ALLIANT
HEALTH SOLUTIONS

END STAGE RENAL DISEASE
NETWORKS 8 & 14

Facility Patient Representative (FPR)

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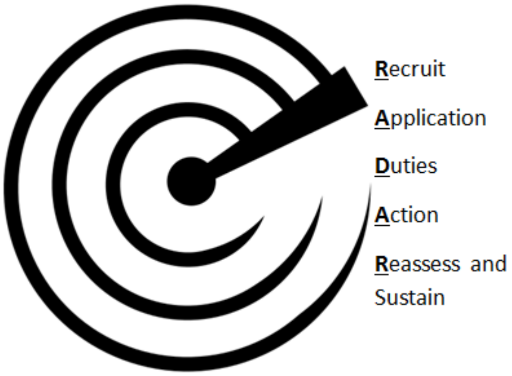
RADAR Model

Recruit - Facilities should assess the patient population and find patients who are engaged and would be good facility patient representatives (FPRs). Once one or more patients have been identified, facilities should have **one-on-one** discussions with the patient(s) to discuss the position. The goal should be for each facility to have at least one FPR per shift.



Application - If the patient(s) are interested, the facility will give the patient an FPR application, which can be found in this FPR toolkit. Facility staff will have the patient fill out the application and then meet **one-on-one** with the patient to discuss the application and address any questions or concerns. The application will be filed at the facility.

Decide and Duties - The facility will have **one-on-one** time with the FPR(s) they've chosen. **Together,** the facility and the FPR will come up with a list of duties or expectations that satisfy the facility's needs and the patient's capabilities. After the duties have been identified, facility staff and the FPR will sign the FPR Agreement. Additional duties can be added to the agreement or typed onto another document and signed.

Action - It's time to utilize your FPR. The facility and the FPR should have worked together in the last step to assess facility needs and work on a list of action items to complete monthly, quarterly, semiannually, annually, etc. The FPR will put these activities into action, perform the agreed-upon duties and communicate with the facility and patient population to address their needs.

Reassess and Sustain - Periodically, facility staff and the FPR will get together and discuss the progress of the goals they set out to accomplish. They can also revisit the FPR duties and responsibilities, along with expectations for the facility, for the FPR to note and immediately address any concerns or misunderstandings. The FPR and the facility should prioritize working together cohesively to meet the patient population's needs.

* See the ***Commonly Used Terms*** section for more information.

Facility Patient Representative Handbook

Recruit

Thank you for agreeing to serve as a facility patient representative (FPR) for your local dialysis center. The most important person on the health care team is YOU, the patient! That's why FPRs are so important.

