



END STAGE RENAL DISEASE NETWORK OF TEXAS

Patient Engagement Learning and Action Network

April 2 (Lubbock) and 9 (San Antonio), 2015

Face-to-Face Meetings

Meeting Minutes

ATTENDANCE

Network 14 Staff: Charlonda Thrower, Debbie O'Daniel, Kelly Shipley, and Rachelle DuBose Caruthers

Patient and Family SMEs: 4 SMEs attended from facilities 452506, 452811, 452821 (facility is not participating in the project), 452895 and 1 patient from facility 672527

Community Partners/Stakeholders:

Facilities Present: 138 staff members from 53 facilities (53/126) = 42.1% facility participation rate. Facilities included 452507, 452506, 452513, 452522, 452540, 452541, 452557, 452602, 452605, 452616, 452668, 452692, 452696, 452722, 452727, 452732, 452735, 452737, 452740, 452742, 452777, 452789, 452797, 452811, 452820, 452821, 452823, 452851, 452864, 452866, 452873, 452895, 453502, 672501, 672515, 672516, 672527, 672534, 672545, 672566, 672573, 672578, 672586, 672590, 672593, 672595, 672617, 672627, 672630, 672662, 672667, 672700, 672735

Facility Staff: The cross-functional PE LAN team included facility staff from multiple disciplines, including Area Managers, Clinic Managers/Facility Administrators, RNs, SWs, RD, Techs, and AAs.

MEETING MINUTES

On Thursdays, April 2 and 9, the face-to-face meetings began with lunch at 11:30 am and discussion convened at 12:30 pm. Both Learning Session 2 meetings featured the following content.

Welcome and Introduction

Rachelle DuBose Caruthers opened the meetings by welcoming all participants and introducing the Network 14 staff, PE LAN members, and patients. Ms. Caruthers asked for a show of hands for each discipline (Area Managers, Clinic Managers/Facility Administrators, RNs, SWs, RD, Techs, and AAs) and for patients. The patients were recognized and applauded for participating in the meetings.

Ms. Caruthers reviewed the agenda, objectives, and Network 14 mission statement. She explained the purpose and goals of Network 14, with which some staff and patients were not familiar.

Statement of Work and Learning and Action Network Structure

Based on a show of hands, it appeared that approximately two thirds of each group of meeting attendees participated in one of the Learning Session 1 webinars and were familiar with the PE LAN project goals. For those that did not participate in Learning Session 1, Ms. Caruthers explained the purpose of the Statement of Work (SOW) and the LAN requirements. She also invited them to view the LS1 webinar recording, which is available at <http://esrdnetwork.org/patients-families/pfcc/>.

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Ms. Caruthers showed a short video (<https://youtu.be/zUnEzRijSBk>) developed by the QIOs that explained the purpose of a LAN. (This clip was included in LS1, but did not play properly on the webinars.) She reviewed the IHI's Breakthrough Collaborative model and explained the process and purpose of the PDSA (plan, do, study, act) cycle and that it is also called Rapid Cycle Improvement.

Ms. Caruthers explained the time constraints established in the SOW and reviewed the project timeline that the LS1 participants voted on: Baseline data collection during April, QIA during May and June, Campaign 1 during June and July, and Campaign 2 during July and August.

All Teach, All Learn: QIA

Next, Ms. Caruthers explained the 2015 PE LAN QIA, which will require all facilities to recruit and train Facility Patient Representatives (FPRs) using the FPR Toolkit. She then asked each table of participants to select a discussion facilitator, a recorder, and a timekeeper. The patients that attended were seated at separate tables from each other to maximize their impact in the discussions and help staff from multiple facilities understand the patient perspective.

The next two hours were spent working through each section of the FPR Toolkit to revise and adapt it for FPR training. The goals of the activity were to make the information complete enough to ensure that FPRs are properly trained, while also being concise enough to not overwhelm patients. The group also developed the framework for an additional tool, the FPR Agreement, which will define the specific role and responsibility for each FPR and be signed by the trainer and the patient. Patients at each meeting expressed the opinion that all patients have skills that the facilities can use to increase engagement. Examples patient presented included producing newsletters, hosting monthly birthday parties, and serving as peer mentors. The staff was reminded that patients had busy, active lives before they became dialysis patients; the skills and education that patients bring to the table can help facilities improve patient-centered care.

Before adjourning for a break at 2:00 pm during the April 9 meeting, Ms. Charlonda Thrower presented several case studies in which the use of FPRs would have been helpful in decreasing conflict. Ms. Thrower explained that properly trained FPRs can help resolve conflict within a dialysis facility, which would help facilities avoid formal grievances and improve patient-centered care.

Rapid Cycle Improvement

The major changes proposed by the patient and staff at the meeting on April 2 were to increase the font, decrease the amount of background information, use plain language, lower the reading level of the content, and add a section to define acronyms and commonly used terms. The changes proposed on April 2 were made to the FPR Toolkit and presented to the patients and staff at the meeting on April 9 for additional revisions. The major changes presented by the April 9 patients and staff included additional terms and acronyms in the Commonly Used Terms and to develop an Orientation Checklist that prioritizes FPR training. The patients at the meeting felt that training FPRs should be done a little at a time to ensure that the patient was not overwhelmed, so a checklist would help the staff cover the most important elements (such as HIPAA and confidentiality) first.



