



Patient Advisory Committee (PAC)

Representative's Guide

2019 Edition

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Welcome

Are you a dialysis or transplant patient or a family member of a patient? Have you ever felt like your concerns were not heard, especially when you knew you could do something that would change things for the better? Have you ever had an idea, but felt reserved about sharing it or didn't know how to go about it?

Well, here is your opportunity!

We invite you to join the Patient Advisory Committee (PAC) and share your knowledge and expertise in the renal community. **YES!** You have unique skills and understanding of the renal world that no one else can impart. For such reason, you are recognized in our group as a Subject Matter Expert (SME).

As SME you have a voice, and your voice counts where it matters most...in the care you receive and/or care your loved ones receive! Your contributions will add tremendous value to the objectives the group aims to achieve.

Come and Be Part of the Action Make the Difference!



This guide is intended to:

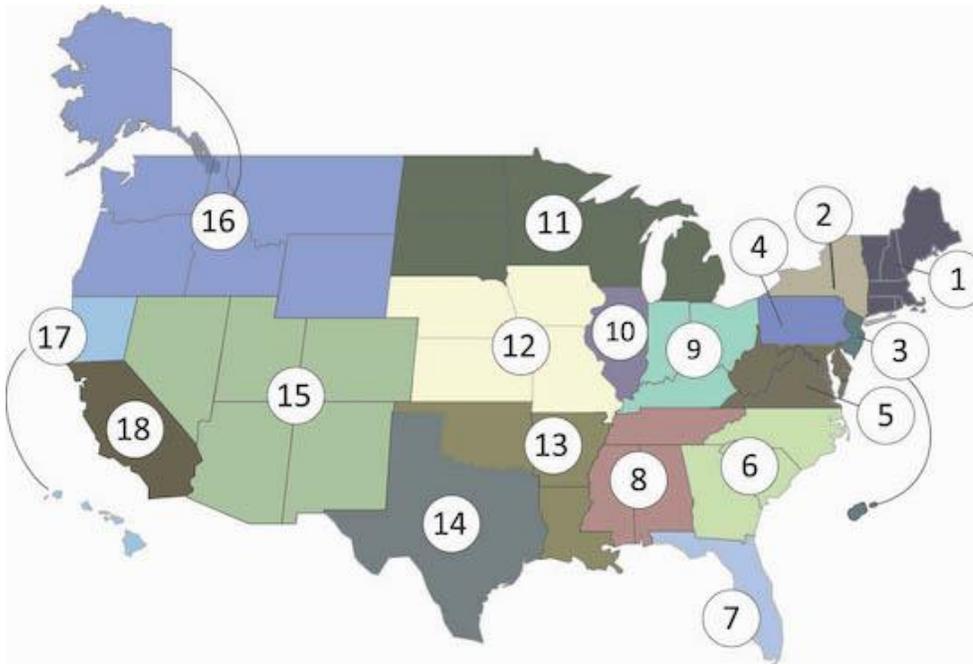
- Inform you about the work of End Stage Renal Disease Network 3 (ESRD Network 3) and the Patient Advisory Committee (PAC)
- Provide you with guidelines to help you be the best SME you can be
- Explain how you can get involved in improving dialysis care

Who is Quality Insights Renal Network 3?

Before introducing the PAC and what you as SME can achieve, let us begin by introducing the End Stage Renal Disease (ESRD) Program and explain how we, Quality Insights, connect to it.

Here is a brief history lesson:

In 1978, the ESRD Network Coordinating Councils were created to oversee the quality of care provided to patients with ESRD and serve as link between the federal government (Centers for Medicare and Medicaid – CMS) and dialysis providers. In 1988, CMS merged areas of the Network Coordinating Councils into 18 geographic areas (U.S. states, territories, including the District of Columbia) and gave contracts to 18 ESRD Network Organizations, now commonly known as the ESRD Networks.



We are known as Quality Insights Renal Network 3 (QIRN3) and we serve as the federal contractor for the **ESRD Network 3 region**, which includes:

- ◆ New Jersey
- ◆ Puerto Rico
- ◆ U.S. Virgin Islands

In ESRD Network 3 there are over 200 hemodialysis facilities and 5 renal transplant centers, providing treatment to more than 20,000 dialysis patients and over 450 transplant recipients.

Some of the ways that QIRN3 promotes dialysis quality improvement include but is not limited to:

- ✓ Educating ESRD patients on the treatment options including home dialysis and transplant
- ✓ Developing standards to improve patient-centered dialysis care
- ✓ Promoting vocational rehabilitation to help patients remain working or return to the work force
- ✓ Supporting dialysis patients and providers in the review and investigation of patient grievances about quality of care
- ✓ Monitoring and reporting ESRD statistics to CMS
- ✓ Providing bilingual (English/Spanish) educational and informational resources for patients, families and professionals
- ✓ Assisting dialysis providers with their patient and family centered care initiatives
- ✓ Incorporating the patient's voice in all Network activities

What is a Subject Matter Expert (SME)?

