



End-Stage Renal Disease
Network Program

Patient Facility Representative (PFR) Alliance Meeting

January 12, 2023



Patient and Family Engagement Program Team



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Today's Agenda



**Meeting
Reminders**



PFR Check-In



**Learn about the PFR
Alliance**



QAPI



New Resources



**Closing
Remarks**



Meeting Reminders

- All phone lines are muted upon entry to eliminate background noise/distractions
- We will be monitoring Chat throughout the meeting for questions or comments
- All slides will be shared within a week of completion of the meeting



Welcome to Our January Meeting!

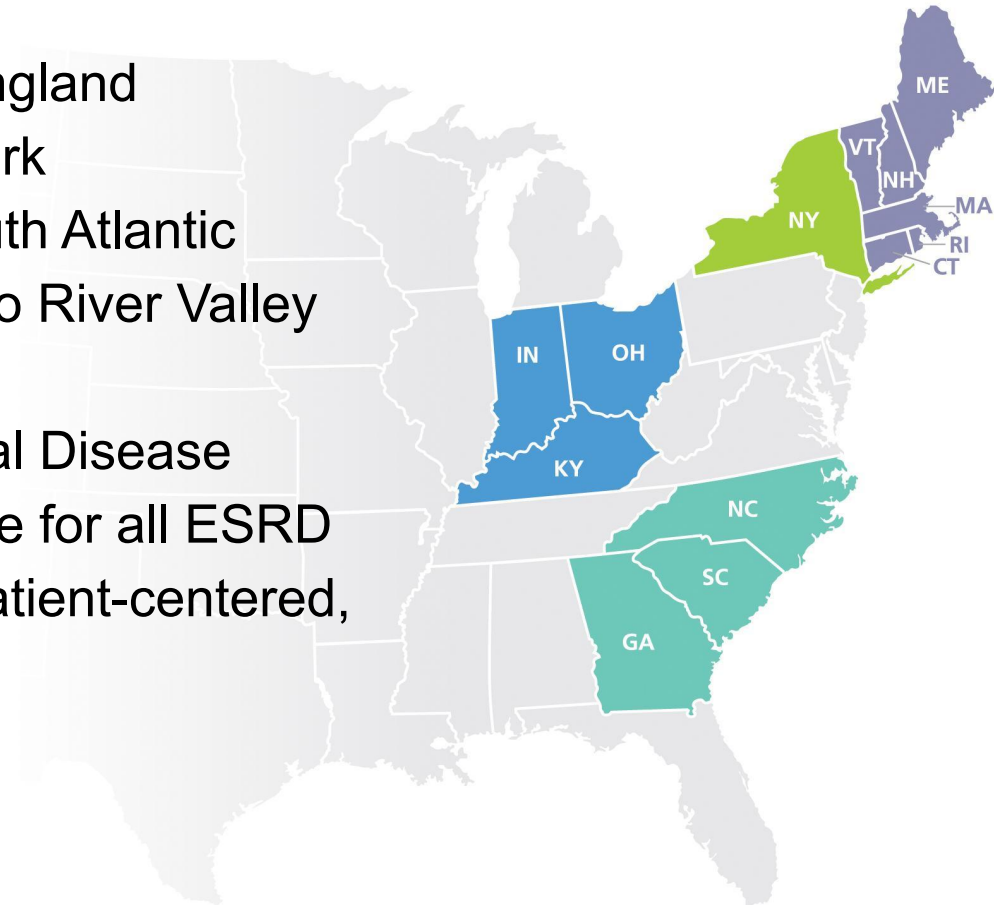


Shezenna Andiappen, MSW
Patient Services Coordinator



IPRO ESRD Network Program

- The IPRO End-Stage Renal Disease Network Program includes four ESRD Networks:
 - Network 1: ESRD Network of New England
 - Network 2: ESRD Network of New York
 - Network 6: ESRD Network of the South Atlantic
 - Network 9: ESRD Network of the Ohio River Valley
- The mission of the IPRO End-Stage Renal Disease Network Program is to promote healthcare for all ESRD patients that is safe, efficient, effective, patient-centered, timely, and equitable.