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After the revisions suggested by PE LAN patients and staff, the FPR Toolkit content (by page number) is as follows:

- 2: **NEW** Commonly Used Terms (acronyms and definitions)
- 3: **NEW** (TOOL) Orientation Checklist
- 4: Overview (reduced from 5 pages)
- 5: What is a FPR/what do they do?
- 6: Grievance Process
- 7: Confidentiality and Medical Information
- 8: Patient Advisory Committee
- 9: Patient Engagement Learning and Action Network
- 10-11: (TOOL) Role Description
- 12: (TOOL) Application
- 13: (TOOL) Staff Referral
- 14: **NEW** (TOOL) Agreement
- 15: Network Contact Information

All Teach, All Learn: Patient Education Campaigns

Campaign 1. Ms. Caruthers introduced the concept of a fluid management patient workbook for Campaign 1. She explained the content outline draft (shown below) that was developed by PE LAN stakeholder and Kidney Smart educator Elizabeth Neumann, a registered dietitian. She invited members to provide feedback on the proposal and identify existing resources that can be included in the workbook. Ms. Caruthers stated that she will work with the leadership of the dialysis organizations to obtain permission to use materials, so the members should propose any tools that are already known to be successful in education patients regarding diet and fluid management.

The workbook content will include the following elements:

- Intro: Set SMART goals for fluid
 - Definitions
 - Goal worksheet
 - Kidney coloring pages
- Module 1: How Much Fluid Can I Have?
 - Fluid tracker worksheet
 - What is EDW
 - High fluid foods
 - Ways to decrease thirst
- Module 2: How Much Salt is Okay to Eat?
 - Low and high salt foods
 - Eating out
 - Cooking ideas
- Module 3: How Can I Still Enjoy Foods I Love? (Portion Control)
 - Examples of portion sizes
 - Puzzle/crossword
- Module 4: How Do I to Manage Diabetes When I Have Kidney Disease?

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The participants submitted workbook content suggestions, as well as ideas for activities that will be engaging and interesting to patients. The group discussed the fact that patients often say they understand information, but do not really understand. By engaging patients in activities such as matching, word searches, and puzzles, the workbook will appeal to people with differing learning styles. Also, staff will be able to identify any gaps in knowledge based on the completed activities, which will enable them to do additional education with individual patients. The April 9 meeting attendees also recommended adding coloring pages that illustrate the body and how the kidneys function. Campaign 2. Both groups spent the majority of their time on the FPR toolkit and Campaign 1 workbook, so Ms. Caruthers explained the concept of a workbook that targets reducing missed treatments. It is expected that the two future Learning Session 2 meetings will spend less time on the FPR Toolkit due to the rapid cycle improvement changes from the first two meetings, and spend more time developing Campaigns 1 and 2.

Baseline Measurement

The PE LAN members that attended LS2 in Lubbock on April 2 requested a revision of the measure wording to collect baseline in April, based on the prior month so that they would consistently be able to meet the data collection deadlines. They agreed on a monthly deadline of the 10th (e.g., June data will be reported by July 10). This will also help the Network provide accurate and complete data on the COR report and DIF. The measures were not collected during the Lubbock meeting due to the changes, but were collected from all facilities attending the San Antonio meeting on April 9.

Network 14 will collect baseline data from all PE LAN facilities during April, preferably during the face-to-face meetings. The monthly Survey Monkey data collection (including baseline) includes the following fields and measures:

1. **Name of person** that will complete the survey each month
2. **Job title** of person completing this survey each month
3. **Email address** of person completing this survey each month
4. **Facility CCN** (6-digit Medicare Provider Number)
5. **Phone number** to reach the person completing the survey
6. QIA: The number of **FPR applications** collected at the facility during the prior month
7. QIA: The **number of FPRs** during the prior month that have received one or more hours of training using the FPR Toolkit
8. Patient Education Campaign 1: Diet (Fluid Management) - The **number of patients** that complete one or more module(s) in the patient workbook during the current month ("Complete" is defined as finishing two or more activities in a module.)
9. Patient Education Campaign 2: Missed Treatments - The **number of unexcused missed treatments** in the prior month
10. Patient Education Campaign 2: Missed Treatments - The **number of scheduled treatments** in the prior month
11. The **total number of patients** in the facility in the prior month

Next Steps and Wrap-up

Ms. Caruthers reminded facilities of the project timeline and that there are two additional LS2 meetings in Dallas on April 23 and Houston on April 30. All PE LAN facilities are expected to attend ONE of the

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FOUR sessions. She thanked all patients and staff for participating in the meeting and invited them to complete an evaluation and submit their notes and recommendations for the project. A summary of the evaluation feedback will be submitted to CMS on the April COR report.

Adjourn

On Thursday, April 2, 2015, the meeting adjourned at 4:02 pm. On Thursday, April 9, meeting adjourned at 3:55 pm.