



Facility Peer Representative Handbook

www.ESRDNetwork10.org



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ESRD Network 10

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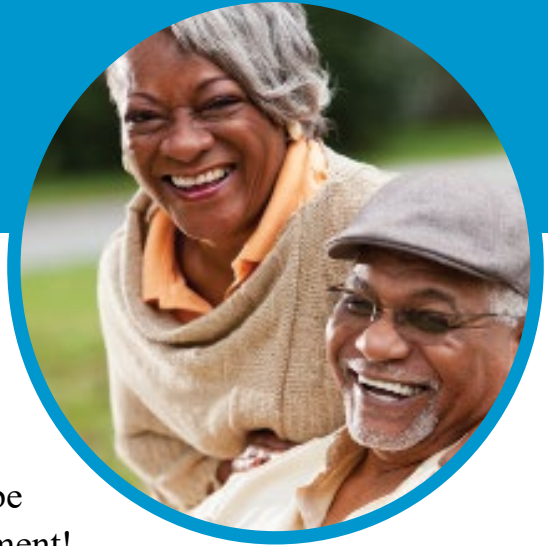
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Congratulations!

You've expressed the desire to improve your dialysis clinic and help your fellow patients by becoming a Facility Peer Representative (FPR)!

The most important person on your healthcare team is YOU, the patient. That's why we celebrate and appreciate your willingness to be the patient voice with a goal for improvement and patient empowerment!



Qsource ESRD Network 10 has always been dedicated to improving the quality of life for End Stage Renal Disease (ESRD) patients. One of the greatest ways Qsource ESRD Network 10 is effective in doing this is highlighting the importance of the patient voice. Research tells us that patients who are knowledgeable about their disease and participate in their healthcare have better health outcomes.

The Network recognizes that patients feel peer to peer communication is one of the most valuable ways to share this knowledge. In an effort to have patients and staff work with us to improve clinic's culture and communication, Network 10 continues to support and to improve the Facility Peer Representative Program.

Your involvement as a Facility Peer Representative helps other patients by:

- Providing a listening ear... someone who has been “in their shoes” and understands the challenges living with kidney disease brings
- Providing the patient voice...to the Network and to your clinic staff giving your perspective to improve care at the clinic and regional level
- Giving others hope...your positive outlook and ability to live well with kidney disease can encourage others that they too can live a good life with kidney disease

The following handbook will provide you with some general information on the Network as well as the Facility Peer Representative program to get you started and share the resources the Network has to support you in this new role.

The Network does many activities to improve the quality of care and life of dialysis and transplant patients. We do this working with both patients and the clinics that provide care.



Network 101: ESRD Network Program History

Network 101: ESRD Network Program History

In 1972, Congress established the End Stage Renal Disease (ESRD) Program as part of the Social Security Administration and established:



Medicare Coverage

Provided Medicare coverage to virtually all individuals with ESRD who require dialysis or transplantation to sustain life.



Health and Safety Standards

Made health and safety standards applicable to dialysis and transplant centers and required the establishment of ESRD Network Coordinating Councils.



ESRD Networks (18 ESRD Networks across the U.S.)

Formed Networks serve as liaisons between Medicare and the providers of ESRD services and as patient advocates.

Qsource and Qsource ESRD Network 10 Overview

Qsource is a not-for-profit, healthcare quality improvement and information technology consultancy headquartered in Memphis, Tennessee, and providing services throughout 11 states: Alabama, Arkansas, Illinois, Indiana, Iowa, Kansas, Kentucky, Mississippi, Missouri, Nebraska and Tennessee. In 2017, Network 10 became part of the ESRD Strategies division of Qsource.

Mission: Qsource ESRD Network 10 promotes and facilitates high quality care standards for dialysis and kidney transplant patients in Illinois.

Vision: Qsource ESRD Network 10 leads and coordinates quality improvement initiatives through collaborative efforts to positively impact the clinical care for chronic kidney disease (CKD) patients.

How we operate: We are overseen by the Executive Committee, which operates as a Board of Directors (BOD) and a Medical Review Board (MRB).

