ESRD Professional Training Series

Establishing Patient Supportive Programs at your Facility

April 2019
IPRO End Stage Renal Disease (ESRD) Network

Part 1: Benefits of Patient and Family Engagement Activities
Part 2: Forming a Support Group
Part 3: Facilitating a Support Group
Part 4: Patient Peer Mentorship
Part 5: Tips and Suggestions
Learning Objectives

At the completion of this activity the learner will be able to:

- List the ESRD Network roles and responsibilities
- Understand Patient and Family Engagement (PFE) initiatives
- Describe the different types of Support Program formats
- Provide support for staff, patients and family members in the creation of a support group
- Coach patient and family members in facilitating a support group
- Describe how Peer Mentoring support can be effective
- Share with others how creating and supporting Patient Support groups can be an effective tool to improve quality and the patient experience of care
ESRD Networks

- Puerto Rico and Virgin Islands are part of Network 3
- Hawaii, Guam, American Samoa are part of Network 17
ESRD Network Structure

Centers for Medicare & Medicaid Services (CMS)

• Sets goals to improve the care of patients in ESRD

18 ESRD Networks

• Works with facilities and patients in their region to design programs to help reach regional and national improvement goals

ESRD National Coordinating Center

• Works with ESRD Networks, CMS, and Patient Subject Matter experts to support the goals and share information on a national level
ESRD Networks are critical to achieving CMS goals for healthcare transformation and improving the patients experience of care by:

- Being leaders, motivators, and organizers
- Producing partnerships and collaboration within the ESRD community
- Promoting outreach and education
- Collecting, analyzing and monitoring data to measure achievement
- Collecting and sharing best practices
- Providing emergency preparedness services for the ESRD community
- Support patients and facilities in resolving grievances

CMS Goal:

- Foster patient and family involvement in the areas of promoting better health for the ESRD population with a focus on creating support/adjustment groups and incorporating patients into quality assurance improvement performance activities
Centers for Medicare & Medicaid Services (CMS) Goals

ESRD Networks are tasked by CMS to support the achievement of national quality improvement goals and statutory requirements by aligning Network activities with the following CMS goals.

- Goal 1: Empower patients and doctors to make decisions about their health care
- Goal 2: Usher in a new era of state flexibility and local leadership
- Goal 3: Support innovative approaches to improve quality, accessibility, and affordability
- Goal 4: Improve the CMS customer experience
Part 1: Benefits of Patient and Family Engagement (PFE)
Why is Patient and Family Engagement (PFE) important?

“Patients are often more satisfied with their care, and express a greater quality of life, when they are able to be active participants in planning and implementation. This level of involvement in their care, and the collaboration, with the rest of their healthcare team, allows them to feel empowered and ultimately leads to improved health outcomes.”

“Patient Self-management of Chronic Disease in Primary Care”
JAMA, 2002
8 Dimensions of Patient Centered Care

- Patients’ Preferences
- Information & Education
- Continuity & Transition
- Emotional Support
- Physical Comfort
- Access to Care
- Coordination of Care
- Family & Friends

8 Dimensions of Patient-Centered Care
Benefits of Implementing Patient Centered Care Activities

- Increased communication between patients and the treatment team
- Promotion of a culture of quality improvement
- Improved patient quality of life
- Strengthened patient and provider relationships
- Empowering patients to take a more active role in their care
- Improved clinical outcomes overall at the facility level
Support comes in Different Formats

- Traditional support groups are typically a group of people who meet at a place on a routine basis in-person to talk with each other.

- Peer Mentorship Support programs connect people in:
  - One on One support with another person such as the ESRD Network Patient Peer Mentorship program.
  - Phone Based Support such as the National Kidney Foundation Peers program.