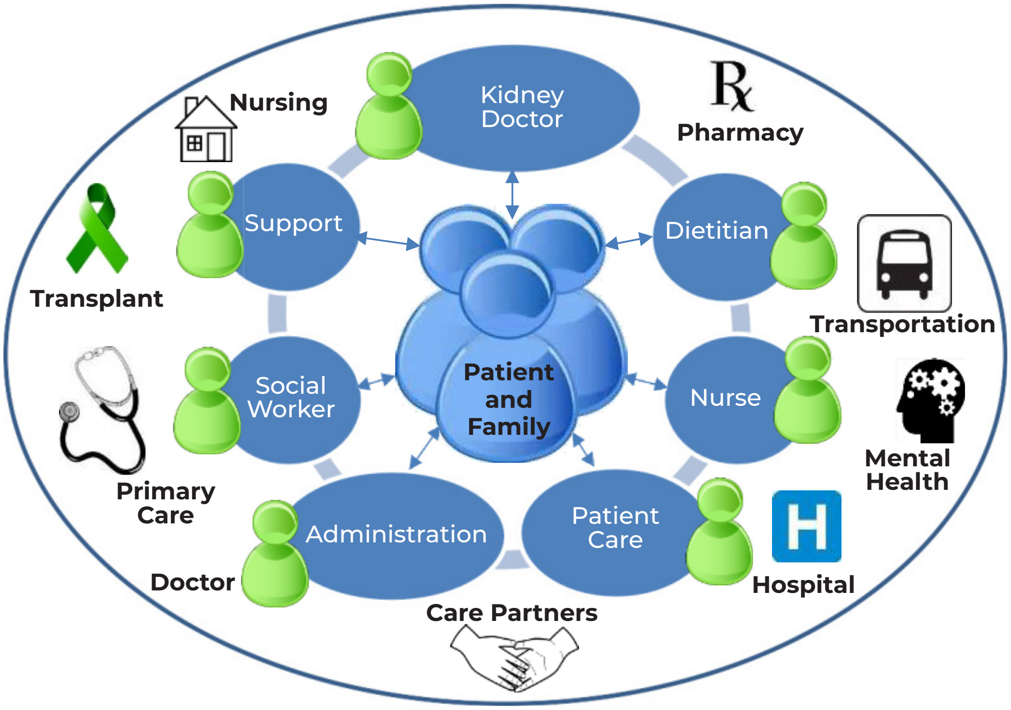
FPR role description

The FPR program is designed for people on dialysis or who have a kidney transplant and their family members. FPRs are selected to represent their fellow patients at a dialysis center. FPRs volunteer to work with staff to foster a positive environment in their dialysis center. FPRs serve as experts on what it is like to be a patient. This helps centers improve patient care.

FPRs should be:

- Willing to serve for one or more years.
- Able to participate in their dialysis center's Quality Assessment and Performance Improvement (QAPI) and/or governing body meetings.
- Willing to respond to the ESRD Network's requests for information and feedback.

When YOU are at the center of your care, you and your family are surrounded by health care professionals and services!



What Is a Facility Patient Representative?

FPRs are the link between the other patients and the center's managers and staff. To improve patient- and family-centered care* in Alabama, Mississippi, Tennessee and Texas, every dialysis center is asked to select at least one patient to serve as an FPR.

How can FPRs help patients who have concerns?

When a patient has a concern, as an FPR, you might be able to help. Here are some steps that you should follow to help improve care at your facility:

- Encourage the patient to talk to staff about the concern.
- If the patient is not comfortable talking to staff, ask the patient for permission to share his or her concern with staff.
- Take a positive approach to all concerns; be cheerful and approach staff at the right time with questions or concerns.
- Most dialysis companies have a department at the corporate level that may be able to help with patient concerns. If the patient is not satisfied with the answer from the center's staff, you can ask the administrator for the corporate contact information.
- If the problem can't be fixed at your dialysis center or the corporate level, the patient may need to file a grievance. You can share the ESRD Network's or state agency's toll-free phone number with any patients who want to discuss concerns or questions about the quality of their care. You should not file a grievance on behalf of another patient.
- You can help patients understand that they have the right to file a grievance. They can't be retaliated against for filing a grievance.

What should FPRs NOT do?

There are some things that FPRs should avoid doing. You should not:

- Try to train or manage staff members.
- Ask staff or patients about confidential patient information.
- Post or share information that the clinic manager has not approved.
- Share the concerns of another patient without the patient's permission.

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* See the ***Commonly Used Terms*** section for more information.

Patient Confidentiality

All FPRs are required to follow the confidentiality of patient personal information.

ALWAYS get the patient's permission before approaching a staff member with a patient concern unless you are afraid the patient could harm themselves or others. Never repeat personal information you may learn in your role as an FPR.

HIPAA
Compliance

Can I share my medical information with other patients?

As an ESRD patient, you have a lot to teach other patients about kidney disease. You can share your own experiences, but you should not give medical information or advice. Medicines or a diet that works for you may be dangerous or even deadly to another patient with different medical conditions. Remember, YOU are the expert on being patient, and medical professionals are the experts on health care.

You can help other patients by sending them to the right staff member:

- For medical questions, always refer to the patient's doctor or nurse.
- For questions about diet, always refer to the dietitian.
- For questions about stress, quality of life and coping concerns, always refer to the social worker.
- For questions about insurance, always refer to the insurance counselor.

The Federal ESRD Program and ESRD Networks

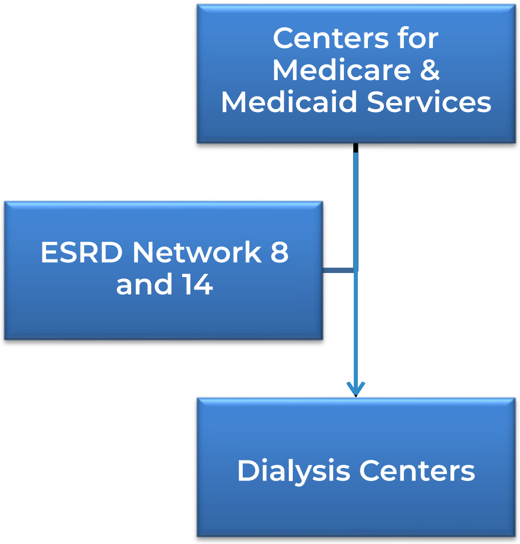
Before Congress passed section 1881 of the Social Security Act in 1972, the *Centers for Medicare & Medicare Services (CMS)** did not cover dialysis treatments. Patients had to pay for their treatment. That changed in 1972 when Congress set up the ESRD Program to pay for dialysis and transplant services through CMS.