- BOD members monitor Network financial decisions, Network staff and office policies/procedures.
- MRB members are responsible for interpreting policy related to the Network's Medicare contract and its focus on continuous quality improvement, including handling grievances.



Meet the Network Staff

We are here for you!

Let us know how we can help.

You may contact us toll free at 1-800-456-6919.



Audrey Broaddus
Executive Director



Mandy Vires
Quality Improvement Director



Jazzmin Kennedy
Quality Improvement Coordinator



Stan Graber
Data Services
Director



Adam Cox
Information Management
Coordinator



Erica Anderson
Patient Services Director



Quin Taylor
Patient Liaison



Roianne Johnson
Community Outreach Coordinator



How the Network Helps...

Patients

- Work through Grievances with their clinics
 - Investigating and addressing the concerns to improve the care provided
 - Provide mediation
 - Referrals to State Agency for safety concerns
- Advocacy for appropriate access to care
 - Involuntary discharge (IVD) prevention
- Develop educational resources
 - Speak Up! Let Your Voice be Heard grievance poster
 - Staff Retaliation Education Poster
- Patient engagement
 - Patient Advisory Council, Facility Peer Representatives, Subject Matter Experts

Clinics

- Liaison between Medicare, dialysis clinics and transplant centers
- Keep clinic staff informed
 - About Network goals, best practices, medical product recalls, government mandates, and clinical information
- Conduct quality improvement activities (QIAs)
 - Checking on clinical quality outcomes, collecting data, and looking for trends
- Monitoring specific quality measures to make sure your clinic delivers quality care
- Provide education to the staff
 - Technical Assistance
 - Emergency Preparedness
 - Patient Engagement Resources

Medicare & Network Focus on...

Patient Engagement

In recent years, Medicare has asked the Network to incorporate patient engagement in all Network activities, recognizing that patient engagement is central to patient-centered care. Patient engagement is patients taking an active part in their own health care.

Evidence continues to grow supporting the premise that patients who take an active role in their health care actually have better health outcomes and can incur less medical costs compared to their unengaged counterpart¹.

Successful patient engagement in action is a shared responsibility between patients (and their families if applicable), healthcare practitioners (the entire team – physicians, nurses, technicians, social workers and dietitians) and healthcare administrators.

Key “engagement” behaviors have been identified by the Center for Advancing Care in their Engagement Behavior Framework and include:

Communicate

with health care professionals.

Treatment Decisions

Make good treatment decisions by gathering information and asking questions about various treatment options.

Participate

in treatment.

Knowledge

seek health knowledge.



Kristin Carman of the American Institutes for Research and coauthors offered a framework that conceptualizes patient engagement taking place on three main levels. The three main levels include:

- 1) direct patient care, in which patients get information and answer questions about their preferences to inform their treatment decisions;
- 2) organizational design and governance, providers reach out for patient input to ensure they will be responsive to patients' needs; and
- 3) policy making, consumers are involved in the decisions that communities make about policies, law and regulations in public health and health care.²



The Network has developed resources to provide dialysis clinics with tools to support a collaborative relationship when providing education and direct care. Although many organizations are beginning to embrace patient engagement in direct patient care, few dialysis clinics include patients in their organizational activities.

In 2017, the Network found that clinics who had been working with a Facility Peer Representative prior to the Grievance Quality Improvement Activity interventions were more likely to engage the patient in their Quality Assurance Performance Improvement team meetings. These clinics had already embraced the idea of engaging a patient to work with other patients and were ready to increase their level of patient engagement.

¹ "Health Policy Brief: Patient Engagement," Health Affairs, February 14, 2013.

² "Health Policy Brief: Patient Engagement," Health Affairs, February 14, 2013.



FPR Program Overview

Structure of the Program

Overall, the Facility Peer Representative Program has two key individuals in each dialysis clinic, the Facility Peer Representative (FPR) and the Facility Staff Coordinator (FSC).

The Facility Peer Representative and the Staff Coordinator will provide information and resources to patients, their families, and caregivers to help them become active with their treatment and advocates in their health care.