- Web-based Support connects a person to many people through Social Media outlets such as Facebook.
Kidney Patient and Family Support Groups

A place for people with kidney disease to meet on a regular basis to:

• Share common concerns and issues
• Provide support and encouragement
• Learn about kidney disease research, treatment options and services
• Discuss coping skills due to the effects of kidney disease
• Empower each other to take an active role in managing their care
Support Programs Help Patients and Family Members

- Find strength in sharing experiences
- Develop empowerment and control over their circumstances
- Gain insight by discussing challenges and successes of others facing similar circumstances
- Provide positive outlets to help reduce stress, allowing for more mindful care
- Identify areas where focused staff education would be helpful
- Increase compliance with treatment recommendations
- Improve clinical outcomes by being empowered with information to be engaged in their care
- Help improve patients’ overall experience of care
Part 2: Forming a Traditional Support Group
Identifying Your Core Group

Survey patients to identify their interest.

Identify a core group of patients or family members interested in forming a support group who:

• Share common challenges and purpose
• Are interested in learning
• Welcome and are willing to help others
• Dependable and interested in meeting regularly

TIP: Market the group with a non-traditional name, such as Kidney Klub, to eliminate any stigma that may be associated with a support group
Support Group Leadership Team

These core group members can have leadership roles in creating the group. Leadership activities include:

• Defining the mission and purpose of the group

• Leading a topic discussion or printing materials

• Helping make phone calls or be in charge of marketing the meeting

• Providing renal-friendly snacks and beverages

• Planning fun activities such as a movie night or bowling night for group members.
Identify a Meeting Place

Consider locations in your area that might offer free space to hold your meeting:

- Local Restaurants
- Community Centers or Churches
- Public Libraries
- Dialysis Centers or Hospitals

After choosing your location:

- Continue to use the same space to eliminate confusion
- Hold the meeting on the same schedule and time, for example the 4th Saturday in the month at 1:00pm
Define your Purpose

A common purpose of kidney support groups is helping those affected with kidney disease live their best life.

Work with your core group to define your own purpose of a kidney disease support group. Some common purposes include a place to:

• Receive emotional support in a safe, welcoming environment
• Share thoughts, feelings and concerns
• Learn from one another’s knowledge and experience
• Problem solve
• Establish friendships and gain a sense of belonging
• Become educated and informed
• Develop skills needed for personal growth and development
Create a Mission Statement

A mission statement briefly describes a group’s purpose, goals, and philosophy.

Your mission or way you accomplish your purpose provides a snapshot of your group to potential new members.

Your mission statement might include:

- Establishing a place where others can share their thoughts, feelings and concerns
- Learning from others knowledge and experience
- Providing resources to understand treatment choices and tips for living well on dialysis
- Creating friendships and gaining a sense of belonging
- Developing skills needed for personal growth and development
Define the Group Rules

Establish a set of rules for the group that can be published. Group Rules created by the members help structure the meeting and give a neutral reference point to keep the group on track.

Things to consider might be:

- No profanity
- No complaints about specific facilities or specific staff members
- Allow every person to be heard
- Listen when others are sharing
- Be respectful to your other peers
- DO NOT share private information shared in the group outside of the group
Creating a Marketing Strategy

Creating a strategy to reach others who would benefit from joining a Kidney Disease support group is important to your success.

• Create a Flyer that can be posted on bulletin board or be given as a hand out
  – Consider if you want to list a phone number or email address on the flyer
  – Consider adding information about the facilitator or core group members.

• Schedule a visit to another facility and talk with patients, share your story and learn about their, invite them to join your group

• Making genuine connections welcomes new patients to feel comfortable joining an existing group

TIP: Create a generic email address DialysisGroupName@gmail.com to but make sure to check it routinely and respond to inquiries
A patients’ health care team lends credibility to other health care providers to feel comfortable about sharing support group information.

Ask area healthcare providers to help you share details about your support group by reaching out to:

- Nephrologist practices
- Transplant Centers
- Acute Care Hospitals
- Home Dialysis Programs
- Vascular Access Clinics
What barriers might you face?

