

HSAG: ESRD Network 13 Network Patient Representative Guide

An Introduction to Being a Network Patient Representative (NPR)

Congratulations on your decision to participate in the Network 13 Network NPR Program!

Thank you for choosing to volunteer with us. The role of an NPR is an important one. This guide will explain more about what your role as your facility's NPR 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 an NPR. After you have had an opportunity to read this guide, please let us know if you have any questions. We look forward to hearing from you and getting your input.

Why You?

You were nominated to be an NPR by a facility staff member, or maybe you saw the information in the patient newsletter and decided to apply. If you were nominated, then the staff member who nominated you believed that you would have much to contribute about the patient experience of care; that you would be a good link between other patients and the facility staff.

What is the NPR Program?

The NPR Program is a communications vehicle developed to have patients:

- Help spread educational information to other patients.
- Provide peer-to-peer support for patients and additional support for staff at the dialysis facility.

Network 13 and the Patient Advisory Committee (PAC) have worked hard to revive this program to help communicate information from the Network and other sources directly to patients. The NPR Program is an essential link between Network 13, your dialysis facility, and fellow patients.

Who are the NPRs?

NPRs are individuals who are on dialysis and who:

- Have chosen to volunteer to assist their facility.
- Have the desire to help improve the patient experience of care.
- Are available to meet with patients to discuss questions, challenges, or concerns related to their personal adjustment to dialysis.
- Are willing to represent the patient voice.
- Should be a positive example in their facilities.

The Network 13 NPRs come from Oklahoma, Arkansas, and Louisiana.

Who NPRs are NOT

NPRs **are not** staff and are never expected to be:

- Distributors of medical advice.
- Contact persons for patient grievances for care being provided at the facility.
- Go-betweens for staff and patients to relay ALL requests and information to address their needs.
- Substitutes for staff members for required care team patient education, assessment, or evaluation.
- Persons responsible for posting or sharing information at the facility that has not been previously approved by the facility staff.
- Permitted to share concerns of another patient without that patient's permission.

If you feel that you are ever being asked to act in any of these capacities, speak to your facility administrator immediately.

Your Role as an NPR

It is up to you to determine how involved you want to be, and that will shape your role as an NPR. Below are some participation ideas. Consider:

- Sharing Network 13 educational materials at your own facility (such as passing out flyers to patients with staff permission).
- Participating in National Learning and Action Network (LAN) phone calls with patients and providers from all over the United States to receive education and best practices.
- Verifying the posting of required Network 13 posters in your facility lobby.
- Helping your facility social worker distribute Network 13 patient newsletters.

- Writing a “patient voice” article for the Network 13 patient newsletter.
- Providing the patient perspective on quality improvement activities (QIAs) in which your facility may be participating with Network 13.
- Participating in Quality Assurance Program Improvement (QAPI) meetings.
- Supporting new patients at your facility/helping establish a support group/new patient adjustment groups.
- Helping staff members decorate for special events/holidays.
- Helping with lobby day education.
- Developing a patient bulletin board.

And More! Your role is not limited to these activities. Discuss additional ideas you have with your facility staff member.

NPR Participation Guidelines

There are certain policies and processes that guide NPR involvement. NPRs:

- Will be sent communication primarily through the facility staff member responsible for the quality improvement activity.
- May receive additional communication/resources via email.
 - It is required that NPRs have an email address that they check regularly.
- 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.

We encourage you to meet with the facility staff member who nominated you to discuss your role and agree on the activities in which you will participate as an NPR. With his or her help, *you* will decide how *you* can make a difference at your facility.

Volunteer Commitment

As a volunteer, we value your time and understand that life and your health can sometimes limit your involvement. There is much to do and therefore, there may be more than one NPR per dialysis facility to help carry the load. More NPRs mean more patient engagement at the facility level! We ask that you serve as NPR for at least one year. If you decide you are no longer able to volunteer, please notify your facility so you

can discontinue your agreement and be relieved of volunteer NPR duties. This will allow your facility to find a replacement NPR to take on your role.

What is a Learning and Action Network (LAN)

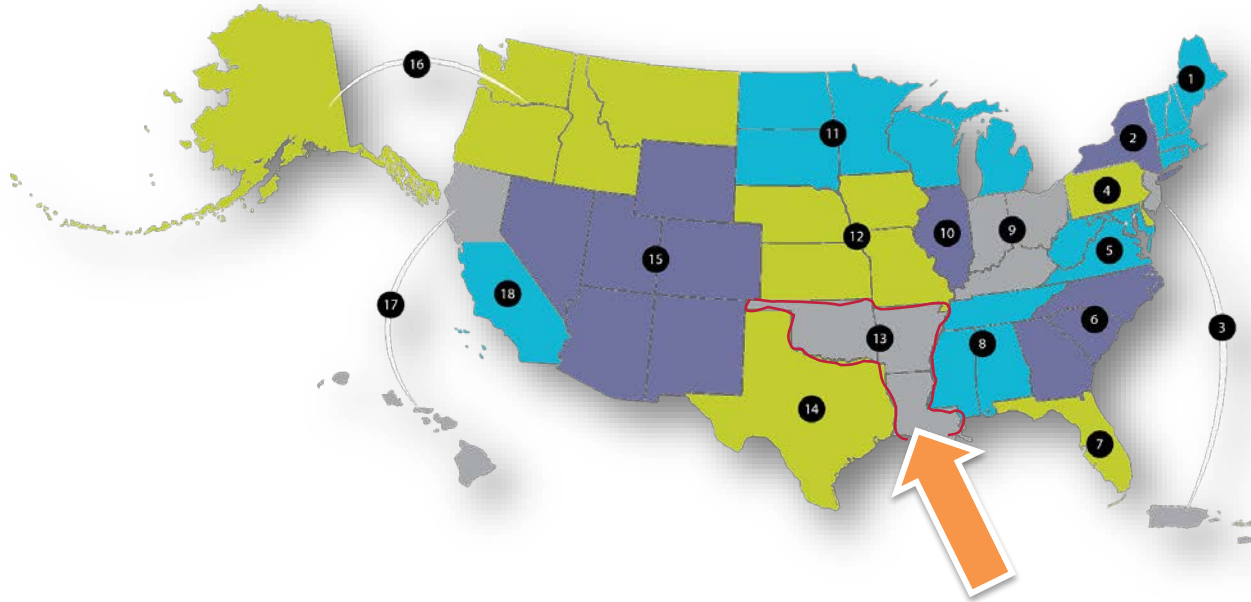
A LAN is a forum for shared communication and collaborative work. The ESRD LANs were formed because the Centers for Medicaid and Medicare Services (CMS) asked the ESRD Networks to bring kidney patients, family members, care partners, and dialysis staff together to improve ESRD care. The ESRD LANs afford patients and dialysis staff the opportunity to work collectively to 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. Together, they find better ways to solve problems. The LANs meet every other month via phone. This year there are four different LANs:

- Patient Experience of Care
 - To discuss grievances and involuntary discharge (IVD) issues
- Healthcare-Associated Infections (HAIs)
- Transplant
- Home Dialysis

Your facility may invite you to participate in a call with them, but another way to receive information about the different LAN calls is to contact the Patient Services Staff at Network 13. (All contact information in on the last page of this guide.) We would love to have you on the call with us!

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 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 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	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 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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