This will help empower patients with knowledge, enhancing their coping skills and quality of life.

Role of the Facility Peer Representative (FPR)

The FPR will work with the clinic and Network staff to develop, and implement, effective patient-centered care educational initiatives. FPRs will be asked to promote patient and family engagement programs within the clinic.

FPRs provide a voice from the patients to the dialysis clinic staff and to the Network staff and committees.

They will:

- 1 Inform patients about the Qsource ESRD Network 10.
- 2 Refer patients and family members to the appropriate dialysis clinic staff member when concerns or complaints are shared.
- 3 Be a role model to other patients through involvement with their own treatment.
- 4 Attend Network-sponsored webinars (preferably together with the Staff Coordinator but can also participate from home if access to a computer and internet connection is available).
- 5 Work with the Network and clinic staff to implement clinic-based activities to promote and engage patients as active members of their own health care team.
- 6 Provide the patient voice as a Subject Matter Experts (SME) for the Centers for Medicare and Medicaid Services (CMS) and the Network as requested. (SMEs are committed and informed patients with unique knowledge and experiences. They are able to provide the patient perspective to the Network's quality improvement activities.)

Role is to...

- Be a positive role model for other patients
- Keep patient matters confidential
- Direct patients to the right staff member that can help them with questions
- Refer patients to Qsource ESRD Network 10 as a resource for questions or concerns, or to submit a grievance
- Help staff promote patient engagement activities at the clinic
- Represent the patient voice and help with quality improvement efforts

Role is NOT to...

- Give medical advice to patients
- Impose your opinions or beliefs on other patients
- Be responsible for handling patient grievances about their care
- Discuss with other people what a patient has shared with you
 - unless they give you permission
 - or the patient may be at risk for harm
- Fix all of the problems another patient has

Network Support

In order to support the FPR program, Qsource ESRD Network 10 continues to build resources to assist with patient engagement and education. Several of these resources include:



Communication



Vocational Rehab



Transplant

- Ideas for monthly education
- Patient engagement resources

You have skills and experiences that can improve your dialysis clinic and help engage your fellow patients. The ways you enhance your clinic may differ from another Facility Peer Representative and that's one of the things that makes this program unique.

You can choose how much you'd like to be involved.

We recommend you volunteer at least one hour a week, but you can divide that time as it best fits your schedule.

The Network will provide opportunities for FPRs to connect with the Network and each other to learn and share with each other through:

- New FPR Orientation webinar- available online at www.therenalnetwork.org
- Monthly Share Calls
- Monthly correspondence from the Patient Liaison



Getting Started as an FPR

Take time to work together with staff and discover their talents and skills and TOGETHER you can decide how EVERYONE can make a difference!

1) Talk with your Facility Staff Coordinator about:

- Activities you'd like to be involved in
- Clinic patient education
- Mentoring patients
- Quality improvement activities and Network projects they are involved in
- Activity ideas for patient education

2) Introduce yourself to other patients by:

- Post/give out a letter introducing yourself as the FPR; and/or
- Share the FPR Brochure with your name, the name of the Shift Spokesperson, and the facility information; and/or
- Ask your clinic social worker to help introduce you to other patients; and/or
- Host a lobby day to meet other patients and introduce yourself as the FPR

Activity Ideas

- Meet with patients to let them share their questions and concerns about their dialysis experience
- Share your experience and how you have adjusted to living well on dialysis
- Help with planning group events
- Help with patient education
 - Review clinic resources and share ideas on what topics you think patients need more information on
 - Hand out patient educational materials
 - Help with a patient bulletin board
- Help with lobby days
- Plan fun activities (games, bingo, movie days, holiday activities)
- Ask to set up a patient suggestion box in the lobby or a common area
- Attend the first 10-15 minutes of the monthly clinic quality improvement meeting and/or administrative meeting to help staff understand patient concerns
- Welcome new patients to the clinic to help them feel more comfortable

For those FPRs who would like to be more involved, work with your Facility Staff Coordinator to develop other projects like:

- A patient newsletter or writing a regular column in the facility newsletter
- A patient-to-patient mentoring program or a support group
- Educational events like a guest speaker or health fair
- A clinic picnic, a holiday dinner or party
- Sharing information about organ donation and/or home dialysis
- Team events like The National Kidney Foundation's Kidney Walk

Creating Clear Boundaries

As a FPR you are in a unique position, you are a peer to other patient and not a professional working with them at the clinic. It is important to make sure you set appropriate boundaries to protect you and the other patients. Boundaries can be defined as the limits we set with other people, which indicate what we find acceptable and unacceptable in their behavior towards us.

