



Patient Representative Handbook



Quality
Insights
Renal Network 4



Rev. 2017

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WELCOME

Thank you for being interested in the Quality Insights Renal Network 4 Patient Representative Program.

The role of a Patient Representative is very important. Patient Representatives help other patients get involved and become active in their own healthcare. As a Patient Representative, your activities might change from dialysis facility to dialysis facility. Quality Insights staff will partner with you to help provide input about the educational needs of patients at your dialysis facility. But primarily, this role is designed to help you encourage fellow patients to become engaged with their healthcare and to partner with their healthcare team.

Ultimately, a Patient Representative serves as a link between fellow patients, the dialysis facility staff and the team at Quality Insights.

In certain instances, a transplanted patient, a family member or caregiver may serve as a Patient Representative and be part of the Patient Representative Program.

All patients have unique skills and a personal understanding of what it is like to have kidney failure. For this reason, we recognize all patients as Subject Matter Experts (SMEs). All SMEs have a voice and each voice counts where it matters most – in the care you receive as a dialysis or transplant patient.

This booklet will:

- Be your guide and help lead to your success as a Network 4 Patient Representative
- Inform you about the work of End Stage Renal Disease (ESRD) Networks
- Describe how Quality Insights involves patient SMEs in Network activities and how you can get involved in improving dialysis care

● ● ● AT A GLANCE: PATIENT REPRESENTATIVES

Each dialysis facility is asked to have at least one Patient Representative.

Having a Patient Representative from each shift is optimal.

Patient Representatives act as the link between patients, facility staff and Quality Insights Renal Network 4.

All patients are SMEs and have a voice in the care they receive.

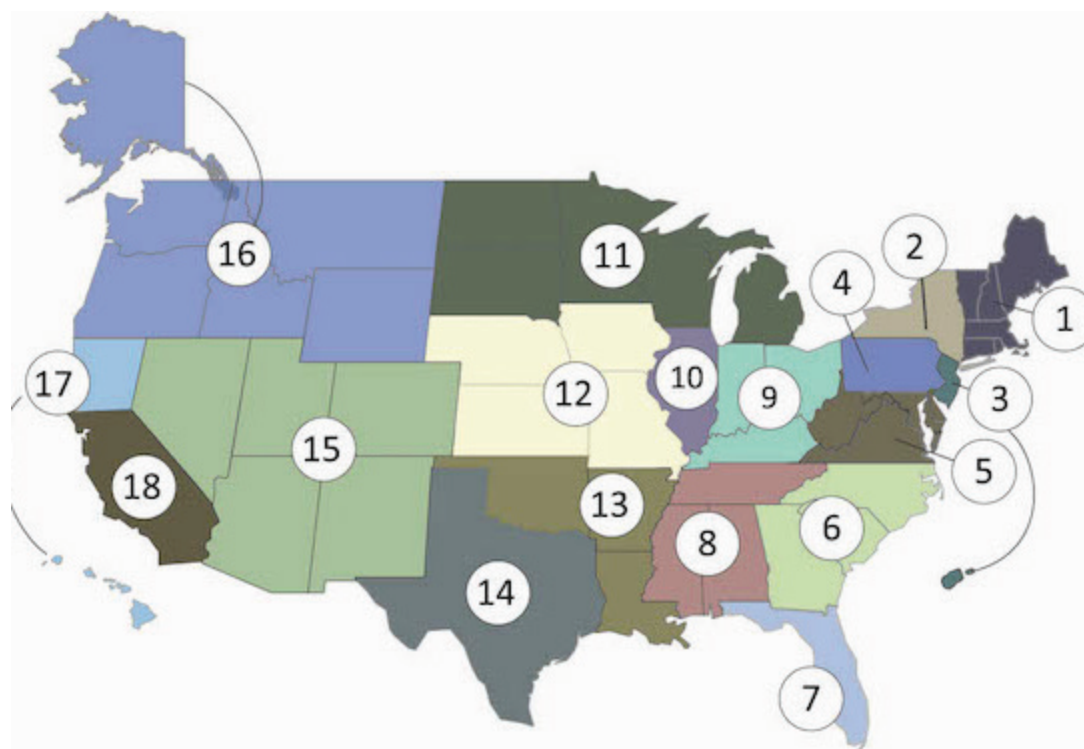
The facility social worker is the Patient Representative's primary facility contact.

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THE FEDERAL END STAGE RENAL DISEASE (ESRD) PROGRAM AND ESRD NETWORKS

In 1972, the United States government began a program to help pay for medical costs for people needing dialysis treatments or a kidney transplant.

The program, run by the Centers for Medicare and Medicaid Services (CMS), uses 18 organizations called “**Networks**” that oversee and promote quality of care for dialysis facilities across the entire United States and its territories.\



Quality Insights is the CMS’s contract holder for the ESRD Network 4 contract. We are known as Quality Insights Renal Network 4 and we are a non-profit organization. Under the direction of CMS, we monitor the care of patients in Pennsylvania and Delaware who need dialysis or a kidney transplant.

WHO ARE WE AND WHAT DO WE DO?

Quality Insights Renal Network 4 is a non-profit organization serving Delaware and Pennsylvania. We are here for our patients. Patients can contact Quality Insights staff at our toll-free number (800) 548-9205 if they have ideas, questions or concerns about the quality of care they receive at their dialysis facility.



Quality
Insights
Renal Network 4

Some of the ways that Quality Insights promotes quality care is by:

- Conducting Quality Improvement Activities (QIAs) at various Network 4 dialysis facilities;
- Educating patients about treatment options;
- Developing methods to improve patient engagement;
- Promoting vocational rehabilitation to help patients remain working or return to the work force;
- Supporting dialysis patients, transplant patients and providers in the review and investigation of patient grievances about quality of care; and
- Monitoring and reporting ESRD care outcomes to CMS.



