that she had taken in less than 2 liters and that she knew that fluid overload was not an issue. I was so proud that she was able to identify what her fluid goal should be.

Campaign 2 Knowledge-sharing

Ms. Caruthers shared Campaign 2 outcomes to-date and emphasized that the measure for missed treatment workbook was the missed treatment rate itself, so it is important to continue educating patients and making an effort to reschedule all missed treatments. She asked patients and staff to complete polling and Chat questions and opened up discussion. One patient shared that they had a contest at her facility and that the small prizes and recognition given to patients during Campaign 1 encouraged even more patients to participate in Campaign 2. Ms. Caruthers responded to feedback from the Chat responses, including encouraging facilities to engage their Medical Directors in patient education for younger patients that "felt good" and had not responded to staff education. She also encouraged Medical Director participation in cases where health issues (diarrhea, etc.) could possibly be treated through diet and/or medication to reduce missed treatments. One social worker shared that the greatest benefit of Campaign 2 in her clinic was to increase the conversation between staff and patients. She held lobby days at both of the clinics she staffs and felt the workbook was beneficial for patients that shorten treatments and those that miss treatments altogether.

POLLING: Does the Missed Treatments workbook include the information recommended by PE LAN members during Learning Session 4?

- Yes: 86/92 respondents=93.5%
- No: 0/92 respondents=0.0%
- I did not attend Learning Session 4: 6/92 respondents=6.5%
- No response: 24/116=20.7% of participants

POLLING: If you responded with No, what should be added to the workbook?

Response: Participation and interest in the project by patients and staff waned as the different modules were presented. We started strong with Fluid Management One; however, it went downhill. Feedback from pts focused in two extremes.

POLLING: How effective is Campaign 2: Missed Treatments Workbook at educating patients at your facility?

- Very effective: 20/91 respondents=22.0%
- Somewhat effective: 56/91 respondents=61.5%
- Somewhat ineffective: 5/91 respondents=5.5%
- Very ineffective: 0/91 respondents=0.0%

4040 McEwen Road, Suite 350, Dallas, Texas 75244
Phone: 972-503-3215 | Fax: 972-503-3219 | info@nw14.esrd.net | www.esrdnetwork.org

Supporting Quality Care



END STAGE RENAL DISEASE NETWORK OF TEXAS

- Unknown, we have not started Campaign 2: 10/91 respondents=11.0%
- No response: 25/116=21.6% of participants

CHAT: How has Campaign 2 impacted the patients at your facility? (A sample of the responses is shown below. For complete list of responses submitted in Chat, see attachment *2015 PE LAN Lessons Learned LS5*.)

- Our SME went from an average of 4 missed treatments in March to 0 missed treatments in the last 3 months. She became very involved in creating a newsletter for our clinic that was appreciated by our patients.
- We had a positive response to the missed treatment workbook. Our Missed treatments have gone down and we raffled some lunch bags to our patients as appreciation for their adherence. Our team reviews weekly on our core team meeting.
- We loved the campaign. It went thru a trial run with the FPR Advisory Council meeting. It was introduced by SW and supported by all teammates with review and follow up. Patients responded quickly. Workbook was assigned for patients with a 1 week turnaround. Patients finished their workbooks by their second treatment. Most all patients seemed to have key takeaways. Risk for death and hospitalization noted. What was interesting is that patients said they felt engaged and felt the team cared enough to sit chairside with the patients for review. We have a very low missed treatment rate; one missed treatment that fits PE-LAN criteria of 1 during August. Even though we have a history of low missed treatment rate patients felt information provided was useful and that they learned something new.
- We have a low missed treatment rate already. Campaign 2 supports and supplements education that we give our patients. We are a growing clinic and will continue to utilize the workbooks with our new patient admits.
- The rate of missed treatments at the clinic have shown a slight decrease and some of the more non-compliant pts have actually not missed as many treatments as before. A patient stated that he finally started to understand why we kept bringing up to him to not miss treatments.

PE LAN Evaluation

Ms. Caruthers reminded PE LAN members that this was the final Learning Session, but that they should complete the September Survey Monkey and that it is important to maintain the progress they have made so far. She presented participants with five questions and asked them to respond in Chat. The instructions and a sample of the responses are shown below. For complete list of responses submitted in Chat, see attachment *2015 PE LAN Lessons Learned LS5*.

CHAT: This activity should include feedback from your FPRs and other interested patients and/or family members. Think about your overall experience with the 2015 PE LAN and answer the following questions.