There are two different types of boundaries (1) **Physical**. These include your body, privacy, and personal space. How close you are comfortable with someone standing next to you while talk to you is an example of a personal physical boundary. (2) **Thoughts and feelings**. These include your thoughts, behaviors, and choices.

Tips to setting boundaries:

1. Identify your boundaries are with different groups such as friends, family, professionals and work colleagues. Once you have set your personal boundaries you will know when you or someone else may be crossing those boundaries.
2. Be aware of your feelings. If you are feeling discomfort or resentment, ask yourself what is causing it. Is it that someone crossed one of my boundaries?
3. Be direct with others if they have crossed boundaries. People may have different communication styles, but explaining directly how you are feeling will cut out miscommunication.
4. Be assertive. After you have identified your personal boundaries, it is important to follow through with them. Practice telling someone that they have crossed your boundaries and explain your thoughts.

Guidelines to Sharing With Other



Listen Listening carefully to what the person is saying.



Think Stop and think about what this person is really trying to tell you before responding.



Speak When sharing you experience, be sure to emphasize that every patients experience is different, and they should always consult a professional with any treatment related questions.

As the FPR, self-disclosure should be rare, and in the patients best interest. Your goal is to be the listening ear, and to share your experience.



Getting Involved with Quality Improvement

One way to help make an impact in the care at your dialysis clinic is to participate as a member of the quality improvement team. Medicare requires all dialysis clinics to develop and maintain a Quality Assurance and Performance Improvement (QAPI) program for their clinic.

The purpose of QAPI is to ensure the clinic is meeting standards of care and using data to track outcomes. QAPI is a proactive and continuous study of processes with the intent to prevent or decrease potential problems and improve health outcomes.

How can you represent the patient voice at QAPI meetings?

Clinics are looking for individuals who are able to:

- Share insights and information about their experiences in ways that others can learn from them
- See beyond their personal experiences
- Show concern for more than one issue
- Listen well
- Respect the perspectives of others
- Interact with many different kinds of people
- Speak comfortably in a group
- Show a positive outlook on life and a sense of humor
- Work in partnership with others

Other tips for being involved in QAPI:

- Believe you can help
- Communicate openly
- Be honest
- Ask questions
- Be open-minded
- Avoid assumptions
- Be willing to partner and learn from others
- Be a team player
- Thank them for asking for your input
- Adapt to different situations
- Try not to complain, and instead offer suggestions on how it could have been made better.

The clinic may invite you to attend at the beginning of the meeting to discuss one or more of the topics to be reviewed. Each time members will provide information based upon their area of expertise, as a patient or family member, you are also an expert because of your experience.

Who is involved in QAPI?



Medical Director



Physician



Nurse



Social worker



Dietitian



FPR/Patient Representative

QAPI: What Information Is Reviewed?

Adequacy

Nutritional Status

Renal Bone Disease

Anemia Management

Vascular Access

Medical Injuries/Errors

Patient Satisfaction/Grievances

Infection Control

Vaccinations

Health Outcomes (Quality of Life & Survival)

What happens during QAPI meetings?

During the meeting the team will review the data for each treatment measure reviewed. They will discuss what the goal is for the measure and their progress toward that goal. One strategy QAPI teams may use is to go through a PDSA process.

Plan-Do-Study-Act walks the team through the improvement process:

Plan: During the planning phase, the team determines specific goals and objective and plan to meet them.

Do: This is where the dialysis clinic staff carry out the plan, document the observations and analyze the data. These steps are important in determining if the problem was corrected.

