

2018
HSAG: ESRD Network 17
Patient Subject Matter Expert Guide

An Introduction to Being a Patient Subject Matter Expert (SME)

Congratulations! You have been nominated to be a Network 17 Patient Subject Matter Expert (SME)!

Thank you for choosing to volunteer with us. The role of a SME is an important one. This guide will explain more about what your role as a Patient SME will be, 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 hearing from you. We look forward to your input.

Why You?

You were nominated to be a SME by your facility's social worker or facility administrator. He or she thought that you would have much to contribute about the patient experience of care; that your input would add great value to the Network's quality improvement efforts. We agree.

By adding your voice to PAC discussions, you provide a voice for all kidney patients and their caregivers. This is at the heart of the PAC's mission. Your active participation will improve the quality and safety of dialysis services by providing the patient voice.

Your Role

Your role may include:

- Helping with the creation of educational materials for patients.
- Developing and reviewing Network documents to make sure they are "patient-centered."
- Sharing your patient story for 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.

More About 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 or in as many ways your time and energy permit. As a patient SME, you are automatically a member of the PAC. PAC members help the Network to:

- Identify patient 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 will 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 2018 contact year:

- Decreasing healthcare-associated infections (HAIs)
- Improving the assessment of pain management
- Increasing the number of patients dialyzing at home
- Increasing the number of patients listed for transplant

- **The National Patient/Family Engagement (NPFE) Learning and Action Network (LAN)**

CMS asked all of the ESRD Networks to bring kidney patients, family members, care partners, and dialysis staff together to improve ESRD care. This group is known as the NPFE LAN. Each of the 18 Networks elect patient SMEs to be a part of the NPFE LAN. The LAN provides a forum for patients and dialysis staff to work collectively. Together they improve the care that kidney patients receive. In the LAN, all members are equal; they are all SMEs with expertise in different areas. Everyone brings something to the discussion; everyone has the opportunity to learn something new; and together they find better ways to solve problems. Patient SMEs elected for this group are required to participate in at least one NPFE conference call per month.

- **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, and support the ESRD Network Program. To ensure the patient's voice is incorporated in all activities, KCER convenes an 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. Patient SMEs assigned to this group are expected to participate in bi-monthly conference calls.
- **The Board of Directors (BOD)**
The Network BOD 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 BOD also ensures strict adherence to corporate compliance and financial management policies and procedures. You may be asked to be a part of the BOD.
- **The Medical Review Board (MRB)**
The Medical Review Board serves as the primary advisory panel for all Network:
 - Quality improvement activities.
 - 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, dietitians, social workers, patients and caregivers. It serves in an advisory capacity. You may be asked to be a part of the NC.

Patient SME Participation Guidelines

There are certain policies that guide Patient SME involvement. Patient SMEs:

- Are members of the Network's PAC.
 - The PAC is made up of kidney patients and family members or care partners who represent the Network's diversity.
- Can be on any modality, including in-center or home dialysis, peritoneal dialysis, or have a functioning kidney transplant.

- Are required to participate in the two PAC calls at minimum and additional calls as needed, based on his/her subgroup assignment.
 - We urge 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 patient SMEs have access to email.
- Are representative of the Network and therefore 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, including phone, email, and mailing address, to the Network's Patient Services staff in a timely manner.
 - This is so we can stay in touch with you.

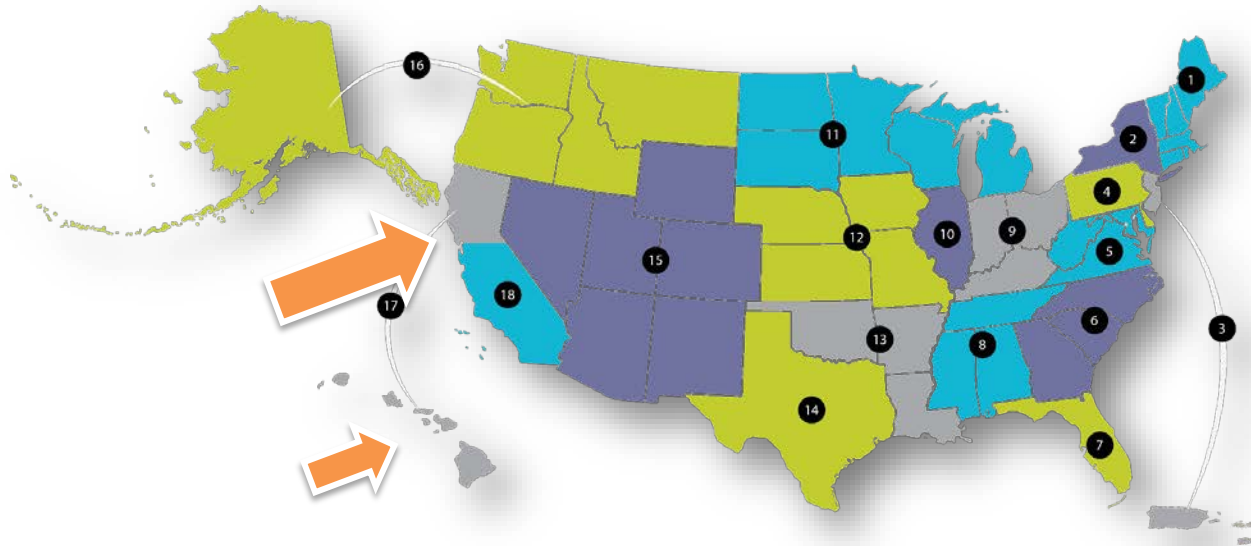
Patient SME Term Limits

The Network strives to include as many patients and caregivers in active SME roles as possible. It is important that everyone have the opportunity to be heard and to speak out for their fellow ESRD patients. We do require that Patient SMEs actively participate while they are on the PAC. This is important because it ensures that all patient 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 to continue or not.
 - If a SME wishes to continue on the PAC, he/she must sign a renewal agreement for one year.
 - As long as the member remains **actively involved**, there are no membership term limits.
 - The Network will always take into consideration special circumstances preventing active participation, as long as the SME communicates such circumstances to the Network.

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 17 covers Northern California, Hawaii, American Samoa, Guam, and Northern Mariana Islands.

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. Our job is 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 several of the ESRD Networks (20% of the ESRD patient population nation-wide), including:

- Network 7
- Network 13
- Network 15
- **Network 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. Basically, 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 help you can give to another patient is to send them to the right staff member.

Resources

HSAG: ESRD Network 17	https://www.hsag.com/en/esrd-networks/esrd-network-17/
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 Northern California	https://www.kidney.org/offices/nkf-serving-northern-california-pacific-northwest
National Kidney Foundation (NKF) of Hawaii	https://kidneyhi.org/
ESRD National Coordinating Center (NCC)	www.esrdncc.org
KCER	www.kcercoalition.com

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