Tell us what you think! Please take a moment to complete a short questionnaire about this Toolkit. We appreciate your insight and suggestions to make our resources better.
https://www.surveymonkey.com/r/ForumResEval
# CONTENTS

**Intro:**
The Patient Grievance Process Toolkit ........................................... Page 1

**Chapter 1:**
Utilizing the Grievance Toolkit ...................................................... Page 2

**Chapter 2:**
Definitions .................................................................................. Page 3-4

**Chapter 3:**
Recommended Patient Rights and Responsibilities ......................... Page 5-7

**Chapter 4:**
Grievances in a Patient Centered Care Environment ......................... Page 8-10

**Chapter 5:**
Barriers to a Successful Grievance Experience ................................ Page 11-14

**Chapter 6:**
What do You do If You Have a Concern or Grievance? ..................... Page 15-16

**Chapter 7:**
The Network’s Role in the Grievance Process ................................. Page 17-19

**Chapter 8:**
Documentation: Before Proceeding with a Grievance ..................... Page 20-23
  - Grievance Preparation Worksheet - #1 ................................ Page 24-25
  - Grievance Preparation Worksheet - #2 ............................... Page 26

**Appendix:**
- QAPI (Quality Assessment and Process Improvement) ............... Page 30-33
- Improvement & Assessment is a Team Effort ............................ Page 34-35
- ESRD Networks’ Patient Toll Free Numbers/Maps ...................... Page 36-37
- Acknowledgements .................................................................. Page 38
- Disclaimer ................................................................................ Page 39
INTRO
THE PATIENT GRIEVANCE PROCESS TOOLKIT

The Forum of End Stage Renal Disease (ESRD) Networks Kidney Patient Advisory Council (KPAC) made The Patient Grievance Process Toolkit to help patients as they work through the Grievance System. We feel that a toolkit designed BY patients and FOR patients will help explain the grievance system to meet patient needs.

The Toolkit could be a useful tool for both patients AND facilities. While most facilities and all Networks have a Grievance Process, this is the first time that process has been explained through the patient’s eyes.

This toolkit would not exist without the help, support, and encouragement from the ESRD Forum’s Executive Director Advisory Council (EDAC) and the Medical Advisory Council (MAC). These tireless people have donated time and information toward creation of this project. Thank you, everyone, for all you have done and continue to do so that we, the patients, can have the best possible life with ESRD.
CHAPTER 1
UTILIZING THE GRIEVANCE TOOLKIT

The KPAC hopes this toolkit will help patients, family members, facilities, and Care Teams. We feel that the information can help everyone create a safe dialysis setting for each and every patient.

We know that not all people learn the same way. This toolkit has definitions, text, work-sheets, and graphs. The index of chapters shows information quickly but there is some overlap of ideas. We suggest that you take the time to read the entire toolkit and mark those areas of special interest to you and your situation.

We believe that this toolkit can be used to help patients form their thoughts and concerns. We provide tips and ideas for positively solving a grievance and provide tools for those who wish to look deeper into the grievance process.

But perhaps our biggest hope is that this toolkit will be used to open communication between patient/families and facilities BEFORE a concern becomes a grievance.
CHAPTER 2
DEFINITIONS

If you are thinking about filing a grievance either with your unit, the ESRD Network or the State Health Department, then something has happened that is worrying you and/or making you unhappy. To make things clear it is important that everyone dealing with the grievance has the same understanding and meanings.

We will use definitions provided by Centers for Medicare & Medicaid Services (CMS) along with some helpful comments.

**Grievance:**
A written or oral communication from an ESRD patient, and/or an individual representing an ESRD patient, and/or another party, alleging that an ESRD service received from a Medicare-certified provider did not meet the grievant’s expectations with respect to safety, civility, patient rights, and/or clinical standards of care. The grievant is not required to explicitly state that the care did not meet professionally recognized standards.

**Grievant:**
An ESRD patient or other individual who files a grievance with a Medicare-certified ESRD provider or the ESRD Network.

**Medicare beneficiary:**
An individual who is enrolled in fee-for-service Medicare or a Medicare health plan to receive benefits under Medicare Part A and/or B.