Network Check-In

- **Which Network are you from?**
 - Network 1 (Connecticut, Massachusetts, Maine, New Hampshire, Rhode Island, Vermont)
 - Network 2 (New York)
 - Network 6 (North Carolina, South Carolina, Georgia)
 - Network 9 (Indiana, Kentucky, Ohio)



Let's Talk: PFR Alliance

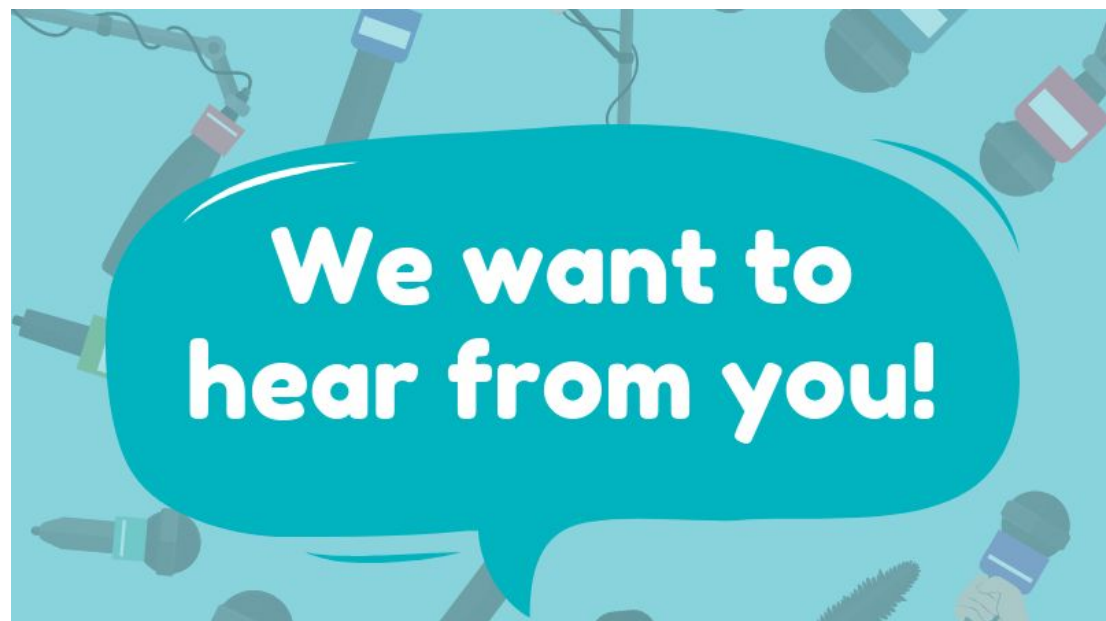


**Danielle Andrews,
MPH, MSW, GCPH
Health Equities Specialist**



Network Check-In

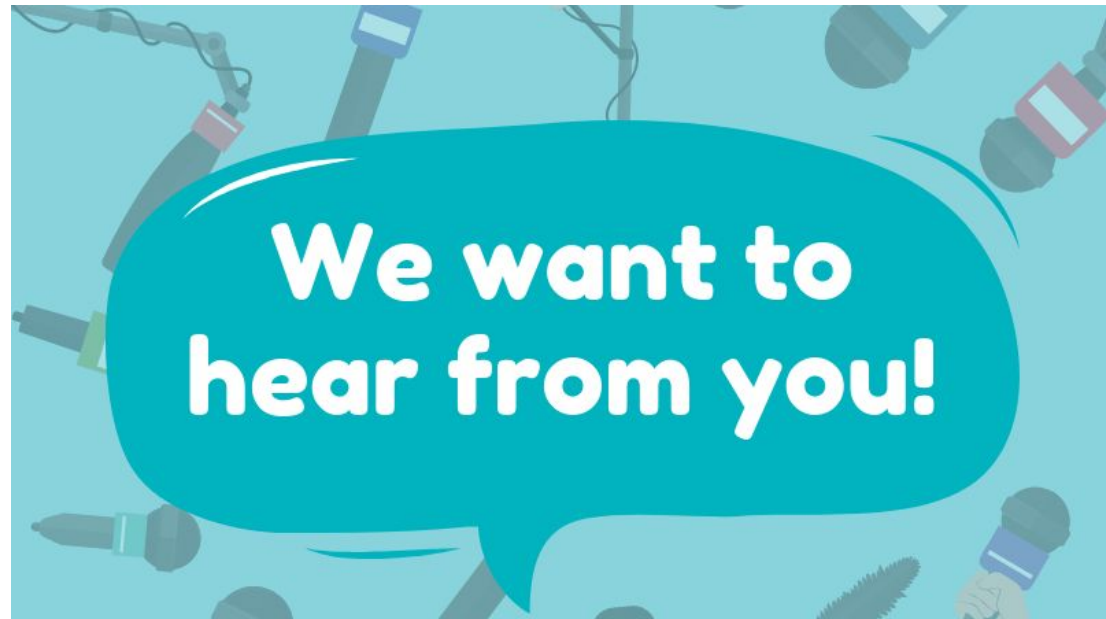
- **Is this your first meeting with the PFR Alliance?**
 - Yes
 - No
 - Unsure





