



Patient & Family Advisory Council (PFAC)

Representative's Guide

2021 -2026 Edition

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Welcome

Are you an in-center or at-home dialysis or transplant patient or a family member/caregiver of a patient?

If so, here is an exclusive opportunity for you!

We invite you to join the Patient and Family Advisory Committee (PFAC) 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. Therefore, 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 one receives! Your contributions will add tremendous value to the goals 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 the Quality Insights Renal Network 3 (QIRN3) and the Patient and Family Advisory Council (PFAC).
- Provide you with guidelines to help you be the best SME you can be.
- Explain how you can get involved in improving dialysis care.

Here is a brief history lesson:

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

In ESRD Network 3 there are over 250 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:

- ✓ **Incorporating the patient and family/cargiver's voice in all Network activities**
- ✓ 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

Who 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 regions (New Jersey, Puerto Rico and U.S. Virgin Islands). 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!

Your role as SME are to:

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



Your involvement will shape the dialysis facilities patient and family-centered culture and promote new ways for you and your peers to become engaged in the care provided.

What is the Patient & Family Advisory Council (PFAC)?

The Patient and Family Advisory Council (PFAC) 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 and family member's voice. Therefore, when developing the PFAC it was important for QIRN3 to include members that represented the diversity of our Network 3 regions (NJ, PR, US VI). Active SMEs participation in the PFAC 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 all aspect of CMS' statement of 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:

- ✓ Development of Network Quality Improvement Activities (QIAs) and projects
- ✓ Interpretation of the Network's QIAs results and development of interventions
- ✓ Content and format of QIRN3's website www.qirn3.org
- ✓ Content and development of informational and educational material for patients and families/caregivers
- ✓ Improvement of communication between patients and facility staff
- ✓ Direct attention to areas/issues of patient concerns
- ✓ Others

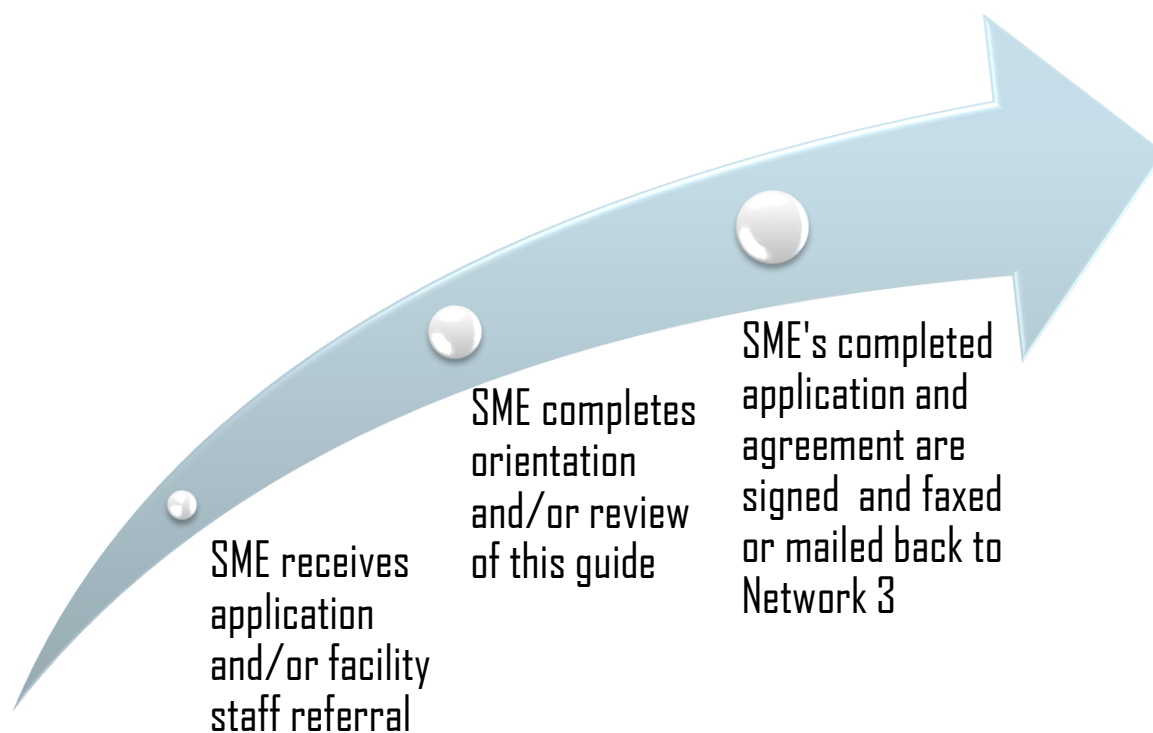
As of May 2022, the PFAC counts on the participation of 53 members (SMEs) who have contributed to the achievements of QIRN3's work.

- 32 New Jersey
- 18 Puerto Rico
- 3 US Virgin Islands

PFAC Mission Statement

The Patient and Family Advisory Council's Subject Matter Experts 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 council's meetings and related functions. SMEs will be engaged in action-based agenda to ensure the activities of the PFAC are focused on the needs of the ESRD community of patients.

What is the SME Recruiting Process?



PFAC - Member Responsibilities


The Patient and Family Advisory Council (PFAC) 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:

- Developing Network Quality Improvement Activities (QIAs) and projects;
- Interpreting the results of all Network QIAs and the development of interventions;
- Assisting with the content development and format of the QIRN3 consumer website;
- Assisting with acquiring and promoting educational materials and resources for ESRD patients and facility staff;
- Facilitating and improving communication between patients/family members and facility staff;
- Directing attention to areas and/or issues of patient and family concern;
- Providing feedback on effectiveness of QIRN3's patient and family-related activities;
- Reviewing and making recommendations regarding patient 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 partnership and role as a representative of their dialysis facility or as a PFAC 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 facility administrator/clinic manager.
- Share the concerns of another patient without their permission.
- Advice or provide patients with clinical information without the approval or supervision of a facility staff. Always encourage them to speak with their facility staff or doctor.



Remember, fostering mutual respect
is your key to success!

Originating Dept: QIRN3 Patient Services
Effective Date: June 2021
Last Review Date: May 2022

PFAC- SME Participation/Membership Policy

PURPOSE

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

PARTICIPATION

Patients and family members/caregiver's engagement as SMEs requires commitment on their part in order to achieve all the potential benefits of membership within the Patient and Family Advisory Committee (PFAC). Active SMEs' participation in meetings and related events will be essential in helping with the analysis and implementation of ideas and plans for Network activities.

MEETING SCHEDULE

Meetings are scheduled via Zoom and phone conference every two months on the second Tuesday of the given month (January, March, May, July, September and November), six (6) meetings total per year. At least one (1) of these meetings may be hosted in person. Phone conference will also be made available for those SMEs who cannot attend the in-person meeting.

STANDARDS FOR ATTENDANCE

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

- (1) SMEs should notify QIRN3 staff of meetings they know they will miss.
- (2) SMEs should confirm/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

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



PLEASE
FAX – MAIL - EMAIL
ALL PATIENT ADVISORY COMMITTEE
MEMBERSHIP APPLICATIONS
& AGREEMENTS TO

Fax: (609)490-0835

Mail: Quality Insights Renal Network 3
PO Box 845
Hightstown, NJ 08520

Email: ycubillo@qualityinsights.org

Yessi Cubillo
Patient Engagement Specialist
(609)490-0310 (Ext. 2431)
ycubillo@qualityinsights.org

Patient Toll Free Number: 1-888-877-8400
www.qirn3.org