Under the definition for Grievance, CMS talks about Patient Rights.
In chapter 3 you will find the CMS defined Patient Rights and Responsibilities made from the Conditions for Coverage for End Stage Renal Disease Facilities, CMS Final Rule Published April 15, 2008, Effective date October 14, 2008.
**Practitioner:**
An individual credentialed in a recognized health care discipline who provides the services of that discipline to patients. Practitioners include physicians, nurses, nurse practitioners, physicians’ assistants, physical therapists, occupational therapists, speech therapists, pharmacists, certified nursing assistant/dialysis technicians, and others.

**Provider:**
A health care facility, organization, or agency that provides ESRD services covered in whole or part by Medicare.
CHAPTER 3
RECOMMENDED PATIENT RIGHTS AND RESPONSIBILITIES

Every patient should be guaranteed safe, effective, high quality care given with respect and dignity. We believe that the informed patient is better able to cope with the stresses and decisions that may happen during his/her treatment.

When you go to a treatment center, ask for a copy of your rights and responsibilities. This will help you know what to expect from your health care team and what they can expect from you. Your center may have lists like the following.

Your Rights

- I have the right to be told about my rights and responsibilities in a way that I understand.
- I have the right to be treated with respect and dignity, and as a unique individual.
- I have the right to privacy and confidentiality in aspects of my treatment and medical records.
- I have the right to review my medical records and obtain copies if desired.
- I have the right to be told about the services offered at the center and any charges for services not covered by insurance or Medicare.
- I have the right to be told about any financial help available to me.
- I have the right to be told about my health in a way that I understand.
- I have the right to meet with my whole health care team to participate as part of the team in the planning of my care.
Your Rights, continued*

- I have the right to be told about and to choose my treatment options, including those not offered by my dialysis unit.
- I have the right to know about the facility’s discharge and transfer policies.
- I have the right to accept or refuse any treatment or medicine my doctor orders for me.
- I have the right to have and execute advance directives.
- I have the right to be told about the rules at the treatment center (for example; rules for Visitors, eating, personal conduct, etc.)
- I have the right to know about grievance process options.

* There are, of course, potential implications and/or consequences for refusing treatment or medicine your doctor has ordered. This refusal may result in a discharge for not following physician orders.

Your Responsibilities

- In order to make your treatment effective and improve the quality of your life, you and your family should take some specific responsibilities in the day-to-day management of your care. To improve your care:
  - I need to participate as part of the health care team in the planning of my care.
  - I need to treat other patients and staff as I would like to be treated, with respect.
  - I need to pay my bills on time. If this is hard for me, I can ask about a payment plan.
  - I need to tell my health care team if I refuse any treatment or medicine that my doctor has ordered for me.
Your Responsibilities, continued

- I need to tell my health-care team if I don't understand my medical condition or treatment plan.
- I need to tell my health care team if I have trouble following my diet, taking my medications, or following any other part of my plan of care.
- I need to be on time for my treatments or other health care appointments.
- I need to tell the staff at the center if I know that I'm going to be late or miss a treatment or other health care appointments.
- I need to tell my health-care team if I have medical problems, am going to the dentist, am being treated by another doctor, or have recently been to the hospital.
- I need to follow the rules of the center.
- I need to get to and from the center for my treatments. I can talk with my social worker if I need help doing this.
- I need to inform staff of other changes such as insurance, address, and telephone number.

Adapted from: [www.medicare.gov/dialysis/home.asp](http://www.medicare.gov/dialysis/home.asp)
CHAPTER 4
GRIEVANCES IN A PATIENT CENTERED CARE ENVIRONMENT

We need to understand both Patient Centered Care (PCC) and grievances. There are many definitions of PCC. Some have been created by healthcare organizations and some by advocacy groups. The Forum of ESRD Networks Kidney Patient Advisory Committee defines PCC as:

"Patient driven healthcare delivered in a way that is focused on an individual patient's values and preferences and involves both sharing information and active shared decision making with patient, family/caregivers, and medical professionals to reach customized, individualized and realistically obtainable goals of care. This is an ongoing process, keeping in mind these goals may change over time."

In Patient Centered Care:

✓ Patients and families are equal members of the treatment team who are expected to be engaged and share in decisions about their care.
✓ Knowing about their disease, its treatment, and options is a critical part of being able to be engaged.

In a Patient Centered Care environment:

✓ Information is freely offered
✓ Questions are encouraged
✓ Patients are consulted about changes and decisions
The Centers for Medicare & Medicaid Services (CMS) defines a grievance as:

“A written or oral communication from an ESRD patient, and/or an individual representing an ESRD patient, and/or another party alleging that a Medicare covered ESRD service did not meet recommended standards of safety or civility, or professionally recognized clinical standards of care”.