Now the program is run by CMS. Under CMS, there are 18 ESRD Networks that oversee the quality of care for dialysis patients. ESRD Networks 8 and 14 are nonprofit organizations contracted by CMS to ensure that people who need dialysis in Alabama, Mississippi, Tennessee and Texas receive good care from their dialysis centers.

What does the ESRD Network do?

ESRD Networks 8 and 14 work with dialysis centers to improve the quality of patient care. Some of the ways that ESRD Networks 8 and 14 improve care are by:

- Helping patients and families understand how to better manage kidney disease by making patient education materials available.
- Helping centers keep good records in the patient database (EQRS*).
- Helping patients and staff improve the quality of care at the center.
  - This includes patient complaints and concerns (grievances*) about dialysis care that patients ask ESRD Networks to help them fix.
- Working with dialysis centers to improve the quality of care for kidney patients.



* See the ***Commonly Used Terms*** section for more information.

Other Ways To Get Involved

In addition to being an FPR, there are several other ways you can get involved. Dialysis and transplant patients and their family members can also volunteer for Network committees. These committees help ESRD Networks understand what is important to patients and their families in order to improve care for all patients.

Join the Patient Advisory Committee

The patient advisory committee (PAC) is comprised of patients, family members or caregivers of ESRD patients and facility staff. The PAC serves as a voice for kidney patients throughout the Network. PAC members help ESRD Networks understand patient concerns, problems and educational needs. PAC projects typically include:

- Contributing ideas to help improve patient-centered care and communication.
- Assisting with the development of patient educational materials.
- Providing input into the development of quality improvement activities.

Become a peer mentor

A peer mentor is a patient who agrees to help empower other patients to make informed decisions and cope with their lives after being diagnosed with ESRD. Peer mentors:

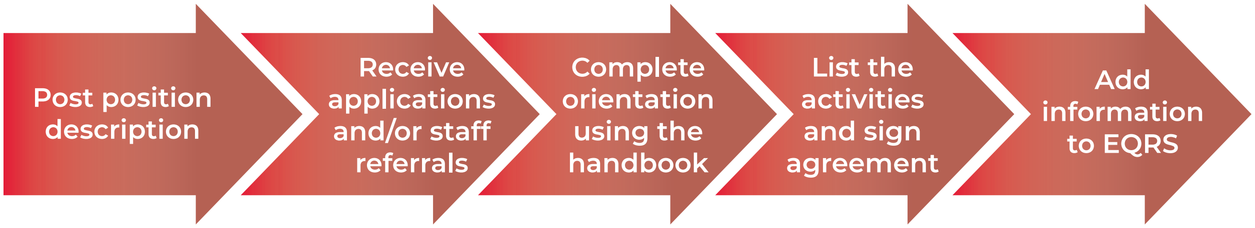
- Help ensure that dialysis facility staff members understand the patients' concerns, issues and priorities.
- Offer patients access to someone who has been through the same experiences and can fully understand their concerns.

Participate in a Patient Engagement Learning and Action Network

Each ESRD Network brings kidney patients, family members and dialysis staff together to improve ESRD care. These groups are known as Patient Engagement Learning and Action Networks (PE LANs). All PE LAN members are considered subject matter experts who can share knowledge and improve care. In a PE LAN, experts on different subjects share their ideas, which helps everyone learn something new and find ways to solve problems.

Participate in your Facility's Quality Assurance & Performance Improvement (QAPI) meetings each month your facility has a QAPI meeting to discuss issues involving the operations of the dialysis facility. Ask to take part in these meetings either in person or by phone. Provide the leadership of your dialysis facility with information from the side of a patient. Speak to your Social Worker or Facility Administrator for more information on how to join these meetings.

FPR Recruiting Process



Orientation Checklist

☐ Facility Patient Representative Handbook

☐ What Is a Facility Patient Representative (FPR)?