Network Check-In

- **Does your facility have other PFRs or Patient Advocates?**
 - Yes
 - No
 - Unsure





What is Patient Facility Representative (PFR) Alliance?

The Patient Facility Representative (PFR) Alliance is a patient advocacy group that provides patients, transplant recipients, and care partners the opportunity to share thoughts and experiences on ESRD care as well as develop different strategies on how to get more ESRD patients to become active within their care. The PFR Alliance also seeks to promote positive relationships between patients, provider staff, ESRD stakeholders, and the Network.

- The PFR Alliance supports the promotion of patient, family, and care partner engagement in ESRD care at the local community level, as well as promoting positive self-care management and relationships between patients, provider staff, renal community stakeholders, and the ESRD Network.



PFR Alliance Group Membership

As an active PFR Member you are expected to:

- Participate in monthly phone calls with the Network to provide feedback on patient's needs, facility issues and educational resources.
- Coordinate social and educational events to increase awareness of ESRD
 - Lobby Days
 - Annual ESRD Luncheon
 - American Association of Kidney Patients (AAKP)/ NKF Patient Panels
- Participate in Network Quality Improvement project with your Facility Social Worker
- Participate in national quality improvement projects
 - ESRD National Coordinating Center Patient and Family Engagement Learning and Action (ESRD NCC NPFE-LAN) Calls
 - NCC Affinity Groups
- Become a Peer Mentor



Patient Facility Representative (PFR) Alliance Levels of Engagement

PFR Members

Are Introductory PFRs, these individuals that are looking to educate themselves on kidney disease and learn different ways to become a healthier patient living with ESRD.

QIA Champion

Are PFR leads, these individuals have demonstrated leadership ability at their dialysis facility and are looking to develop their advocacy skills.

- They speak with their ESRD peers and share their advice and experiences and act as a link between the ESRD community and the Network
- Participate in facility activities associated with QIA project

PFR-Patient Subject Matter Experts (PSME)

Are long-term dialysis or transplant patients that have been selected by the Network because of their dedication to patient advocacy.

- They conduct and participate in national, regional, and community programs focusing on CKD and ESRD
- Engage in resource development and are peer mentors



The Role of a PFR Member

- PFR Members are introductory members and are beginning to take on an active role as a member of their healthcare team by:
 - Working in collaboration with your medical team (nutritionist, nephrologist, social worker, etc) to determine your plan of care
 - Engage in early levels of Patient Advocacy within their facility
- PFR Members use their knowledge to educate their ESRD Peers by:
 - Reviewing and providing feedback on patient resources
 - Distributing resources to ESRD peers and Social Workers
- PFR Members attend Network-hosted webinars, meetings, lobby days, and informational sessions
- PFR Members will receive newsletters and text messages from the Network about newly created educational materials.
- Engage with the Network and other PFRs through our Facebook PFR Alliance Group