Creating and sustaining a support group can be challenging. Support groups need local leadership who have the time, vision and passion to keep the group going. Challenges can include:

- Transportation to meeting
- Desire to spend non-treatment time at the facility if the meeting is held at the facility
- Finding a central location that is free
- Identifying a core group of people to provide leadership for the group
Addressing barriers you might face?

The best way to address challenges is working with facility staff and core group members to brainstorm solutions. Solutions may include:

- Holding your meeting near a bus stop for people who use public transportation
- Share the work. Have several core members call libraries, churches, or community centers to locate a free space
- Meet for a meal at a local restaurant
- Join with other local facilities to locate more leaders in the community
Part 3: Facilitating a Traditional Support Group
In addition to support and sharing, it is helpful to plan for a topic at each meeting. Planned topics provide structure and a focal point for discussion.

Consider these tips:

- Survey participants on topics of their interest
- Create a yearly topic calendar that can be shared with the group
- Consider bringing in a guest speaker to cover a topic
- Download a podcast to play and then discuss the information shared
Develop a List of Topics

Popular topics for support group meetings:

• Modality Choices
• Minimizing Problems of Long Term Dialysis
• Going Back to Work
• Coping with the Renal Diet
• Learning How Others Have Successfully Lived with ESRD
• Communicating with Your Physician.
• Programs on Renal Vacations
• Holiday Recipes
• Travel
Secure a speaker to support discussion around a particular topic

Guest speakers could include:

• Dialysis social workers or nurses
• Transplant Center Coordinators
• Renal Dieticians
• Nephrologists or Kidney Doctors
• Transplant Surgeons
• Vascular Access Coordinators or Surgeons
• Home Dialysis Program Managers
• Vocational Rehab or Employment Network Representatives
• Mental Health Professionals
Facilitating a Support Group Meeting

Often times patients join support group meetings in hopes of sharing their frustrations, learning from each other and seeking answers to specific questions or problems.

When facilitating a meeting it is helpful to:

- Create a sign in sheet for people to leave their name, email address and phone number to easily invite them to a future meeting
- Begin the meeting by asking each member to give a short introduction or goal they would like to achieve
- Review the group rules or have printed copies for people to reference
- Focus the meeting on ways to help patients become better problem solvers
- Be mindful that each participant has an equal amount of time to share
- Set the tone for the meeting so that everyone has a chance to speak

TIP: If one person is focused on a specific issue or topic for too long, acknowledge the issue and offer to speak with the person one on one after the meeting.
Ending a meeting on a positive note is important as it encourages attendees to leave with hope and promise as opposed to feeling overwhelmed by the challenges that may have been discussed.

Consider these tips when closing your meeting:

• End with a brief summary of what was discussed and accomplished
• Close with an affirmation or a positive message
• Remind attendees of the next meeting’s date, time and topic
• Set aside time for one on one connections to be made after the meeting
• Bring books or educational resources to share with members

TIP: Consider becoming familiar with additional websites and resource materials so you can share with members who have unique needs. Talking with dialysis professionals is a great way to learn about online resources.
Measuring Success

It is important to evaluate from attendees whether the support group is meeting their needs and expectations to identify ways to improve.

Survey Tips:

- Provide a paper survey and ask people to anonymously complete and leave at the end of the meeting.
- Create an electronic survey using free tools like Survey Monkey to evaluate on a quarterly basis the effectiveness of the meetings.
- Ask for feedback on a one on one basis. Always be receptive to new ideas and trying different things.

Remember: There isn’t a right or a wrong way to facilitate a support group as long as attendees leave with valuable, correct information and feel empowered by helping others and themselves live well with dialysis.
Part 4: Peer Mentorship Support Programs
What is Peer Mentoring?

• A **peer** is someone who has had similar experiences as another person.

• A **mentor** is someone who has experience or knowledge that he/she shares with another person to help them.

• A **mentee** is a person who is advised, trained or counseled by a mentor.

