

Health Services Advisory Group (HSAG): End Stage Renal Disease (ESRD) Network 7 Subject Matter Expert (SME) Guide

An Introduction to Being a SME

Congratulations!

You have been nominated to be a Network 7 SME!

Thank you for choosing to volunteer with us. The role of a SME is an important one. This guide will explain more about your role as a SME, including:

- Why you were selected.
- How you can help.
- What is expected of you.
- Who the Network is.
- What the Network, with your help, hopes to achieve.

Your time and effort are greatly appreciated. Thank you for your willingness to work with us as a SME on the Patient Advisory Council (PAC). After you have had a chance to read this guide, please let us know if you have any questions. We look forward to your input.

Why You?

More than likely, you were nominated to be a SME by a facility social worker. He or she thought your input about the patient/caregiver experience would add great value to the Network's quality improvement efforts. Your participation will give all kidney patients and their caregivers a voice in PAC discussions and will help to improve the quality and safety of dialysis services. This is at the heart of the PAC's mission.

Your Role

Your role may include:

- Helping with the creation of educational materials for patients and their caregivers.
- Developing and reviewing Network documents to make sure they are "patient-centered."
- Sharing your patient/caregiver experience in the newsletter.
- Joining conference calls.
- Providing the patient perspective on Network activities.
- Evaluating quality improvement activities (QIAs).
- Maintaining an awareness of all Network programs that directly affect patients.
- Spreading the work of the Network and increasing overall awareness.

Committees, Boards, and Councils

There are a lot of moving parts to the Network. Your involvement is one of the most important. You can participate in just one way or in as many as your time and energy permit. As a SME, you are automatically a member of the PAC. PAC members help the Network to:

- Identify patient/caregiver concerns, problems, and educational needs.
- Improve health outcomes and quality of life for kidney patients.
- Promote a higher standard of care through patient-centeredness.
- Advocate for patient rights.
- Identify and address barriers to quality end stage renal disease (ESRD) care.
- Develop QIAs.

Read about some of the other groups you could join:

- **QIA Subgroups**

Based on the area of interest you indicate on your participation agreement, you could be placed into one or more QIA subgroups. The Centers for Medicare & Medicaid Services (CMS) determines the focus of each QIA and requires patient SME participation. Participation expectations vary by QIA and may include additional conference calls and/or review of educational material with the provision of feedback. CMS has assigned the Network the following QIAs for the 2019

contract year:

- Decreasing bloodstream infections (BSIs)
 - Increasing the number of patients dialyzing at home
 - Increasing the number of patients listed for transplant
 - A population health-focused pilot project (topic not yet determined)
- **The National Patient/Family Engagement Learning and Action Network (NPFE-LAN)**
The NPFE-LAN brings kidney patients, family members, and caregivers/care partners together to improve ESRD care. Each of the 18 Networks elects patient and caregiver SMEs to be a part of the NPFE-LAN. Together, SMEs improve the care that kidney patients receive. In the NPFE-LAN, all members:
 - Are equal.
 - Contribute expertise in different areas.
 - Bring something to the discussion.

SMEs elected for this group are expected to participate in at least one NPFE-LAN conference call per month and cannot participate for more than three consecutive years.

- **National Kidney Community Emergency Response (KCER) LAN**

The KCER Program provides disaster preparedness resources to:

- Save lives.
- Improve outcomes.
- Empower patients and families.
- Educate healthcare workers.
- Build partnerships with stakeholders.
- Promote readiness in the renal community.
- Support the ESRD Network Program.

To ensure the patient's voice is incorporated in all activities, KCER convenes the National KCER patient and Family- (N-KPFE-) LAN that includes representation from patients, families, and caregivers. The N-KPFE-LAN focuses on topics chosen by the participating patients, families, and caregivers, who will provide a patient perspective for efforts to improve emergency/disaster preparedness and response for the ESRD population. SMEs assigned to this group are required to participate in bi-monthly conference calls.

- **The Corporate Governing Body (CGB)**

The Network CGB oversees the operations of each of the ESRD Network contracts with CMS. It ensures that each contract is effectively managed in accordance with contract requirements. The CGB also ensures strict adherence to corporate compliance and financial management policies and procedures. You may be asked to be a part of the CGB.

- **The Medical Review Board (MRB)**

The MRB serves as the primary advisory panel for all Network:

- QIAs.
- Patient grievances.
- Special studies and surveys regarding healthcare delivery to ESRD patients.

You may be asked to be a part of the MRB.

- **The Network Council (NC)**

The NC is representative of the Network population and includes nephrologists, nurses, dieticians, social workers, patients and caregivers. It serves in an advisory capacity. You may be asked to be a part of the NC.

SME Participation Guidelines

There are certain policies that guide SME involvement. SMEs:

- Are members of the Network's PAC.
- Can be on any modality or the caregiver of a patient.
 - This includes in-center or home hemodialysis, peritoneal dialysis, or those who have a functioning kidney transplant.
- Are required to participate in two PAC calls, at minimum, and additional calls as needed, based on his/her subgroup assignment.
 - The Network urges you to voice your opinion during these calls. Your input is what makes the PAC work.
- Will be sent communication through email.
 - Although not required, it is preferred that SMEs have access to email.
- Are representative of the Network and are expected to act in a respectful manner at all times.
 - This includes refraining from offensive language regarding race, gender, ethnicity, and/or sexual orientation.
- Must report changes in contact information.
 - Phone, email, and mailing address updates should be reported to Network Patient Services staff in a timely manner so we can stay in touch with you.