1. ALL: What did you learn?
 - Patient: The awareness of how missed treatments can affect you.
 - Patient: This is my first webinar. I'm a new FPR, new to my center, and new to dialysis. Patients are totally overwhelmed with information when they start and quickly forget the basics. Repetition is important - very important.
 - Patient: greater understanding and manner in which fluid intake and treatment compliance will benefit all dialysis patients
2. FPRs/Patients/Families: What was the greatest benefit to you?
 - Patient: The greatest benefit to me was having the opportunity to share experiences with other patients. They were ready to share as well. It is unfortunate that I have limited time, but we look forward to recruiting more FPRs.
 - We feel the workbooks were easy to follow, which covers the wide range of our patient demographics. The FPR's were an asset as they help reinforced the goals and objectives we were trying to discuss.

4040 McEwen Road, Suite 350, Dallas, Texas 75244
Phone: 972-503-3215 | Fax: 972-503-3219 | info@nw14.esrd.net | www.esrdnetwork.org

Supporting Quality Care



END STAGE RENAL DISEASE NETWORK OF TEXAS

- The greatest benefit to me was seeing the increased communication between our staff and the patients. It had been such that things were "the same old thing" all the time. This gave us other ways to discuss topics and how to create fun things to use to involve patients and families.
3. All: What was the greatest challenge?
- The material covered is fundamental to successful treatments, but there are different levels of patient comprehension (too easy for some, too difficult for others). Most patients in our clinic find it a "chore" to complete written materials but on the other hand love the personal interaction.
 - Greatest challenge was completing workbooks within time frame for staff who are only at each clinic 1 day per week. Utilized other staff some to assist when they were willing.
 - Biggest challenge was getting patients to do the workbook. Once we started offering prizes our completion rate jumped to 50% on campaign 1. On campaign 2 we did not have work on getting patients involved.
4. All: How did you overcome the challenge(s)?
- The greatest challenge has been to find the time to coordinate projects within the clinic; an enthusiastic FPR has helped.
 - This year I have been trying to recruit more staff to help me so that I don't get burnt out as the only clinic social worker.
 - Once we got the whole staff involved, it made it so much easier.
5. All: How did you recognize/celebrate patients that completed the workbooks?
- We celebrated by ringing a bell by the scale when pts meet their EDW. Or they would ring the bell if they met their IDWG goal. Then the team would cheer and congratulate the pts. IDWG >5% decreased from 51.6% to 36.4% in the past 3 months.
 - We had a Lunch and Learn for our FPRs. 3 out of the 5 came and it was very positive.
 - Monthly meeting with patients and doing games and giving prizes is really helpful and make treatment more fun they have something different to look forward too.

Next Steps and Wrap-up

Ms. Caruthers concluded the Learning Session by thanking participants for the feedback and discussion and asked them to complete a poll to evaluate the PE LAN and Learning Session 5. The poll results were reviewed and Ms. Caruthers invited the participants that indicated they still had questions to come forward, either in Chat or to queue up for questions on the phone. However, no additional questions were submitted by participants.

POLLING

1. Overall, participating in the 2015 PE LAN has improved patient engagement at my facility.
- Strongly Agree: 18/86 respondents=20.9%
 - Agree: 62/86 respondents=72.1%
 - Disagree: 6/86 respondents=7.0%
 - Strongly Disagree: 0/86 respondents=0.0%
 - No response: 28/114 participants=24.6%
2. This webinar met its stated objectives.
- Strongly Agree: 26/89 respondents=29.2%
 - Agree: 62/89 respondents=69.7%
 - Disagree: 1/89 respondents=1.1%
 - Strongly Disagree: 0/89 respondents=0.0%

4040 McEwen Road, Suite 350, Dallas, Texas 75244
Phone: 972-503-3215 | Fax: 972-503-3219 | info@nw14.esrd.net | www.esrdnetwork.org

Supporting Quality Care



END STAGE RENAL DISEASE NETWORK OF TEXAS

- No response: 28/117 participants=23.9%
3. This webinar will help us be successful on the PE LAN project.
- Strongly Agree: 20/89 respondents=22.5%
 - Agree: 67/89 respondents=75.3%
 - Disagree: 2/89 respondents=2.2%
 - Strongly Disagree: 0/89 respondents=0.0%
 - No response: 28/117 participants=23.9%
4. Our team's questions about this project were answered during the webinar.
- Strongly Agree: 19/84 respondents=22.6%
 - Agree: 62/84 respondents=73.8%
 - Disagree: 3/84 respondents=3.6%
 - Strongly Disagree: 0/84 respondents=0.0%
 - No response: 33/117 participants=28.2%

Adjourn

On Wednesday, September 2, 2015, the meeting adjourned at 11:05 a.m. On Thursday, September 3, 2015, the meeting adjourned at 3:00 p.m. The webinar recording will be posted to the Network website when it is available.