The Role of QIA Champions

- These individuals are patients that have taken on a leadership role within their dialysis facility
- Participate with the Network at the local facility-level, as a patient representative in Quality Improvement Projects
 - Patient Family Engagement (PFE)
 - Peer Mentoring, Quality Assurance Performance Improvement (QAPI), and Life Planning
 - Behavioral Health (Depression)
 - Vaccinations
 - Hospitalizations
 - Home Dialysis
 - Transplant
- Attend monthly PFR meetings and participate in presentations from their QIA leads to further understand their role in the ongoing project
- Assist facilities in creating activities and interventions that educate and help patients cope and adjust to changes made to improve dialysis treatment
- Develop educational bulletin boards, host lobby days, community fairs, and distribute resources to patients and staff at the facility and in your community
- Gathering patient feedback in the facility on Network Interventions



The Role of the PFR:Patient Subject Matter Experts (PSMEs)

- Provide input to the Network into the development of informational or educational materials for patients and families and caregivers
- Participate in the Network's quality improvement projects
- Engagement in the Network quality improvement project to ensure the highest level of care
 - Offers a patient perspective during Network QIAs presentations and huddles
 - Offers a patient perspective to the Network during the development of interventions and resources
 - Provides patient education and work with their facilities in the QAPI meetings to promote best practice strategies
 - Assists in Network educational resource creation
 - Becomes an ambassador for your QIA project
 - Actively engage with your ESRD peers and promote and dispense your QIA project materials and resources



PSME-ESRD NCC NPFE LAN/ Affinity Groups

Each year, the NPFE-LAN holds four separate groups, called Affinity Groups, focused on specific areas of dialysis and transplant care. The groups meet bi-monthly by webinar (phone and/or computer) to share experiences and discuss ways to improve the quality of care for kidney patients and meet the Centers for Medicare & Medicaid Services (CMS) quality improvement goals.

- Five PSMEs from each Network are nominated to work collaboratively with the NCC
- Attendance is mandatory with the exception of illness and home life stressors
- The Affinity Groups meet monthly to discuss:
 - Patient's perspectives on the national issues pertaining to dialysis
 - Patient's feedback on ESRD NCC Resources and videos
 - National discussions on the following topics:
 - Depression
 - COVID-19
 - Transplant
 - Hospitalization/Nursing Homes
 - Vaccinations



COR Call Participation

Each month, each Network meets with our Centers for Medicare and Medicaid Services (CMS) Contracting Officer's Representative (COR) to provide updates on the Network's collaborative efforts with the PSMEs and the PFR Alliance.

- If asked each participating PSME will provide:
 - Discuss the collaborative work being conducted between the PSMEs and The Network (Resource Development), as well as ongoing PFR Alliance activities
 - Discuss Affinity Group participation (if applicable)
 - Feedback on issues that are prominent within their Dialysis Facility and the ESRD Community
 - Discuss the additional work that PSMEs are working on outside of the Network




Patient Voice: Expert Thoughts

Connecting the Community


Every month the Network created a Newsletter that highlights upcoming events, Community Awareness (i.e. Sepsis Awareness Month, Suicide Awareness Month, Hispanic Heritage)

- We share new ESRD Resources (flyers, informationals, educational webinars)
- Provide access to ongoing to programs with Affiliated Programs (AAKP, DPC, Renal Support Network)



End-Stage Renal Disease
Network Program


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Patient Voice: Expert Thoughts






INSIGHTS FROM PATIENT SUBJECT MATTER EXPERTS (PSMEs)


The Network would like to formally welcome you all to our new Patient Facility Representative (PFR) Alliance formally known as the PAC (Patient Advisory Committee).



As an organization, the IPRO ESRD Network Program, thanks you for volunteering your time, passion, expertise, and energy to help provide an important connection between ESRD patients, family members/care partners, dialysis facilities, and the ESRD Network community.

Welcome to the PFR Alliance Team!





Mark Your Calendars With Important Upcoming Events!


[Click Here to Access our Monthly Calendar](#)

Join Our First PFR Alliance Monthly Call

October 7, 2021 at 5:30 PM ET

Meeting Link: <https://ipro.webex.com/ipro/j.php?MTID=m52088e1c96d0c6a3286e3010805e3448>

Meeting Number: 161 535 6519



Questions? Comments?



Engaging in QAPI as a Patient Facility Representative



Shezenna Andiappen, MSW
Patient Services Coordinator



Quality Assurance and Performance Improvement “QAPI”

QAPI is a combined approach that focuses on Quality Assurance (QA) and Performance Improvement (PI). QAPI uses patient and facility experiences as well as data to maintain and improve the safety and quality of care within dialysis and transplant facilities. While also incorporating caregivers and family members experiences in overall problem solving.



