

HSAG: ESRD Network 13 Patient Subject Matter Expert Guide

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

Congratulations! You have been nominated to be a Network 13 Patient SME!

Thank you for choosing to volunteer with us. The role of an 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 you applied after seeing the flyer!). He or she thought that you would have much to contribute about the patient experience of care. Your input will add great value to the Network's quality improvement efforts. We agree. By adding your voice to PAC discussions, you will 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.
 - Specifically, the Centers for Medicare & Medicaid Services (CMS) Monthly Conference Call.

- Each SME is required to attend one of these calls during the year. Dates and times will be provided in advance.
- Providing the patient perspective on Network activities.
- Attending the quarterly PAC call.
 - Dates will be provided in advance.
- 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, as you are a member of an elite group. 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 and educational materials.
 - These materials are given to Network Patient Representatives (NPRs) at the facilities to distribute.

Read about some of the other groups you could join:

- **QIA Workgroups**

Based on the area of interest you indicate on your participation agreement, you will be placed into one or more QIA workgroups. CMS determines the focus of each QIA and requires patient SME participation in each of them. Participation expectations vary by workgroup. Some workgroups may include additional conference calls. Some may require you to review educational material and provide feedback. CMS has assigned the Network the following QIAs for the 2018 contract year:

 - Reducing Healthcare-Associated Infections (HAIs)
 - Improving Mental Health
 - Promoting Home Dialysis
 - Improving Transplant Coordination

- **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. Six SMEs, including one family member or care partner, are needed.

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

The KCER Program provides emergency 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 a LAN that includes representation from patients, families, and caregivers. This is called the National KCER Patient and Family Engagement (N-KPFE) LAN. The N-KPFE-LAN focuses on topics chosen by the participating patients, families, and caregivers, who provide the 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 Corporate Governing Body (CGB)**

The Network CGB, formerly known as the Board of Directors, 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. Two patient SMEs are needed on the CGB.

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

The MRB serves as the primary advisory panel for the Network's QIAs, patient grievances, and special studies and surveys regarding healthcare delivery to ESRD patients. You may be asked to be a part of the MRB. Two patient SMEs are needed on the MRB.

- **The Network Council (NC)**

The NC is representative of the Network population and includes nephrologists, nurses, dietitians, social workers, patient and caregivers. It serves in an advisory capacity for determining education and outreach needs within the ESRD communities served by the Network. You may be asked to be a part of the NC. Two patient SMEs are needed on 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 hemodialysis, peritoneal dialysis, or have a functioning kidney transplant.
- Are required to participate in the four PAC calls each year and additional calls (e.g., CMS Call, State Survey Agency Call) as needed, based on his/her workgroup assignment. The Network does understand that life happens, but we do appreciate notice if you will not be able to attend a call. This will be an excused absence.
 - We urge you to voice your opinion during these calls. Your input is what makes the PAC work.
- Will be sent communication through email.
 - Patient SMEs *must* have access to email. This is a requirement.
- Are representatives 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.

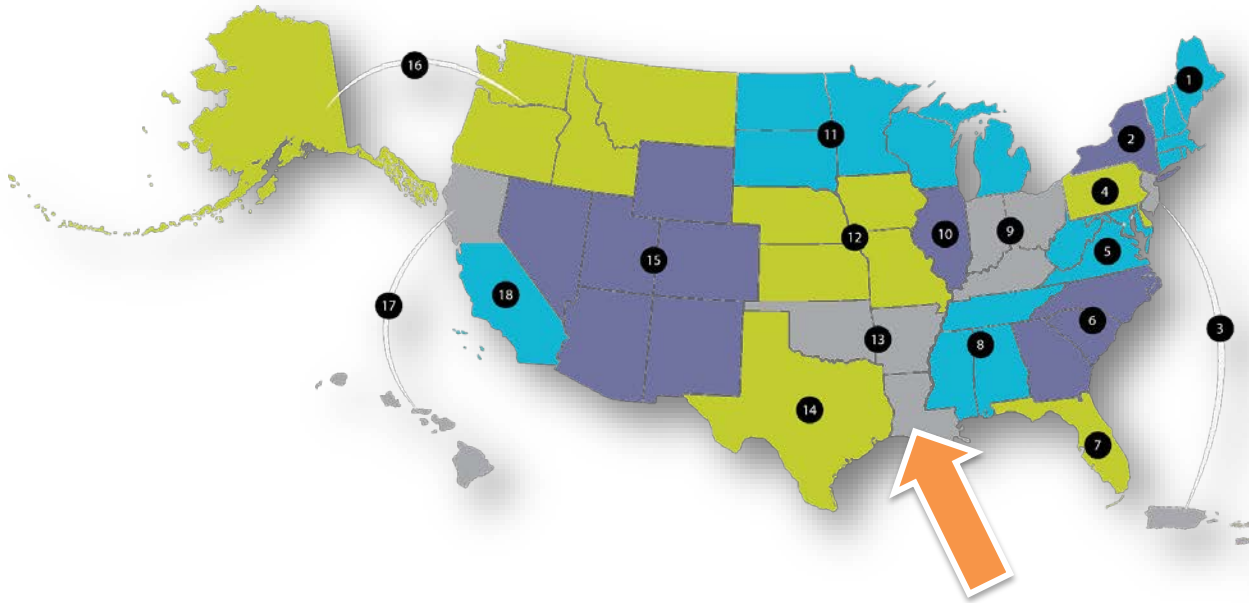
Patient SME Term Limits

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. To ensure this happens, the Network does set some term limitations and does 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, however the Network is required by CMS to have one quarter of the members to be new participants.
 - The Network will always take into consideration special circumstances preventing active participation, 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 13 covers Oklahoma, Arkansas, and Louisiana.