So if someone feels that care is not safe, that staff is not civil, or that the care did not meet requirements, they may file a grievance about their care with the ESRD Network that covers their area and/or the State Health Department. You may, of course, contact your Network any time you have a question or concern.

Most of the time, problems don’t start out as a grievance. Patients may have questions or concerns, or feel they are not being treated with respect. They may feel that these concerns are not handled by the facility as quickly or as completely as they should be.

There is usually one person on staff that a patient or family member trusts and feels comfortable talking with when a problem comes up. This is the best place to start. In a true PCC environment, there should be several people like this, including at least one Facility Patient Representative (FPR). An FPR is a patient in the same center that has had some training and agrees to speak for patients with the leaders of the facility. One or more FPRs may be on the Governing Body of the facility or involved in a Patient-Family Council where patients, families and staff work together to create a welcoming environment. There may also be suggestion boxes that are used to collect ideas. In a PCC environment, a suggestion to improve is viewed as a successful partnership with an engaged patient.
In a PCC environment patients and families know how to address their concerns. All centers are required by Medicare to post information in common areas about how to file a grievance. This information will explain how to file a grievance at the facility, how to contact their ESRD Network and the State Health Department, and how to report unsafe practices. Many of the dialysis corporations have 800 numbers for grievances to be handled at a higher level than the facility.

If there is not a trusted person you feel you can talk to, or you are not satisfied with the way a complaint has been handled, you may contact either your ESRD Network or State Health Department to look into your complaint.

**REALITY CHECK**

**If you contact the Network for help, THEY CAN:**

✓ Give you names and phone numbers of people you can speak to at your clinic’s corporate offices.

✓ Give you information about Medicare regulations and your rights under Medicare.

✓ Contact the clinic and conduct a confidential investigation into your grievance, which may include one or more of the following actions:
  
  • Request medical records
  • Interview staff members or patients and asking for details about a grievance
  • If necessary, visit a clinic in person
  • Confidential means we will not tell anyone at the facility or clinic your name, unless you give us permission to do so

**If you contact the Network for help, THEY CANNOT:**

✓ Force a clinic or doctor to accept a patient.

✓ Guarantee you can choose which staff members put your needles in.

✓ Change or get involved in anything that has to do with personnel policies and procedures.

✓ Get a doctor, nurse or patient care technician “fired” or transferred.
CHAPTER 5
BARRIERS TO A SUCCESSFUL GRIEVANCE EXPERIENCE

There may be barriers that you might face through the Grievance Experience. This chapter will identify some of the most common. If you understand these barriers, you can solve problems faster and more effectively.

BARRIERS CAN BE CLASSIFIED IN ANY OR ALL OF THREE CATEGORIES

I. Barriers of Information and Awareness
II. Barriers of Trust and Confidence
III. Barriers of Strength and Ability

I. Barriers of Information and Awareness

1. Know your Patient Rights
   (Chapter 4)
2. Write your Concerns (sample forms are in pages 24 & 26)
   a. What happened?
   b. When did it happen?
   c. Who was involved?
   d. Who did you talk to about the concern?
3. Follow the Process (Chapter 6)
4. Evaluate how the Grievance Process worked
   e. Is the concern resolved?
   f. If not, are there any further steps you can take?

The first and most obvious barrier to be overcome is a lack of knowledge and understanding of the Grievance Process. The process, at times, can be involved and without a “roadmap” it is easy to get lost.

No two grievances are the same. The process can change from situation to situation and from grievance to grievance. A grievance may be as simple as a verbal complaint or as complicated as a formal complaint to a State Regulating Agency. If certain steps are followed, the grievance experience can be positive and effective.
II. Barriers of Trust and Confidence

Trust and/or Fear of Reprisal

The most common concern expressed by patients is a fear of reprisal or payback. The fear of reprisal is a natural concern resulting from the vulnerability many patients feel. Unlike grievances filed with a hospital after a patient has been discharged, grievances filed with a unit are processed and investigated while the patient is still dialyzing on the premises.