Whether you are a dialysis patient receiving dialysis in-center or at home, a transplant patient, or a family member or caregiver of a patient, you have unique experiences and understanding of the renal world unlike anyone else. As someone with this experience, we find it appropriate to recognize you as a **Subject Matter Expert (SME)**.

What do SMEs do?

You are the link to promoting patient and family-centered care throughout our Network 3's region. You have unique skills that you can share with the others. Take time to share your talents and ideas with the Network staff, and learn more about the things that are happening in your center and the renal community. YOU can decide how YOU can make a difference!

Ultimately, your responsibilities as an SME are to:

- ✓ Help Network staff understand what is important to patients
- ✓ Enable positive communication
- ✓ Share useful ideas and experiences
- ✓ Serve as a role model to other patients

Your involvement will help develop a patient and family-centered culture at the facility and create ways for you and your peers to become engaged in the care provided.



What is the Patient Advisory Committee (PAC)?

The Patient Advisory Committee (PAC) was organized in 2006 with volunteers from throughout Network 3. Quality Insights Renal Network 3 (QIRN3) supports CMS' vision that the Network's work can be enriched by including the patient's voice. Therefore, when developing the PAC it was important for QIRN3 to include members that represented the diversity of our Network 3 regions (NJ, PR, US VI). Active participation of PAC SMEs includes committed and informed peritoneal dialysis patients, hemodialysis patients, transplant recipients, family members and caregivers, facility staff and ESRD Network 3 staff.

SMEs have been instrumental in the development and sustainability of QIRN3's work to promote beneficiary and family engagement, and improve quality of care throughout the renal community.

PAC SMEs provide a patient perspective to the Network on matter such as, but not limited to:

- ✓ Selection and development of Network Quality Improvement Activities (QIAs)
- ✓ Interpretation of Network QIA results and the development of interventions
- ✓ Content and format of QIRN3's website
- ✓ Content and development of informational and educational material for patients and families/caregivers such as the PAC newsletter- ***Kidneys R Us***
- ✓ Improvement of communication between patients and facility staff
- ✓ Direct attention to areas/issues of patient concerns
- ✓ Others (*More to be included under PAC Member Responsibilities*)

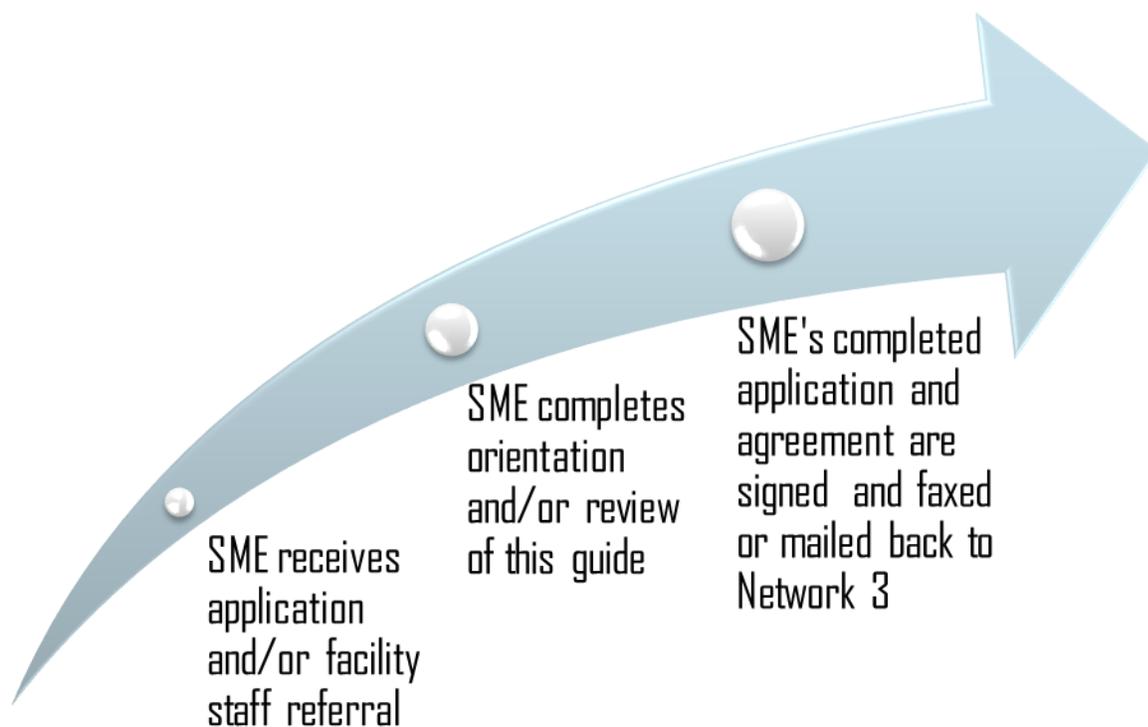
As of October 2018, there are 59 registered members (SMEs) in the PAC who contributed to the achievements of QIRN3's work.