YOU can make a difference.  
Be the Change. Get Involved.
How Can Mentors Help Mentees?

• Peer mentors may have experiences overcoming the same challenges as their mentee

• A mentee could be facing a lack of support from friends and family, which may make it difficult to follow his or her treatment plan

• A mentee might have limited one on one support from medical staff and have unanswered questions
Who is an Ideal Peer Mentor?

A PERSON FROM ANY BACKGROUND OR EXPERIENCE LEVEL WHO:

- Has a positive outlook in dealing with kidney disease.
- Is achieving his/her treatment goals and would like to take a leadership role in helping others do the same.
- Likes to connect with peers and use that connection to engage and educate.
- Is open to learning about available resources on kidney care choices.
- Is comfortable helping patients talk with their care teams and take an active role in their care plans.
Roles of a Peer Mentor

- Providing educational information
- Discussing kidney care choices
- Be a positive role model
- Listening to concerns
- Offering encouragement
- Sharing common experiences
- Relieving anxiety
Program Support Materials

Share your experiences
Have you ever wanted to help others by sharing your own experiences with kidney disease?

Yes!
If your answer is yes, the IPRO ESRD Network’s Peer Mentor Program is for you!

To learn more about your facility’s Peer Mentor Program, contact:
Network Materials for Recruitment

Member Application

Thank you for your interest in the Peer Mentorship Program. Please answer the questions on this application as best as you can. This will help us pair you with another participant. Please note that your answers will be kept confidential in accordance with HIPAA laws.

Mentors must complete training before they can participate in the program. Your dialysis facility will help you get training and put you in touch with other patients who are interested in learning about your experiences in managing kidney disease. Your role will be to help answer their questions and help them be informed to make decisions about kidney care options.

Mentors will be paired with a mentee. As a mentee, you will be able to meet with a peer mentor from your dialysis facility who can share their experience as being a dialysis patient. Mentors can also help provide education about End-Stage Renal Disease to help support you in making more informed decisions about kidney care options.

Are you interested in being a Mentee or Mentor?

Name: ______________________

Facility Name: ______________________

Please share your E-mail address: ______________________

2. What is your access type? __ Fistula __ Catheter

3. What is your current treatment type? __ In-Center Hemodialysis __ Peritoneal Dialysis __ Home Hemodialysis

4. What is your current treatment schedule? __ Monday/Wednesday/Friday __ Tuesday/Thursday/Saturday __ Everyday __ Other: ______________________

5. Are you on the transplant waitlist? __ Yes __ No

6. When do you usually arrive for dialysis? __ On-time __ Early __ Late

Sample Peer Mentorship Program Consent Form

A mentor is someone who has experience or knowledge that he/she shares with another person to help them, who is willing to share information that will help the other person. Should you participate, you will be communicating with a mentee who will be assigned to work with you at ______________________ where the mentee receives treatment.

Facility Name: ______________________

By agreeing to participate in this program, you agree to the following:

1. ______ (Initials of Mentor) I am acknowledging that I have completed the ESRD Peer Mentorship Training Program.
2. ______ (Initials of Mentor) I am acknowledging that I have completed the facility’s HIPAA Privacy and Compliance Policy.
3. ______ (Initials of Mentor) I have been given a copy of the facility’s policies and procedures. I agree to abide by the facility’s policies and procedures while I am on their premises.
4. ______ (Initials of Mentor) I agree that any meetings with the mentee must take place only at the facility.
5. ______ (Initials of Mentor) I agree that all peer mentor communications will be kept confidential unless I have to report an emergency to the facility. I understand that if I should violate this confidentiality, I may be excluded from future participation in this program.