Any and all grievances filed with your Network can be done:

1. Anonymously (no disclosure/no name given)
2. Confidentially (only the Network knows who you are)
3. With full disclosure (your name is attached to the grievance)

Filing without a name can help to ease this fear. But some Grievances are event specific and the grievant is often obvious. While CMS and the Networks do all that they can to lessen the fear of reprisal, grievances are often emotional. Both staff and patients are only human. Sometimes these emotions lead to poor decisions in talking with each other after a grievance has been filed.

While there have been some proven incidents of reprisal, most units are run professionally and make every effort to handle Grievances without emotion. Many units see this as a chance to improve patient safety and approval.

Confidence

Patients sometimes have a lack of confidence in their view of a concern. They may feel they are over-reacting to something they saw or that no one
else cares. Some may feel that they can’t change the system and that their voice won’t make any difference anyway so why bother.

After thinking about it, if you decide that your concern deserves a grievance, don’t second guess the power of one voice. For every one that speaks up, there may be several that have been too uninterested or too afraid to speak up. If no one steps forward to be heard, nothing will improve.

“You should never second guess the power of one voice”

III. Barriers of Strength and Ability

Perhaps the least recognized barriers to a successful grievance are those of strength and ability. The Grievance process is never easy and can be made even harder by the very things we are working to improve and preserve – the health and vitality of the patient.

Certain groups of patients face greater barriers, such as:

1. Patients in poorer health

2. Patients without the energy to complete the process

   *Dealing with ESRD by itself is a draining situation. Many patients are tired and using all of their energy just coping with the basic needs of life. When the stress of filing a Grievance is added, it may seem like too much to get through.*

3. Patients with language barriers

4. Patients with ethnic or cultural barriers

   *If a language barrier exists, making your concerns known and understood will be much more difficult. Being able to present your point of view well and understand the other side becomes less likely with a language barrier.*
Also, ethnic and cultural barriers can keep a grievance being as useful. Certain cultural limits to talking may exist but not be understood by everyone.

Emotional Stress

There are also the barriers related to the Emotional Stress of filing a Grievance. There could be concerns on the time of the process and the possible effect on your how others think of you. Patients may be angry, scared, and/or resentful going into the grievance process. Feelings of a lack of control and protection about a grievance may add more stress.

A Possible Solution

These barriers of Strength and Ability may be helped or overcome by the use of a patient advocate. If the patient has a family member or personal representative able to stand beside them and work through the process, it can ease much of the burden. Someone who is familiar with both sides of the problem can often help find language and cultural barriers. If the unit has a Peer Mentoring program in place, this can help with communication and relieve some of the stress.

Patients and providers who work together can create a sense of understanding. Once a sense of understanding is reached, it is easier to work together in overcoming the barrier.
CHAPTER 6
WHAT DO YOU DO IF YOU HAVE A CONCERN OR GRIEVANCE?

*Please note that these steps are not required to be followed in any specific order*

Speak to Members of your Medical Team

♦ You can make an appointment to speak with the facility administrator, the social worker, or your kidney Doctor. You can meet in private where your concerns will be discussed in a confidential manner.

♦ Remain calm. Take some time, if needed, to become collected.

♦ Do not use foul language or yell.

♦ Be careful not to make threats or accuse people.

♦ Write down your concerns. This will help you be clear.

Attend/Request a Patient Care Plan Meeting

♦ Each facility is required to hold periodic patient care plan meetings to discuss your care. During each meeting, you and your medical team talk about concerns and work together for your best care.

♦ Know your Rights and Know your Responsibilities. Both are presented in this toolkit (pages 5-7) and both will help prepare you for this meeting and for all further steps in the grievance process.

File a Complaint with Your Facility

♦ Learn about your facility’s policy on filing complaints and grievances.
♦ Members of the facility's administrative team such as the manager or risk manager will address your issues and/or concerns.

Contact Your ESRD Network Office

♦ This will begin the Network grievance process. You will be given the option of whether or not you wish to use your name or remain unknown.

♦ You have several choices with the ESRD Network. You may switch at any time or completely withdraw your request for assistance.

✓ **Confidential Consultation**
  If you want to talk with someone at the Network about your care or you want information and resources.

✓ **Immediate Advocacy**
  If you want the Network to quickly help you and your facility work out a problem you are having. Immediate advocacy must be completed by the Network in seven (7) calendar days.

✓ **Quality of Care Review**
  If you feel that the concerns you have involve poor care to you and/or other patients. These reviews are more involved and may take up to 60 days for a full investigation. Medical records may need to be reviewed.