Quality Assurance and Performance Improvement “QAPI”

QA-Quality Assurance: focuses on the standards for quality of treatment and outcomes, as well as a the organization’s process throughout the organization for assuring acceptable standards of care is maintained.

QA is an ongoing process, the uses both present and past efforts to identify how an organization is performing, including where and why a facility’s performance is at risk or has failed to meet standards.



Quality Assurance and Performance Improvement “QAPI”

PI-Performance Improvement (also called Quality Improvement - QI) is the continuous study and improvement of processes with the intent to better services or outcomes, and prevent or decrease the likelihood of problems, by identifying areas of opportunity and testing new approaches to fix underlying causes of persistent/systemic problems or barriers to improvement. PI attempts to improve the processes involved in health care delivery and patient's quality of life.



Why you should participate in your facility's QAPI Meeting

As a Patient Facility Representative your facility should be inviting you to their facility QAPI meetings:

- The QAPI meeting gives you the chance to talk to your dialysis facility staff about your concerns and other patient issues. Many times, the ideas and decisions that come out of QAPI meetings affect how the dialysis facility is run.

How to participate in your facility's QAPI Meeting



- Once you're invited to the QAPI meeting prepare the following:
 - Think about questions, concerns, or feedback you and/or other patients may have.
 - Be prepared to answer questions such as:
 - What do you think we are doing well in the dialysis facility?
 - What areas do you think we could improve in the dialysis facility?
 - What do you think are the most common reasons patients miss or shorten treatments?
 - What is the best way for staff to communicate with patients about their treatment?



PFR Involvement in QAPI

Help Patients Understand Their Role in Quality Assessment & Performance Improvement (QAPI)



Research shows that when patients are engaged in their healthcare, it can lead to measurable improvements in safety and quality.¹ Patient and family engagement includes bringing patient and family perspectives directly into the planning, delivery, and evaluation of healthcare, thereby improving the quality and safety of the care provided.²

The Centers for Medicare & Medicaid Services (CMS) encourages dialysis facilities to include patients in QAPI meetings to ensure the patient voice is included in how care is delivered. The meetings give dialysis staff an opportunity to talk to patients about their concerns and other patient issues.

Use this checklist to help patients understand the purpose of QAPI meetings. It also provides recommendations for getting patients to participate in QAPI meetings. Check off each box once you have completed the step.

☐ Step 1. Patient Selection—Select a person who:

- Can see beyond his/her personal experiences.
- Shows concern for more than one issue.
- Has a positive outlook on life.
- Listens well.
- Shows respect for others' perspectives.
- Can interact with different people.
- Speaks openly in a group setting.



☐ Step 2. Make it Personal—Consider these process tips:

- Pull the selected patient aside or sit chairside when you invite the patient.
- Use patient-friendly language.
- Explain the purpose of QAPI.
- Share the reasons why you invited the patient.
— For example, "I've noticed you ... share your ideas, get along well with patients and staff, and have an interest in your care and the facility."
- Give the patient an invitation to the meeting with the date, time, and location.
- Give the patient the "Because Your Voice Matters!" handout.



☐ Step 3. Prepare for the Meeting—It is important to attend to each item:

Staff

- Talk to the clinic's medical director about the importance of including a patient in QAPI meetings.
- Ask staff members to prepare directed questions.
- Tell all team members a patient will be in attendance.
- Remind staff not to reveal other patients' personal health information.
- Review staff roles during the meeting.
- Use visuals when available.
- Provide topic-specific information to help patients prepare for the discussion. For example, standards and goals.
- Encourage the patient to write down his/her ideas, questions, concerns, and feedback.
- Remind the patient about the meeting as the date nears.

☐ Step 3. Prepare for the Meeting—It is important to attend to each item:

Patient

- Accommodate the patient's schedule to attend the meeting.
- Tell the patient that he/she can attend in person or virtually.
- Plan for the patient to attend for the first 15–20 minutes.

Scheduling

- Confirm patient attendance
— If the patient says "yes," educate the patient on the topic(s) that will be covered during the meeting and ask if he/she has any questions.