☐ Patient Confidentiality

☐ The Federal ESRD Program and ESRD Networks

☐ Other Ways To Get Involved

☐ Commonly Used Terms

☐ Additional Resources

☐ Contact Information

☐ Facility Patient Representative (FPR) Application

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☐ Facility Patient Representative (FPR) Agreement

☐ Add Patient Representative (FPR) to EQRS

Commonly Used Terms

Acronyms

AMA: Against Medical Advice

BMI: Body Mass Index

CfC: Conditions for Coverage. These are the rules centers must follow to be paid by CMS for dialysis treatments.

CKD: Chronic Kidney Disease

CMS: Centers for Medicare & Medicaid Services

EDW: Estimated Dry Weight

ESRD: End-Stage Renal Disease

FDOD: First Date of Dialysis

FPR: Facility Patient Representative

HIPAA: Health Insurance Portability and Accountability Act of 1996

ICH: In-Center Hemodialysis

IDT: Interdisciplinary Team

MWF/TTS: Monday, Wednesday, and Friday dialysis schedules; Tuesday, Thursday and Saturday dialysis schedules

PAC: Patient Advisory Committee

PD: Peritoneal Dialysis

PE LAN: Patient Engagement Learning and Action Network

POC: Plan of Care

QAPI: Quality Assessment and Performance Improvement

SSA: Social Security Administration

SME: Subject Matter Expert

TKHC: Texas Kidney Health Care

Commonly Used Terms

Definitions

Advocate: A person who looks out for another person's best interests

Centers for Medicare & Medicaid Services (CMS): An federal government agency that sets rules for dialysis centers and pays for treatment for patients that get Medicare benefits.

Confidentiality: Protecting private information like patient medical records.

EQRS: EQRS is Medicare's patient database. This is where medical information is reported by your center and stored by CMS.

Governing Body: Each center's governing body includes the manager, kidney doctor (nephrologist), and area manager.

Grievances: Patient concerns or complaints reported to ESRD Networks to help fix the problem.

Mentor: A teacher, guide or source of information.

Modalities: Different kinds of dialysis treatments like in-center hemodialysis, peritoneal dialysis, home hemodialysis, and transplant.

Patient-and Family-Centered Care (PFCC): Patient- and family-centered care means that health care decisions are made WITH patients and not FOR them. It means that patients and their loved ones are an important part of the health care team and that staff respect patients' wishes about their care.

Peer: A group of people who are going through the same experiences in life

Transplant: When an organ like a kidney is removed from one person (a donor) and placed in another person (the recipient).

Additional Resources

For additional information, please visit the following websites:

- American Association of Kidney Patients (AAKP) - www.aakp.org
- American Kidney Fund (AKF) - https://www.kidneyfund.org/
- Dialysis Patient Citizens (DPC) - https://www.dialysispatients.org/
- National Kidney Foundation (NKF) - https://www.kidney.org
- The State of Texas Kidney Foundation - https://txkidney.org/
- National Kidney Foundation Transplant Resources - https://www.kidney.org/atoz/content/kidney-transplant
- Matching Donors website - https://matchingdonors.com/life/
- Life Options = www.lifeoptions.org
- United Network for Organ Sharing (UNOS) - https://unos.org/
- Home Dialysis Central - www.homedialysis.org
- Social Security (Voc Rehab) – Ticket to Work - www.ssa.gov/work
- Department of Rehabilitation Services - https://dds.dc.gov/
- Centers for Medicare & Medicaid Services (CMS) - www.medicare.gov/dialysis
- Renal Support Network – 1-800-579-1970, https://www.rsnhope.org/
- Social Security – 1-800-772-1213, www.ssa.gov

Contact Information

We, ESRD Networks 8 and 14, and your dialysis facility look forward to working with you as an FPR. If you have questions or would like to discuss any concerns or recommendations from your facility, please call the Network's toll-free number listed below.

ESRD Networks 8 and 14

ESRD Network 8
(Alabama, Mississippi, Tennessee)
775 Woodlands Parkway, Suite 310
Ridgeland, MS 39157
Patient toll-free number:
1-877-936-9260
Fax: 601-932-4446
https://quality.allianthealth.org/topic/esrd-nw8/

ESRD Network 14 (Texas)
4099 McEwen Rd, Suite 820
Dallas, Texas 75244
Patient toll-free number:
1-877-886-4435
Fax: 972-503-3219
https://quality.allianthealth.org/topic/esrd-nw14/

State Agencies

Alabama Department of Public Health
1-800-356-9596

Mississippi State Department of Health
1-800-227-7308

Tennessee Department of Health
1-877-287-0010

Texas Department of State Health Services
1-888-973-0022

Facility Patient Representative (FPR) Application

Applicant Information – to be completed by the patient

Name: ______________________________ Email: ____

Address: ____

City: __________________________________ State: ______________ Zip Code: __________________

Home Phone: ______________________________ Cell Phone: ______________________________

Modality: ☐ Home Hemodialysis ☐ In-center Hemodialysis ☐ Peritoneal Dialysis ☐ Transplant

If you are a dialysis patient or family member, are you or the patient on a transplant list?