✓ **Referral**
  If your situation or concerns require help from another agency you will be provided with the contact information for an agency that can help.

Contact Your State Department of Health

Especially if your concern is in regard to safety and/or infection control.
CHAPTER 7
THE NETWORK’S ROLE IN THE GRIEVANCE PROCESS

It is always good to allow the facility to address your grievance first. This is not a requirement.

<table>
<thead>
<tr>
<th>THE NETWORK WILL BECOME INVOLVED IF:</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. You are not comfortable handling the issue at the facility.</td>
</tr>
<tr>
<td>b. You believe your concerns were not resolved at the facility.</td>
</tr>
</tbody>
</table>

Q. 1 - How do I contact the Network?

The Network will investigate grievances received by:

- Phone
- Fax
- or in Writing

Your ESRD Network believes that every patient should receive quality care. The Network can help dialysis patients with concerns about their care. If you have a concern, the Network’s role is to serve as an investigator, facilitator, referral agent, coordinator, and/or educator.

The purpose of the ESRD Network in a grievance is to:

- Keep communications open between patients and ESRD facility staff on issues, problems, or grievances.
- Ensure problems are solved as quickly as possible.
- Help patients feel comfortable taking their concerns to an appropriate authority without fear of mistreatment or retaliation.
- Help patients through the grievance process.
Sometimes grievances cannot be resolved with the Network’s help. If the Network cannot resolve your grievance, you may be referred to an agency that can help you.

**Q. 2 - Will the dialysis or transplant facility know that I have filed a grievance?**

Anonymous or unknown grievances can be filed. You should know that it is more difficult to get the needed information though. You will be informed if that is the case.

**Q. 3 - Can someone else represent me?**

You may have a representative or someone to help explain the problem. In this case, you may choose anyone you wish. If you have a representative, the ESRD Network must have your approval for this person to process the grievance for you.

**Q. 4 - What if the issue is life threatening?**

When appropriate, the Network’s Medical Review Board (MRB) appoints a committee to handle the issues raised in a grievance. These reviews are known as Quality Case Reviews or Peer Reviews. Reviewers may include MRB members and Network staff. The Network assures that no one involved with the grievance or the facility is a reviewer. In some cases, the grievance may be reported to the State Survey Agency or Department of Health. This agency inspects dialysis facilities for Medicare. In issues of “immediate jeopardy”, life-threatening situations, the state agency has the authority to shut down a facility until it is safe.

Network staff will determine the best method to handle a grievance.

Network staff will notify you by mail on the next business day if a case is referred to another agency.
Many cases can be resolved quickly through immediate advocacy. In these situations, Network staff acts as a mediator between the patient and the facility. Everyone must be willing to work together. Every effort is made to work out the problem within 7 calendar days.

More serious cases may be required to go through a quality care review. In these situations, medical records are requested, staff and patients may be interviewed, and other provider records may be reviewed. The patient’s written consent may be required.

Every effort is made to complete all investigations within 60 days. If the case is not closed within 60 days, everyone will be told of the delay and when it is expected to conclude.

The patient or his/her representative will be told who to contact if not satisfied with the Network’s handling of the grievance.

A follow up contact may be made at the end of the investigation. This contact is to find out if you are satisfied with the grievance process. It is your choice to participate in the follow up.

Call your Network if you have any other specific questions. They will gladly assist you.
Organizing or forming your thoughts helps you remember exactly what happened and helps you to explain your concerns in a way others can understand. This will help you to gather the specific information or things needed by those who are investigating the grievance.

There are a couple of ways to organize your thoughts:

1. Write it down! While the events and concerns are fresh in your memory, write them down. This helps you to keep the facts clear and avoid purely emotional reactions.

2. One of the easiest and most effective ways is to talk to a friend or family member and tell them what happened. They may be able to point out areas that aren’t clear or need further explanation.

3. Contact your Network. If you have concerns/things you’ve seen that you feel should be handled but you need help on how to proceed, your Network can help you by:
   a. Giving you information on the grievance process
   b. Making necessary calls/contacts for you
   c. Helping you organize your thoughts
In this section we have provided two (2) worksheets that you can use to organize your thoughts before you file a grievance.

**Note:** These worksheets are for your personal use only and are not part of a formal grievance report.

Here are some tips to consider in documenting a grievance worksheet:

1. The ESRD Network can be contacted with any concern. They are there to help you with your concerns by working together with your dialysis/transplant facilities to improve the quality of care.