☐ Step 4. During the Meeting—Be sure to:

- Introduce the staff members in attendance and their roles.
- Introduce the patient and explain why having a patient present for QAPI is important.
- Not share any patient information, including names or specific cases.
- Use plain language—Don't use acronyms, even those that may seem to be commonly understood.



☐ Step 5. Follow-up—To support the best experience for all:

- Debrief with the staff to identify what worked well and how the process could be improved.
- Discuss with the patient what worked well and what could be improved.
- Follow up with the patient directly on topics that he/she provided feedback or suggested for improvements.
- Ask the patient to share his/her QAPI meeting experience with others.

Please visit the End Stage Renal Disease (ESRD) National Coordinating Center (NCC) website for additional resources to help your patients understand the purpose of QAPI meetings and why their participation is important.

- [Because Your Voice Matters!](#)
- [Because Your Voice Matters! Patient Video](#)

For more information, visit www.esrdncc.org/professionals.

1. Agency for Healthcare Research and Quality (AHRQ). Guide to patient and family engagement in hospital quality and safety. Available at <https://www.ahrq.gov/patient-safety/patients-families/engagingfamilies/guide.html>. Accessed on March 16, 2021.

2. Institute for Healthcare Improvement (IHI). Advancing the Practice of Patient- and Family-Centered Care How to Get Started. Bethesda, Maryland: Institute for Family-Centered Care; 2008. Available at <http://www.ihi.org/resources/Pages/Publications/AdvancingthePracticePFCOHowtoGetStarted.aspx>. Accessed on March 16, 2021.



This resource was adapted with permission from the Qsource ESRD Network 12 webinar, Engaging Patients in Quality Assurance and Performance Improvement and Governance Teams.

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PFR Involvement in QAPI

Because Your Voice Matters!



Your dialysis facility often invites patients like you to take part in what is called a Quality Assessment & Performance Improvement (QAPI) meeting. You can also ask to take part in a QAPI meeting. This meeting gives you the chance to talk to the dialysis facility leaders about your concerns and other patient issues. Many times, the ideas and decisions that come out of QAPI meetings affect how the dialysis facility is run.



To have a good QAPI meeting experience, use this document to help you before, during, and after the meeting. Write down notes on what you would like to talk about with the healthcare team. This will help you stay on track during the meeting. Remember, your ideas can help make patient care better.

Before the QAPI Meeting

To prepare, think about questions, concerns, or feedback you and/or other patients may have. Ask the manager what topics will be discussed at the meeting. This might include:

 Facility improvement	 Home dialysis and kidney transplant education
 Preventing infections	 Emergency preparedness education
 Fistula/Catheter education	 Reducing patient hospitalizations

During the Meeting

In most cases, you will only be in the meeting for the first 15 minutes. You will be asked to offer suggestions for improving patient engagement and care. The dialysis facility leaders may ask you for your opinion and/or to share your experiences. The questions are meant to help the staff make the dialysis experience better for patients. If you do not understand something, just ask! You may be asked questions like:

- What do you think we are doing well in the dialysis facility?
- What areas do you think we could improve in the dialysis facility?
- What do you think are the most common reasons patients miss or shorten treatments?
- What is the best way for staff to communicate with patients about their treatment?

For more information, visit www.esrdncc.org/patients.

After the Meeting

Follow up with the facility administrator or clinic manager about decisions or plans made during the meeting that will affect what happens on the dialysis floor. Keep sharing your ideas with staff. Tell them if you would like to attend a QAPI meeting again in the future. If you are comfortable, share your experience with other patients.

Discussion Topic <i>During the meeting, write down discussion topics</i>	Follow-up Items <i>Shortly after the meeting</i>	Results <i>By the end of the month of the meeting</i>
<i>Example:</i> Reducing infection rate in clinic.	<i>Example:</i> I asked staff to provide more information about the importance of washing hands.	<i>Example:</i> Nurse posted Clean Hands poster above sink.

For more information, visit www.esrdncc.org/patients.



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This resource was adapted from ESRD Networks 7 and 8 Quality Assessment and Performance (QAPI) Patient and Family Meeting Notes.