☐ Yes ☐ No

Dialysis Schedule: ☐ M/W/F Time: ______________________ ☐T/T/S Time: ______________________

Do you have computer access? ☐ Yes ☐ No

Please read the following statements and check if you agree (all must be checked to be considered):

☐ I have read the FPR role description and agree to fulfill the responsibilities to the best of my ability.

☐ I authorize ESRD Network 8/14 and ______________________________________ (dialysis center) to utilize my name and email address for specific Facility Patient Representative (FPR) communications.

☐ I further authorize ______________________________________ (dialysis center) to use my name where necessary in FPR meeting minutes and other business documentation.

Facility Information – to be completed by a staff member

Name of Dialysis Center: ____

CCN *(six-digit Medicare provider number)*:

Staff Member's Name: ________________________ Email: ____________________________________

Staff Member's Phone Number: ____

Please complete this form and submit it to your facility social worker. Thank you!

Facility Patient Representative (FPR) Staff Referral

FPR Candidate Information

Name: ______________________________ Email: ____

Address: ____

City: __________________________________ State: ______________ Zip Code: __________________

Home Phone: ______________________________ Cell Phone: ______________________________

Modality: ☐ Home Hemodialysis ☐ In-center Hemodialysis ☐ Peritoneal Dialysis ☐ Transplant

If you are a dialysis patient or family member, are you or the patient on a transplant list?

☐ Yes ☐ No

Dialysis Schedule: ☐ M/W/F Time: ____________________ ☐ T/T/S Time: ____________________

FDOD: _______________________________ Transplant Date: ________________________________

Does the candidate have computer access? ☐ Yes ☐ No

Are there any treatment adherence concerns with this candidate? ☐ Yes ☐ No ☐ Unsure

If yes, explain: ____

____

____

____

Comments: ____

____

____

Facility Information
Name of Dialysis Center: ____
CCN *(six-digit Medicare provider number)*:

Staff Member Referring Candidate: ____

Email: ____

Please complete this form and submit it to your facility social worker. Thank you!

Facility Patient Representative (FPR) Agreement

Reassess

This agreement is between the patient, ______________________________ and the facility, ____, CNN _____________.

By signing this agreement, the patient shows that she/he understands that:

- The agreement is between the FPR and the facility.
- The FPR is willing to help at the facility during personal time (not during treatment).
- The facility will share the FPR's name with other patients so they can talk to the FPR about their concerns.
- The patient has the right to resign if she/he is no longer able to serve as an FPR.
- The agreement can be ended by the patient or facility at any time without retaliation.
- The FPR understands that patient information is confidential and will respect the privacy of other patients.
- The best way to reach the patient is: ☐ phone number: ____________________
  and/or ☐ email: ____

The FPR and staff agree that the FPR will help by (check all that apply):

☐ Welcoming new patients
☐ Help staff give out information
☐ Mentor or coach other patients by helping them understand handouts
☐ Go to the first 10 or 15 minutes of the monthly quality meeting (Quality Assessment and Performance Improvement*) and/or governing body* meetings to help staff understand patient concerns
☐ Help with lobby day education
☐ Work with staff to start and run patient and family groups like Patient Advisory Councils or support groups
☐ Start a newsletter for your center
☐ Write articles or poems for the Network newsletter
☐ Plan patient and staff events like picnics, holiday parties and art shows
☐ Decorate the center for holidays and events
☐ Participate in community health fairs
☐ Share information about organ donation
☐ Help patients understand how to work with staff to fix problems
☐ Make a patient bulletin board and/or activity calendar
☐ Organize team events, like a Kidney Walk

☐ ____

☐ ____

Patient Signature: ____

Date: ________________________________

Staff Signature: ____

Date: ________________________________

Staff Name (print) and Title: _____________________________________

* See the ***Commonly Used Terms*** section for more information

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