Mentor Signature: ______________________ Date: ______________________

Facility Name: ______________________

Signature of Facility Authorized Representative: ______________________ Date: ______________________

This document shall be maintained by the facility in accordance with its policy.
Peer Mentorship Training Modules

**Foundation Modules**
- Mentoring to Support Choices
- Talking Effectively with Another Patient

**Focus Topic Modules**
- Discussing Transplant as an Option
- Discussing Home Dialysis as an Option
- Helping Mentees Plan for a Vascular Access
Mentoring to Support Choices

Content

• Introduction to Peer Mentorship
• Learning the Role as a Mentor
• Understanding the Program focus areas and guidelines
• Tips for getting started and planning for success
Talking Effectively with Another Patient

Content

• What is a peer mentor and their role?
• What are the benefits of peer mentorship?
• What are the rules to follow in becoming a peer mentor? (HIPAA, Confidentiality, Ethics, Cultural Diversity, Language Barriers)
• Skills to help peer mentors succeed
• Communication/Leadership development
Discussing Transplant as an Option

Content

• Learning the basics of Kidney Transplantation
• Review and become familiar with the transplant resource toolkit
• Understand how to use the toolkit when talking to other patients
Discussing Home Dialysis as an Option

Content

• Learning about Home Dialysis Options

• Choosing the right option based on patient lifestyle

• Review and become familiar with the transplant resource toolkit

• Understand how to use the toolkit when talking to other patients
Helping Mentees Plan for a Vascular Access

Content

• The types of vascular accesses
• How to make a vascular access plan
• Introduction to the vascular access planning resource toolkit
IPRO ESRD Program E-University

Platform website: https://esrdlms.ipro.org

- Online Learning Management System
- Patient and Professional Training Modules
- Track user login, course completion, course evaluations/quiz, distribute CEs and provide completion certificates on topics provided.
- Printable slide available to support different learning styles
- Allow the Network to easily track the usefulness, effectiveness of training for the community.
Other Patient Peer Mentorship Programs

Transplant Peer Mentor Program

- Introduces Dialysis facility leadership to Peer Mentorship Program
- Provides recruitment and screening tools for transplanted patient peer mentors
- Training materials for both facility leadership and peer mentors
- Information on how to plan and report activities to evaluate the effectiveness of peer mentorship
Part 5: Tips and Suggestions
Tips for Getting Started

• Be Persistent - It takes a time to be known in your area and for people to see your group as a resource.

• Don’t be Discouraged - The first few sessions may have very limited attendance

• Identify your core group and learn about each other, identify commonalities. An effective support group will build relationships inside and outside of the topic of kidney disease

• Don’t overcomplicate the design of the support group, a few basic ground rules will help your group stay organized but keeping it simple will allow you flexibility.

• Be consistent. Holding your meeting at the same place and time will allow people to come as they are able and not be confusing.
Tips to Sustain Your Patient Engagement Program

- Connect with other Kidney Support group leaders through the American Association of Kidney Patients (AAKP) website https://aakp.org/support-groups
- Notify the AAKP so they can post the information about your group on their website
- Contact the ESRD Network, the Network can connect you with other facilities that have successfully implemented programs
- Utilize the NKF Peers program to connect your core group / patient peer mentors to others who can share ideas on ways to overcome barriers
Additional Resources


- American Association of Kidney Patients (AAKP): Support Group Guidebook


- IPRO ESRD Network has several resources that can assist [www.ipro.org](http://www.ipro.org)

- IPRO E-University Patient Peer Mentorship program [https://esrdlms.ipro.org](https://esrdlms.ipro.org)
Next Steps

• Complete the Establishing Patient Support Groups Module review quiz.

• Facility staff and patient facility representative should work together to discuss ideas for creating patient supportive programs for patients in your area.

• Facility staff and patients facility representatives can work to identify other patients who can be core members of the group.

• Consider hosting the first few meetings as meet and greets for patients to get to know each other or host a meeting with a guest speaker on an education topic that aligns with your facilities quality improvement strategies.
Celebrate each success you have in empowering patients to be involved in their healthcare and supporting each other in learning to live well with kidney disease.

Thank you for your hard work and commitment to helping patients!
You have completed training on Establishing Patient Supportive Programs at your Facility!