2. Write down all the facts of the situation
   a. Make sure you have the details of who, what, where, when and how.
   b. If you have willing support witnesses, make a list of them as well as their contact information.
   c. Keep a record of exactly who you have spoken to about your concern, when you talked with them, and what was said.

3. Decide what you want to have happen from this grievance.
   a. Be reasonable and make sure what you want applies to the problem you had.
   b. If you have more than one thing you want that you would be satisfied with, make a list in order of importance to you.
Grievance Preparation Worksheets

You may use these worksheets to organize your thoughts as you prepare to file a grievance
Page Intentionally Left Blank
Grievance Preparation Worksheet - #1

Date of the Occurrence/Observation: ________________________________

1. Who is involved in this grievance? *(name everyone involved)*
   ________________________________________________________________

2. What was the problem?
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________

3. When did it occur?
   ________________________________________________________________

4. Where did it take place?
   ________________________________________________________________

5. What records/documents affect this grievance?
   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________

6. Why is this a grievance?
   ________________________________________________________________

7. How should this grievance be settled?
   ________________________________________________________________
   ________________________________________________________________
8. Other related information
Grievance Preparation Worksheet - #2

Grievance Involves (check all directly involved)

☐ Facility/Unit Staff

Name: ___________________________ Title: ___________________________
Name: ___________________________ Title: ___________________________
Name: ___________________________ Title: ___________________________

☐ Physicians(s)

Name: ___________________________
Name: ___________________________
Name: ___________________________

☐ Other (Specify)

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________

Describe your Concern or Grievance in Detail

____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
____________________________________________________________________
Page Intentionally Left Blank
QAPI (QUALITY ASSESSMENT AND PROCESS IMPROVEMENT)

This chapter of the Grievance Toolkit is going to deal with the process by which dialysis units make changes and improvements in their patient care. While not strictly a part of the Grievance Filing Process, it is good to know how long term improvements are made and the part Quality Assessment and Process Improvement (QAPI) plays.

By federal regulation, every Medicare certified dialysis facility must have a grievance process, tell patients about it, and keep a grievance log, which is a part of their QAPI.

**Patient Centered Care is about Teamwork.**

**QAPI incorporates this Teamwork approach.**

This is where Patient participation can play a vital role in the success of the improvement program. An effective team is composed of:

- System Leadership
- Technical Expertise
- Day to Day Leadership

Patients can provide both technical expertise and day to day leadership positions in most teams. An example of an effective team may be:

- Floor Nurse
- Patients
- Administrator
- Floor PCT
- Social Worker
- Dietitian
- Medical Director
In a truly Patient Centered Care approach to improvement, patients will be involved in selecting improvements related to their care. However, this is only possible if patients are willing to work with the facility as a team member.

**How does Quality Assessment and Process Improvement (QAPI) relate to Grievances?**

As discussed in previous chapters, grievances are usually filed for one of three reasons. We have seen or experienced something that:

- *a. Endangers us or others*
- *b. Violates our Patient Rights*
- *c. Violates Clinical Standards of Care*

What resolution do we want to see? Ultimately we want to create a culture of safety and communication for the long term in our unit. It is in everyone’s best interest if patients are aware of the process used to create these improvements.

Facilities may make these necessary changes through QAPI. QAPI is a formal system that utilizes data and information to make long term and effective improvement, often through a four step process called the PDSA cycle for Plan, Do, Study, and Act, explained briefly below:
1. Plan

*There are at least two steps necessary in the Planning stage*

i) **State the objectives and set the goals**

To develop a good objective several questions will need to be asked such as

- “Where are we currently and why is this a problem?”
- “Where do we want to be?”
- “What knowledge do we have?”
- “What is our goal?”

In stating a goal it is necessary to be realistic, and set both long term and short term goals. It is also important to understand CMS or Network-set goals vs. Facility or Corporate set goals. Some goals (CMS and Network) are mandated and required. These goals are set **FOR** the unit and are not negotiable. Often facility or corporate goals can be tweaked and these are the goals in which patients can participate.

ii) **Develop a plan**

The plan will include such things as what you are trying to accomplish, the specific steps that will be tested, and how you will know whether or not the change is an improvement. Not all changes will correct the problem and several solutions may need to be considered.