PFR Involvement in QAPI (HIPAA)

- HIPAA or the Health Insurance Portability and Accountability Act was passed by Congress in 1996. It requires the protection and confidential handling of protected health information
- This resource addresses the following:
 - Why is it important to allow posting of some patient information?
 - How can a facility prevent HIPAA violations when posting information?
 - What can a facility do to make sure HIPAA requirements are being met?

Help With
HIPAA

HIPAA or the Health Insurance Portability and Accountability Act was passed by Congress in 1996. It requires the protection and confidential handling of protected health information

All dialysis patients have rights and responsibilities, which are reviewed with them upon initiation of treatment. One of the rights listed, and extensively reviewed, are patient's privacy rights or HIPAA.

Why is it important to allow posting of some patient information?
Patient involvement is strongly encouraged to meet quality improvement goals set by CMS. One of the best ways to engage patients is to share information about patient progress in the facility.

How can a facility prevent HIPAA violations when posting information?
Protecting patients against any HIPAA violations is of utmost importance. In order to ensure patients are protected, many facilities have initiated a consent process which allows information sharing with permission from patients.

What can a facility do to make sure HIPAA requirements are being met?

- ☐ Create an admission process to obtain written consent from patients to share their information and images, and provide details on the type of updates the facility likes to post
- ☐ Annually review forms on every patient to ensure consent is current, and have patients review and resign any necessary paperwork
- ☐ Keep lists of patients who have not signed consent for information sharing, up-to-date and easily available to all staff, so they can check before posting any patient updates

Examples of activities where patients may have personal information disclosed about them:

Activity	Facility Concern	How to Ensure HIPAA Compliance
Sharing a patient's transplant status with other patients using the "Newly Transplanted, Let's Celebrate" poster	Poster includes patient photo; patient will not want their transplant status disclosed; poster is displayed in public area	<ul style="list-style-type: none">✓ Before or following the transplant, ask the patient for verbal permission to display the poster and/or tell other patients about their status✓ Allow the patient to set boundaries on how much information they would like disclosed. Do not display poster if the patient declines.
Inviting patients to the facility's monthly Quality Assurance and Performance Improvement (QAPI) meetings	Facilities are concerned about patients hearing staff discuss treatment and clinical information about other patients in the facility	<ul style="list-style-type: none">✓ When inviting patients to participate in QAPI, designate a portion of the meeting (either beginning or end) to have them speak about patient activities, concerns, and/or ideas✓ Avoid talking about other patient-specific information during this time

IPRO
Better healthcare, realized.

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Developed by the IPRO
ESRD Network Program
while under contract
with Centers for
Medicare & Medicaid
Services, Contract #
75FMC1900029
02/21/22 Version 1

p. 29

Let's Patient Resources



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Patient Facility Alliance Manual

This brand new patient vetted resource includes the following:

- What is IPRO
- What is the IPRO ESRD Network Program
- What is the PFR Alliance?
- The PFR Structure (by tiers)
- Roles and Responsibilities
- How to stay active
- How to Join our Events
- Tips for Success
- PFR “Don’ts”
- How to become a Peer Mentor
- QAPI Meeting

https://esrd.ipro.org/wp-content/uploads/2023/01/ESRD-PFRA-Manual-2022_v7-508c-updated.pdf







Guidelines for PFRs and QAPI Meetings

This brand new patient resource includes guided instructions for all PFRs as they participate in their facility's QAPI Meeting as well as task to take in the event that they cannot attend an upcoming meeting.

https://esrd.ipro.org/wp-content/uploads/2022/12/ESRD_GuidelinesPatientReps-QAPI_v2-508c_patient.pdf



End-Stage Renal Disease
Network Program



IPRO ESRD NETWORK PROGRAM
PATIENT FACILITY REPRESENTATIVE
ALLIANCE
Working Together
for better health.