- **42 New Jersey**
- **16 Puerto Rico**
- **1 US Virgin Islands**

PAC Mission Statement

The Patient Advisory Committee's Subject Matter Experts will support the mission of Quality Insights Renal Network 3 to enhance and advocate for the best quality of care possible provided to End-Stage Renal Disease patients, to represent and support the ESRD patient population by actively participating in the committee responsibilities and related functions. SMEs will be engaged in action-based agenda to ensure the activities of the PAC will be focused on the needs of the ESRD community of patients.

What is the SME Recruiting Process?



PAC - Member Responsibilities

This committee is charged with providing consumer advice to QIRN3's Medical Review Board and/or the Board of Directors and other committees and staff on such matters as, but not limited to:

- Selecting and developing Network Quality Improvement Activities (QIAs);
- Interpreting the results of all Network QIAs and the development of interventions;
- Assisting with the content development and format of the QIRN3 consumer website and patient newsletter (Kidneys R Us);
- Assisting with acquiring and promoting educational materials and resources for ESRD patients;
- Facilitating and improving communication between consumers and facility staff;
- Directing attention to areas and/or issues of consumer concern;
- Providing feedback on effectiveness of QIRN3's beneficiary-related activities;
- Reviewing and making recommendations regarding beneficiary-related health care messages, materials and activities planned by the QIRN3;
- Assisting in identification of barriers to obtaining quality health care from all perspectives on behalf of ESRD beneficiaries;
- Assisting in the development of patient engagement and development of patient and family-centered culture throughout Network 3;
- Attending meetings and showing commitment to QIRN3;
- Keeping informed on issues and agenda items in advance of meetings;
- Contributing skills, knowledge and experience when appropriate;
- Listening respectfully to others' points of view;
- Assisting the Network in recruitment of other patients;
- Maintaining confidentiality and privacy as appropriate.

What should SMEs not do?

There are things that SMEs should avoid doing to ensure their partnerships and role as a representative of their dialysis facility or as a PAC member are not placed at risk. As SME, **You should not:**

- Try to manage staff members or dictate their work.
- Expect to have every request granted - be realistic and work together with staff when setting goals.
- Ask staff or patients about confidential information.
- Post or share information that has not been approved by the clinic manager.
- Share the concerns of another patient without the patient's permission.
- Advise or provide patients with clinical information. Always encourage them to speak with their doctor.



**REMEMBER, FOSTERING MUTUAL RESPECT
IS YOUR KEY TO SUCCESS!**

Originating Dept: QIRN3 Patient Services
Effective Date: January 2016
Last Review Date: December 2017

PAC- SME Participation/Membership Policy

PURPOSE

To establish standards for SMEs' attendance at regularly scheduled meetings via teleconference or in-person.

DEFINITIONS

SMEs participation is a positive process which requires enthusiasm and commitment on their part in order to achieve all the potential benefits of membership on the Patient Advisory Committee. Members missing meetings reduces the effectiveness of the entire group. Active SMEs' participation will be essential in helping with the analysis and implementation of ideas and plans for Network activities.

MEETING SCHEDULE

Meetings are scheduled via teleconference on the second Tuesday of every two months, six (6) meetings per year starting with January as the first meeting month, with at least one (1) of these meeting hosted in person. Teleconference will also be made available for those SMEs who cannot attend the in-person meetings.

STANDARDS FOR ATTENDANCE

In order to effectively execute membership responsibilities, SMEs shall regularly attend scheduled meetings.

- (1) SMEs are expected to notify QIRN3 staff of meetings they know they will miss.
- (2) SMEs are expected to notify QIRN3 staff of meetings they will attend.
 - (a) communications may be via phone call, voicemail or email
- (3) SME shall be deemed to be out of conformity with the requirement to regularly attend meetings if:
 - (a) the member has three consecutive unexcused absences from meetings within a one year period

REMEDY FOR FAILURE TO MEET STANDARDS OF ATTENDANCE

- (1) If a SME fails to meet standards for attendance, the Network shall:
 - (a) discuss the member's difficulties with him/her, and attempt to resolve them;
 - (b) provide the SME with one additional opportunity to continue membership by participating in the following scheduled meeting; and
 - (c) provide SME the opportunity to confirm directly with QIRN3 staff their continued interest in maintaining membership.
- (2) If the SME does not wish to continue his/her participation, the SME must notify the Network.
- (3) If SME misses a fourth consecutive meeting without following up with the Network subsequent to the previous steps:
 - (a) SME will receive letter/email from Network thanking them for their participation and informing of their completion of tenure.

Contact Information



Quality
Insights

Renal Network 3

PLEASE
FAX OR MAIL
ALL PATIENT ADVISORY COMMITTEE
MEMBERSHIP APPLICATIONS
& AGREEMENTS TO

Fax: (609)490-0835

Mail: Quality Insights Renal Network 3
109 South Main St, Suite 21
Cranbury, NJ 08512

Yessi Cubillo

Patient Services Coordinator

(609)490-0310 (Ext. 2431)

ycubillo@nw3.esrd.net

To file a grievance please contact:

Joan Wickizer

Patient Services Director

(609)490-0310 (Ext. 2430)

jwickizer@nw3.esrd.net

Patient Toll Free Number: 1-888-877-8400

www.qirn3.org