2. Do

This is where the facilities carry out the plan, document the observations and analyze the data. These steps are important in determining if the problem was corrected or not and may result in information that can be shared with other facilities facing the same problems.
3. **Study**

This may be the most important step. It will tell you whether or not goals were achieved. But it is important to note that failure to achieve the goal set does not mean that the QAPI was not successful. Once the analysis is complete the facility can summarize what was learned and move forward with another plan. The process may be long and you may not see immediate victories through QAPI, but all lessons learned are valuable and should be shared.

4. **Act**

If the change tested was successful, act to implement system-wide. This may be the result of a grievance that was filed and a determination that a change or an improvement is necessary.

**How does this improve communication?**

Patient involvement can be the most effective method of opening up long term communication. Patients and staff will have many opportunities to share their unique perspectives while working together to achieve the desired goal. Once this level of communication has been established in one area, it can carry over into all areas of patient/staff interaction and result in many opportunities to work together to resolve problems BEFORE they rise to the level of grievance.
We can all agree that the best method to develop and sustain improvement is through effective teamwork. This is no different in a grievance setting. Once a problem/issue is identified it is in everyone’s best interest to look at it from several different perspectives and choose a solution that best meets the needs of everyone.

From a Patient Perspective

As a patient in a setting where a grievance has been filed, it can be very difficult to consider sitting down with the staff and looking at possible solutions. There may be some perceived “hard feelings” on either or both sides. But as adults in a professional setting, it is important to put aside any residual negative feelings and be part of the solution.

From the Staff Perspective

Teams are a common occurrence in most units. As in all Quality Improvement Initiatives, a strong team is a critical component of success. Individual team members provide a unique perspective on the issues under consideration and teams can play on the strengths of each individual team member.

Characteristics of a Strong Team

When you are selecting your team you should avoid the trap of looking for “like minded” people. It is often felt that having people with the same perspectives will result in a cohesive team. This, however, will deprive you of the advantages of working with diverse visions and ideas and will result in a solution that only appeals to a small population.
If you are able to staff your team with members falling within these categories AND give them equal input and respect on the problem being investigated, you will have a winning combination of insights and talents.

Another advantage to the team approach for improvement and assessment is the cross coverage provided by a fully informed team. Team members are people, and, as such, are subject to all of life’s interferences. If one member is unable to participate or complete their assignments, other informed team members can help fill in the gaps until a new team member can be found. This cross coverage can be vital to keeping timelines in place as circumstances change.

The Patient’s Place in the Team

Patients are a vital part of any improvement and/or assessment team because of their unique perspective. The decisions and protocols developed by the team will impact patients on the ground floor. They are in a position that allows for repetitive observation of most initiatives and can report back on what they are seeing or not seeing. This reporting can be a critical step.

Perhaps most importantly, if a patient is involved in the grievance process, inclusion in the team can dramatically open up their perspective and demonstrate the unit’s commitment to solving the problem. Seeing the situation from the eyes of all team members can help to bring everything into perspective.

“Patients are a vital part of any improvement and/or assessment team”

Some of the individual characteristics you can look for in selecting your team are:

- The organizer
- The creative thinker
- The empathic listener
- The historian
- The innovator
<table>
<thead>
<tr>
<th>Network</th>
<th>State(s) Covered</th>
<th>Patient Toll Free Telephone #</th>
</tr>
</thead>
<tbody>
<tr>
<td>Network 1</td>
<td>CT, MA, ME, NH, RI, VT</td>
<td>(866) 286-3773</td>
</tr>
<tr>
<td>Network 2</td>
<td>NY</td>
<td>(800) 238-3773</td>
</tr>
<tr>
<td>Network 3</td>
<td>NJ, PR, US VI</td>
<td>(888) 877-8400</td>
</tr>
<tr>
<td>Network 4</td>
<td>DE, PA</td>
<td>(800) 548-9205</td>
</tr>
<tr>
<td>Network 5</td>
<td>DC, MD, VA, WV</td>
<td>(866) 651-6272</td>
</tr>
<tr>
<td>Network 6</td>
<td>GA, NC, SC</td>
<td>(800) 524-7139</td>
</tr>
<tr>
<td>Network 7</td>
<td>FL</td>
<td>(800) 826-3773</td>
</tr>
<tr>
<td>Network 8</td>
<td>AL, MS, TN</td>
<td>(877) 936-9260</td>
</tr>
<tr>
<td>Network 9</td>
<td>IN, KY, OH</td>
<td>(844) 819-3010</td>
</tr>
<tr>
<td>Network 10</td>
<td>IL</td>
<td>(800) 456-6919</td>
</tr>
<tr>
<td>Network 11</td>
<td>MI, MN, ND, SD, WI</td>
<td>(800) 973-3773</td>
</tr>
<tr>
<td>Network 12</td>
<td>IA, KS, MO, NE</td>
<td>(800) 444-9965</td>
</tr>
<tr>
<td>Network 13</td>
<td>AR, LA, OK</td>
<td>(800) 472-8664</td>
</tr>
<tr>
<td>Network 14</td>
<td>TX</td>
<td>(877) 886-4435</td>
</tr>
<tr>
<td>Network 15</td>
<td>AZ, CO, NM, NV, UT, WY</td>
<td>(800) 783-8818</td>
</tr>
<tr>
<td>Network 16</td>
<td>AK, ID, MT, OR, WA</td>
<td>(800) 262-1514</td>
</tr>
<tr>
<td>Network 17</td>
<td>AS, GU, HI, MP, N. CA</td>
<td>(800) 232-3773</td>
</tr>
<tr>
<td>Network 18</td>
<td>S. CA</td>
<td>(800) 637-4767</td>
</tr>
</tbody>
</table>
You may visit the ESRD National Coordinating Center (NCC) website http://esrdncc.org/professionals/all-esrd-networks/ for your ESRD Network’s information and resources in your state or region.
Acknowledgements

This toolkit was written by Patients for Patients. It was developed by members of the Forum of ESRD Networks’ Kidney Patient Advisory Council (KPAC) and other members of the Forum of ESRD Networks.

Derek Forfang – Committee Chair
Kidney Patient Advisory Council
ESRD Network 17

Allen Nelson
Kidney Patient Advisory Council
ESRD Network 4

Dee LeDuc
Forum Staff
Forum of ESRD Networks

Glenda Harbert, RN, CNN, CPHQ
Executive Director Liaison, KPAC
ESRD Network 14

Joseph Karan
Kidney Patient Advisory Council
ESRD Network 7

Lana Schmidt
Kidney Patient Advisory Council (past member)
ESRD Network 9/10

Louis Raymond, MD
Medical Advisory Council (past member)
ESRD Network 11

Maggie Carey
Kidney Patient Advisory Council
ESRD Network 11

Ralph Atkinson, MD
Medical Advisory Council
ESRD Network 8

Renae Nelson, MSW, LCSW
Patient Services Liaison, KPAC
ESRD Network 11

Robin Blomberg
Kidney Patient Advisory Council
ESRD Network 16

Yessi Cubillo, BA
Patient Services Liaison, KPAC
ESRD Network 3

We would like to acknowledge ESRD Networks 3, 5, 6, 7, 10, 11, 12, 13 & 14 for their contribution in the review of this toolkit
Disclaimer

All materials herein were developed by The Forum of ESRD Networks ("The Forum") in cooperation with the ESRD Networks. The Forum and contributors hereby provide limited permission for the user of this information to reproduce, retransmit, or reprint for such user's or other individual's or entities' own personal use (and for such personal use only) provided credit is given and copies are not intended for sale. Use or inclusion of any portion of this document in another work intended for commercial use is prohibited without prior written consent of the Forum and its contributors before any material is reproduced, retransmitted, or reprinted. All other rights reserved.

The Forum is providing information and services as a benefit and service. The Forum makes no representations about the suitability of this information and these services for any purpose. The Forum is not responsible for any material posted by any third party, and The Forum specifically disclaims any and all liability for any claims or damages that result from any posting by third parties. The Forum is not liable to anyone for inaccuracies, errors, or omissions with respect to any material or the transmission or delivery of any material obtained from The Forum; any injury and/or damage to persons or property as a matter of products liability, negligence, or otherwise from any use or operation of any methods, products, instructions, or ideas contained in the material herein.

This Toolkit is a guide, created by subject matter experts and professionals using the available evidence, produced by the Kidney Patient Advisory Council (KPAC) of the Forum of ESRD Networks. The details of the sections may change as guidelines change, and the KPAC anticipates revisions and additions to the Toolkit overtime. The Toolkit is meant as a resource and should not be referenced as a regulatory statement. As with other Forum Toolkits, this document is meant to help guide patients, care givers, and providers.