PAC SME Term Limits

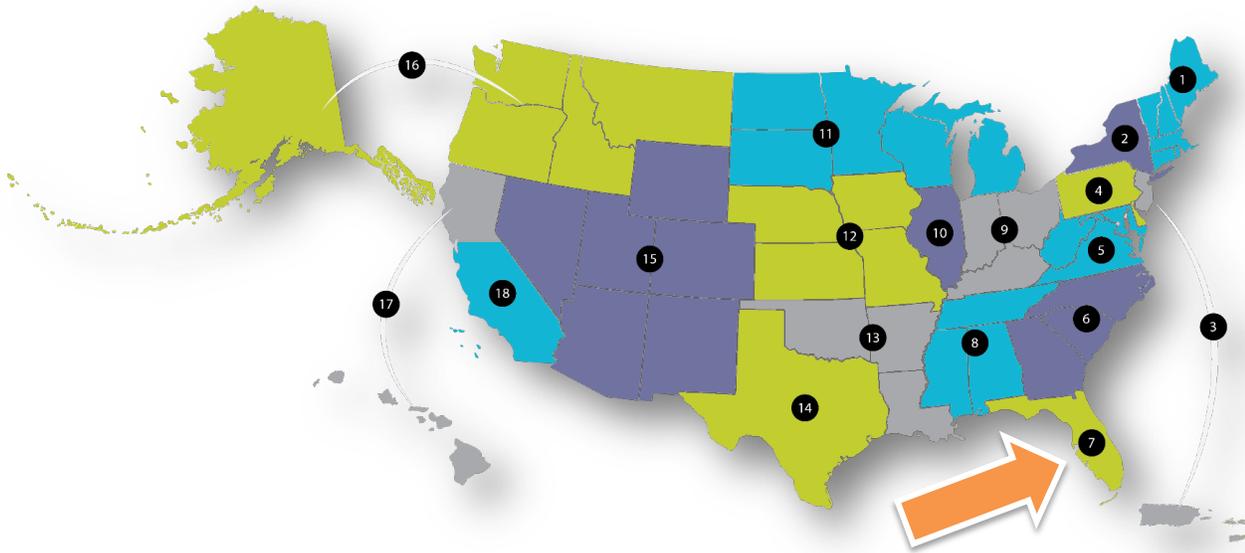
The Network strives to include as many patients and caregivers in active SME roles as possible; it is important that everyone has the opportunity to be heard and to speak for their fellow ESRD patients. SMEs are required to actively participate while they are on the PAC to ensure that all perspectives and cultural viewpoints are represented at all times.

- SMEs must sign an agreement to participate/volunteer for at least one year.
 - At the end of each year, a SME may choose whether he/she wishes to continue.
 - If a SME wishes to continue on the PAC, he/she must sign a renewal agreement for one year.
 - As long as the PAC member remains **actively involved**, there are no membership term limits.
 - The Network will always take special circumstances preventing active participation into consideration, as long as the SME communicates such circumstances to the Network.

- The PAC chair position has a term limit of three years.
 - At the end of three years, the Network will open the opportunity to any PAC member interested in the position.
 - If no PAC member wishes to run for chair-elect, then the previous chair will be allowed to continue in the position for another term.
 - In the event that the chair needs to resign, a new chair shall be elected by the PAC as soon as possible.

Background of the Federal ESRD Program and ESRD Networks

Prior to 1972, Medicare did not pay for any care specific to ESRD. Patients had to pay for their own treatments. Then, in 1972, Congress passed section 1881 of the Social Security Act (SSA). The SSA established the ESRD Program. Now, under the ESRD Program, Medicare pays for dialysis and transplant services and oversees all ESRD care. There are 18 ESRD Networks across the country.



HSAG: ESRD Network 7 covers the state of Florida.

Goals of the CMS ESRD Network Program

The goals of the ESRD Network Program are to:

- Empower patients and doctors to make decisions about their health care.
- Usher in a new era of state flexibility and local leadership.
- Support innovative approaches to improve quality, accessibility, and affordability.
- Improve the CMS customer experience.

Who is Health Services Advisory Group (HSAG)?

HSAG is contracted by CMS to improve the quality of healthcare for Medicare patients. We do that by keeping patients, like you, at the center of all healthcare decisions.

HSAG is responsible for managing four of the ESRD Networks (20 percent of the ESRD patient population nation-wide), including Networks 7, 13, 15, and 17.

HIPAA and the Privacy of Medical Information

What is HIPAA?

HIPAA is the Health Insurance Portability and Accountability Act of 1996. This act protects the healthcare privacy of all Americans. Primarily, it means that all information about your health is private and should be kept private.

Sharing Your Medical Information with Other Patients

You may choose to share your health information with others, but that is up to you. If someone shares their health information with you, you must keep it confidential.

Do *Not* Give Medical Advice

As kidney patients, you have a lot to teach each other, and you are free to share your own experiences. But be careful! ***Never*** act as an authority regarding medical information. ***Never*** give medical advice. Medicines or a diet that works for you may be dangerous, or even deadly, to another patient. Even a tiny difference in a person's medical condition can make a difference. Remember, you are the expert on being a patient. Medical professionals are the experts on healthcare. The best medical help you can give to another patient is to send them to the right staff member.

Resources

HSAG: ESRD Network 7	www.hsag.com/esrdnetwork7
American Association of Kidney Patients (AAKP)	www.aakp.org
American Kidney Fund (AKF)	www.kidneyfund.org
Dialysis Facility Compare	www.medicare.gov/dialysisfacilitycompare
Forum of ESRD Networks	www.esrdnetworks.org
National Kidney Foundation (NKF) of Florida	www.kidneyfl.org
ESRD National Coordinating Center	www.esrdncc.org
KCER	www.kcercoalition.com

Contact Information

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