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 healthcare.
- Usher in a new era of state flexibility and local leadership.
- Support innovative approaches to improve quality, accessibility, and affordability of ESRD care.
- 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 four of the 18 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. This 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. Medicine 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 cause a problem. 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 13	www.hsag.com/esrdnetwork13
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)	www.kidney.org
ESRD National Coordinating Center (NCC)	www.esrdncc.org
KCER	www.kcercoalition.com
Renal Support Network (RSN)	http://www.rsnhope.org/
Medical Education Institute (MEI)	https://meiresearch.org/
In-Center Hemodialysis CAHPS	https://ichcahps.org/
United Network for Organ Sharing (UNOS)	https://unos.org/
National Living Donor Assistance Center (NLDAC)	https://www.livingdonorassistance.org/home/default.aspx

Acronym Guide

2728	ESRD Medical Evidence Report
A	
AAKP	American Association of Kidney Patients
AKF	American Kidney Fund
APRN	Advanced Practice Registered Nurse
AVF	Arteriovenous Fistula
AVG	Arteriovenous Graft
B	
BFR	Blood Flow Rate
BMI	Body Mass Index
BOD	Board of Directors
BP	Blood Pressure
BSI	Bloodstream Infection
BUN	Blood Urea Nitrogen
C	
CAPD	Continuous Ambulatory Peritoneal Dialysis
CCHT	Certified Clinical Hemodialysis Technician
CCN	CMS Certification Number (Previously MPN)
CCPD	Continuous Cycling Peritoneal Dialysis
CDC	Centers for Disease Control and Prevention
CDN	Certified Dialysis Nurse
CEU	Continuing Education Unit
CfC	Conditions for Coverage
CHT	Certified Hemodialysis Technician
CKD	Chronic Kidney Disease
CM	Clinic Manager
CMS	Centers for Medicare & Medicaid Services
COPD	Chronic Obstructive Pulmonary Disease
COR	Contract Office Representative
CW	CROWNWeb
D	
DFC	Dialysis Facility Compare

E	
EMR	Electronic Medical Record
EMTALA	Emergency Medical Treatment and Labor Act of 1986
EPO	Epogen or Erythropoietin
ESRD	End Stage Renal Disease
ESRD NCC	End Stage Renal Disease National Coordinating Center
F	
FA	Facility Administrator
FOIA	Freedom of Information Act
H	
HAI	Healthcare-Associated Infection
HbsAb	Hepatitis B Surface Antibody
HbsAg	Hepatitis B Surface Antigen
HBV	Hepatitis B Virus
HD	Hemodialysis
HGB	Hemoglobin
HHD	Home Hemodialysis
HIPPA	Health Information Portability and Accountability Act of 1996
HSAG	Health Services Advisory Group, Inc.
I	
ICHD	In-Center Hemodialysis
ICH CAHPS	In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems
IDT	Inter-Disciplinary Team
IVD	Involuntary Discharge
IVT	Involuntary Transfer
K	
KCER	Kidney Community Emergency Response
KDOQI	Kidney Disease Outcomes Quality Initiative
KDQOL	Kidney Disease Quality of Life Survey
Kt/V	Method to Measure Adequacy of Dialysis: K = the Dialyzer Clearance, T = Time on Dialysis, and V = Volume of Water in the Patient's Body

L	
LAN	Learning and Action Network
LDO	Large Dialysis Organization
LTC	Long Term Catheter
M	
MRB	Medical Review Board
N	
NC	Network Council
NCC	National Coordinating Center
NKF	National Kidney Foundation
NPFE LAN	National Patient and Family Engagement Learning and Action Network
O	
OCR	Office for Civil Rights (Organization within HHS)
P	
PA	Physician Assistant
PAC	Patient Advisory Committee
PCP	Primary Care Physician, Primary Care Provider, Primary Care Practitioner
PCT	Patient Care Technician
PD	Peritoneal Dialysis
PEP	Performance Evaluation Program
PFE	Patient and Family Engagement
POA	Power of Attorney
POC	Plan of Care
PPE	Personal Protective Equipment
PSC	Patient Services Coordinator
PSC/PSR	Performance Score Certificate or Performance Score Report
PSD	Patient Services Director
Q	
QAPI	Quality Assessment and Performance Improvement
QI	Quality Improvement
QIA	Quality Improvement Activity
QIC	Quality Improvement Coordinator
QID	Quality Improvement Director

R	
RCA	Root Cause Analysis
RD	Registered Dietician
REMIS	Renal Management Information System
RN	Registered Nurse
S	
SME	Subject Matter Expert
SSA	State Survey Agency
SSDI	Supplemental Security Disability Insurance, Social Security Disability Insurance
SSI	Supplemental Security Income
SSN	Social Security Number
T	
TPS	Total Performance Score
U	
UNOS	United Network of Organ Sharing
UPI	Unique Patient Identifier

Contact Information

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