Study: During this phase, the team reviews how the intervention(s) is working. The team determines if it is successful, needs to be continued or something else needs to be tested.

Act: If the change was successful, act to implement system-wide.



Additional Resources

Qsource ESRD Network 10 Web Site: www.therenalnetwork.org

Facebook: www.facebook.com/TheRenalNetwork

American Association of Kidney Patients (AAKP)—A national non-profit organization founded by kidney patients for kidney patients, striving to educate and improve the health and well-being of chronic kidney disease (CKD) patients.

Web Site: www.aakp.org | Contact: 1-800-749-2257

American Kidney Fund (AKF)—Mission is to fight kidney disease through direct financial support to patients, health education, and prevention efforts.

Web Site: www.kidneyfund.org | Contact: 1-800-638-8299

Dialysis Patient Citizens (DPC)—An independent organization of patients and families, led by patients, who provide education and advocacy for people affected by kidney disease.

Web Site: www.dialysispatients.org | Contact: 1-866-877-4242

Kidney School—A free online education program including 16 interactive modules with printable PDFs, pre- and post quizzes, and audio book chapters. Web Site: www.kidneyschool.org

Life Options—Free research-based education materials including printable booklets, fact sheets, tips, message boards, and links, as well as a Helpline to call and talk to experts about your questions.

Web Site: www.lifeoptions.org | Contact: 1-800-468-7777

National Forum of ESRD Networks- Dialysis Patients Grievance Toolkit

Web Site: www.esrdncc.org/GrievanceToolkit

National Kidney Disease Education Program—Improving understanding, detection, and management of kidney disease through education.

Web Site: www.nkdep.nih.gov | Contact: 1-866-4-KIDNEY (1-866-454-3639)

National Kidney Foundation (NKF) —The National Kidney Foundation is an organization in the U.S. dedicated to the awareness, prevention and treatment of kidney disease. NKF offers many resources and education materials related to living with kidney disease. Web Site: www.kidney.org

Illinois

Phone: (312) 321-1500

Toll Free: (800) 954-3639

E-mail: kidney@nkfi.org

Web Site: www.nkfi.org

Renal Support Network—A patient-focused, patient-run organization that provides many resources including patient newsletters, podcasts, and the HOPEline Peer Support phone line which allows you to connect with another person who is living successfully with chronic kidney disease.

Web Site: www.rsnhope.org | Contact: HOPEline: 1-800-579-1970

State Survey Agencies—address patient grievances about dialysis care and may go on-site to inspect a clinic. If it is a life-threatening situation, the State Survey Agency makes sure the clinic is running safely. You can contact the State Survey Agency for Illinois at:

Illinois Department of Public Health | 800-252-4343

Appendices

- A. National Forum of ESRD Networks-Dialysis Patients
– Grievance Toolkit Summary flyer

- B. List of Acronyms



Dialysis Patients

Grievance Toolkit Summary

The grievance process provides a method for patients to voice their concerns about the services received by a provider that did not meet care standards with respect to safety, civility, patients' rights, and/or clinical standards of care.

To help guide patients through the grievance process, the Forum of ESRD Networks' Kidney Patient Advisory Council (KPAC) developed an educational toolkit.

This toolkit was developed BY patients FOR patients!

This summary explains what is in each chapter of the patient toolkit. If you need assistance with understanding the toolkit, you can ask your social worker to help you!

To view or print a chapter, visit The National Forum of ESRD Networks' website at www.esrdncc.org/GrievanceToolkit

What is the Dialysis Patient Grievance Toolkit?

A guidebook designed by patients for patients to help explain the grievance system.

Ch. 1: Utilizing the Grievance Toolkit

Explains how the toolkit can be used to create a safe dialysis setting for all patients. It can be downloaded as one guidebook or by each chapter.

Ch. 2: Definitions

Describes words and terms that are used during the grievance process. To make sure patients understand what is happening, learn these words and key terms.

Ch. 3: Recommended Patient Rights and Responsibilities

Outlines the patients' responsibilities and explains what patients can expect from their health care team.