Guidelines for Patient Representatives Who Attend QAPI Meetings

1. No personal information about any patient will be discussed.
2. No identifying information that relates to or could connect to a particular patient or a staff member shall be discussed when a patient representative is present.
3. Input from patient representatives is given first priority in QAPI meetings. Patients need to share their positive and negative experiences during the preceding month.
4. To ensure the patient perspective is accurately represented, select patients from each shift to participate in the QAPI meeting. If this practice is not feasible, a facility may have one designated patient and continue to make efforts to recruit additional patients.
5. QAPI should serve as a platform to address center-wide issues and not individual or personal concerns. For individual and personal concerns, we have the grievance process. Patient representatives should help direct and guide the focus of the center's patient related QAPI goals.
6. The role of the patient representative is to voice any general comments, concerns "top of list" issues that matter most to patients on dialysis. This includes any suggestions for improvements that would result in making patients' visits to our facility more enjoyable, calm and comfortable as well as suggestions about needed patient education (e.g., insurance changes, Medicare or Medicaid rules, travel rules and requirements, etc.)
7. Patient representatives should be aware of the behaviors that could lead to an Involuntary Discharge, as well as the process, e.g., non-payment of co-payments or threats to other patients, staff members or any providers, etc.
8. Patients who act as a QAPI representative should be active members of the quality improvement team at the facility working with facility leadership on quality activities. They should also be active patient liaisons assisting new patients and existing patients to better understand and advocate for their care.
9. If patients are unable to attend the QAPI meeting they can also provide a written report or call into the meeting to provide their updates to encourage attendance.

To file a grievance, please contact us:

IPRO End-Stage Renal Disease Network Program

Corporate Office: 1979 Marcus Avenue, Lake Success, NY 11042-1072

• Patient Services: (516) 231-9767 • Toll-Free: (800) 238-3773

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Developed by the IPRO ESRD Network Program while under contract with the Centers for Medicare & Medicaid Services.
Contract # 75FCMC19D0029 Publication # ESRD.IPRO-G3-NW-20221003-137 v.2 12/12/2022

IPRO, the End-Stage Renal Disease Organization for the Network of New England, Network of New York, Network of the South Atlantic, and Network of the Ohio River Valley, prepared this material under contract with the Centers for Medicare & Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services. CMS Contract Number: 75FCMC19D0029. CMS Task Order Numbers: 75FCMC21F0001 (Network 1), 75FCMC21F0002 (Network 2), 75FCMC21F0003 (Network 6), 75FCMC21F0004 (Network 9).

Next Steps



Network Check-In

- **Are you interested in participating in a call with Network staff and CMS to share your experience as a PFR, address issues impacting your facility and peers, and offer recommendations on how to improve patient care?**
 - Yes
 - No
 - Unsure





Patient Virtual Support Group

Join the Network in our virtual monthly patient support group!

- We want to understand your thoughts and experiences as an ESRD patient or caregiver
- Let us know what could have been done better, and what is working for you

Every 4th Wednesday of the month at 5:00pm ET

- Meeting Link:
<https://ipro.webex.com/ipro/j.php?MTID=m6de0a2dc11398746344a8dc525b9e7eb>
- Call-In: 1-855-797-9485
- Access Code: 616 535 334





Next Steps

- **Follow** us on social media!
- **Join** the PFR Alliance Facebook Group
<https://www.facebook.com/groups/ipropfralliance>
- **Create** your IPRO Learn Account <https://esrd.iprolearn.org/login/index.php/>
- **Save the Date:** February 2, 2022
- **Participate** in a call with Network staff and CMS to share your experience as a PFR, address issues impacting your facility and peers, and offer recommendations on how to improve patient care - volunteers needed each month!
- **Become** a Peer Mentor:
 - Understand the steps <https://esrd.ipro.org/patients-family/pfe/peer-mentoring/>
 - Register online: <https://redcap.ipro.org/surveys/?s=CJMXNF9DNR>
 - Have questions?
 - Review the Frequently Asked Questions resource
<https://esrdncc.org/globalassets/peer-mentoring-operational-toolkit/14pmlmsfaq508.pdf>
 - Contact Danielle Andrews at 516-209-5549



Follow Us on Social Media



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- [I PRO ESRD Patient Facility Representative \(PFR\) Alliance Group](#)



- [I PRO ESRD Network Program's Twitter Page](#)



- [I PRO ESRD Network Program's LinkedIn Page](#)



- [I PRO ESRD Network Program's Instagram](#)

Questions? Comments?



Thank you for your ongoing commitment to the ESRD community!

For more information, contact:

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realized.

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