Ch. 4: Grievances in a Patient Centered Care (PCC) Environment

PCC is care that is focused on patients' values and preferences and involves sharing information and active shared decision making with patients.

Ch. 5: Barriers to a Successful Grievance Experience

Identifies some common barriers patients may face through the grievance experience. It is never too late to file a grievance.

Ch. 6: What do Patients do If They Have a Concern or Grievance

Discusses steps patients can take if they have a concern or grievance, and explains patients' rights.

Ch. 7: The Network's Role in the Grievance Process

The ESRD Network's role is to serve as an investigator, facilitator, referral agent, coordinator, and/or educator.

Ch. 8: Document Before Proceeding with a Grievance

Before filing a grievance, it is important to organize your thoughts about the grievance. The toolkit provides patients with optional resources to assist them in organizing and recording their concerns.



F. List of Acronyms

A

AAKP.....American Association of Kidney Patients
ADL.....Activities of Daily Living
AKF.....American Kidney Fund
ANNA.....American Nephrology Nurses' Association
AP.....Arterial Pressure
AVF.....Arteriovenous Fistula
AVG.....Arteriovenous Graft

B

BFR.....Blood Flow Rate
BOD.....Board of Directors
BM.....Bowel Movement
BMI.....Body Mass Index
BMR.....Basal Metabolic Rate
BSN.....Bachelor of Science in Nursing
BUN.....Blood Urea Nitrogen

C

CAPD.....Continuous Ambulatory Peritoneal Dialysis
CCHT.....Certified Clinical Hemodialysis Technician
CCPD.....Continuous Cycling Peritoneal Dialysis
CDC.....Centers for Disease Control and Prevention
CfC.....Conditions for Coverage
CKD.....Chronic Kidney Disease
CMS.....Centers for Medicare & Medicaid Services
CPR.....Cardiopulmonary Resuscitation
CVD.....Cardiovascular Disease

D

DFC.....Dialysis Facility Compare

E

Ekt/V.....Equilibrated Kt/V (See Kt/V)
EDW.....Estimated Dry Weight
EPO.....Epogen or Erythropoietin
ESA.....Erythropoietin-Stimulating Agent
ESRD.....End Stage Renal Disease

G

GFR.....Glomerular Filtration Rate
GI.....Gastrointestinal

H

HBV.....Hepatitis B Virus
HCT.....Hematocrit
HD.....Hemodialysis
HGB.....Hemoglobin
HIPAA.....Health Information Portability and Accountability Act

I

IV.....Intravenous

K

Kt/V.....A 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

LPN.....Licensed Practical Nurse

M

MD.....Medical Doctor
MI.....Myocardial Infarction (Commonly Known As A Heart Attack)
MRB.....Medical Review Board
MSW.....Master of Social Work

N

NP.....Nurse Practitioner
FPR.....Facility Peer Representative

P

P&P.....Policies & Procedures
PA.....Physician's Assistant
PAC.....Patient Advisory Committee
PCT.....Patient Care Technician
PD.....Peritoneal Dialysis
PHI.....Personal Health Information
POA.....Power of Attorney for Health Care Decisions
PPV.....Pneumococcal Polysaccharide Vaccine
PTH.....Parathyroid Hormone

Q

QIP.....Quality Incentive Program

R

RD.....Registered Dietician
RN.....Registered Nurse

S

SHIP.....State Health Insurance Assistance Program

T

TSAT.....Transferrin Saturation
TST.....Tuberculin Skin Test

U

UF.....Ultra Filtration Rate
URI.....Upper Respiratory Infection
URR.....Urea Reduction Ratio
UTI.....Urinary Tract Infection

V

VA.....Vascular Access
VP.....Venous Pressure
VR.....Vocational Rehabilitation



For more information or to file a grievance, please contact Qsource ESRD Network 10 at:
Address: 911 E. 86th Street, Suite 202 | Indianapolis, IN 46240
Phone: 800-456-6919 | E-mail: info@therenalnetwork.org | Web: www.therenalnetwork.org
Social Media: www.facebook.com/TheRenalNetwork