THE ROLE OF A PATIENT REPRESENTATIVE

Patient Representatives are dialysis patients (as well as transplant patients, caregivers or family members) who are interested in doing more than just coming to dialysis. Patient Representatives want to get involved in making dialysis a better experience for everyone. This role is designed to help bring the patient's voice to the healthcare team at the dialysis facility.

The ultimate goal for the Patient Representative Program is to have at least one Patient Representative in each Network 4 facility. The Patient Representative may:

- Help dialysis facility staff understand what is important to patients
- Help facilitate positive communication between patients and staff
- Share useful ideas and experiences with patients and staff
- Serve as a role model to other patients
- Serve as a mentor and advocate for other patients
- Demonstrate to fellow patients that ***Dialysis Means Life (DML)***
- **Encourage fellow patient's to complete and follow their prescribed treatment prescription**

These goals help to formulate the role of the Patient Representative. Their role depends not only on the level of involvement the Patient Representative is comfortable with, but also the unique needs of the dialysis facility.

DML: Where did this unique acronym come from?

Quality Insights staff partners with patients within the Network 4 community. A Network 4 patient partner once explained how the concept of dialysis gives him hope. His passionate discussion led the Quality Insights staff to adopt not only his belief that ***Dialysis Means Life***, but to embrace that very concept and use it on the Network 4 Patient Representative pins. You will receive your Patient Representative pin once you have completed your introductory Patient Representative training. We hope you wear the pin proudly and help spread the word to your fellow patients! Dialysis Means Life. DML!



PATIENT REPRESENTATIVE TRAINING

Quality Insights will help train and support all Patient Representatives so they can feel comfortable with their new Patient Representative role. All Patient Representatives will be required to read this handbook as well as complete one introductory training session. This training session will be offered by the Quality Insights staff throughout the year, but it is also available by request and can be found online at our Quality Insights Renal Network 4 website (www.qirn4.org).

After initial training is complete, Patient Representatives will have an opportunity to complete additional trainings in the topics of peer mentorship, patient support groups, quality improvement, or leadership. Patient Representatives can choose to complete as much additional training as they desire. Contact the Network 4 Patient Engagement Coordinator for more information.

SPECIFIC PATIENT REPRESENTATIVE ACTIVITIES

When you complete your introductory training as a Patient Representative, we encourage you to get involved at your dialysis facility by doing any of the following activities:

- Meet and greet all patients. Share your experiences and support the new patients. Let them know about **DML – Dialysis Means Life**. Act as a mentor.
- Pass out educational flyers to patients at your facility as requested by facility staff or the Quality Insights staff.
- Become involved in the planning of facility celebrations.
- Bring concerns and questions to the facility manager on behalf of other patients.
- Provide suggestions to the health care team and /or the network staff for educational needs based on the most frequently asked questions from patients.
- Participate in the production and distribution of a facility patient newsletter after it has been approved by the Social Worker or Facility Administrator
- Participate in the production and distribution of the Network 4 patient newsletter.
- Share Quality Insights information with fellow patients, including patient rights and responsibilities, grievance procedures, Network 4 Quality Improvement Activities or patient newsletters.
- Provide feedback to your facility staff about opportunities for improvement from a patient's perspective.
- Inform the Quality Insights staff about unresolved patient concerns or questions from a facility.
- Participate in Network 4 Patient Representative Committee meetings.

- Become involved in Quality Insights activities as a Network 4 Patient SME (*see “Network 4 Subject Matter Experts (SMEs)” section*).
- Or a variety of other activities as requested by your Facility Staff or Medical Director
- Become aware of the Network 4 documents that are required to be posted at your dialysis facility; share this important information with fellow patients as the situation warrants (see appendix for a copy of the required Network 4 Postables)

If you have completed additional training as a Patient Representative, you will receive a certificate for completion and we encourage you to:

- Become an official patient mentor.
- Help form a patient support group.
- Participate in your dialysis facility’s quality meetings to ensure the patient voice is included when developing improvement plans.
- Give your facility’s management team feedback on new policies or changes that directly impact the patient’s experience of care.

ADDITIONAL PATIENT REPRESENTATIVE ACTIVITIES

As a Patient Representative, you may want to work with your facility social worker to see if any of the following activities are possible:

-
- Send articles, poems or other items to Quality Insights for consideration in its Network-wide patient newsletter.
- Plan events, such as picnics and holiday parties.
- Work at community health fairs.
- Promote organ donation.
- Set up problem-solving meetings between fellow patients and staff.

DEALING WITH PATIENT CONCERNS

You may share your personal experiences with other patients if you desire, **BUT** you **MAY NOT** give any medical advice. Your treatment prescription or your current diet may work well for you but it **MAY** be very harmful to another patient. When patients have questions about their treatment or diet, or if they are having problems coping, encourage them to talk to an appropriate healthcare professional.

- **Treatment questions:** Encourage patients to speak to their doctor or nurse.
- **Diet questions:** Encourage patients to speak to their dietitian.
- **Problems coping or having feelings of anger/depression:** **Highly encourage** the patient to speak to his or her doctor or social worker, who is specifically trained to help with these issues. Quality Insights has an experienced social worker on staff. This person can also assist if the facility social worker is not available.

WHAT TO DO WHEN A FELLOW PATIENT HAS A CONCERN OR PROBLEM

As a Patient Representative, you may encounter fellow patients with concerns or problems. If this happens, we encourage you to consider these steps.

1. Know the grievance policies and procedures in your facility and inform the patient about this procedure. To resolve the complaint with the treatment team.
2. Become familiar with Quality Insights' grievance procedures for concerns that cannot be resolved between the patient and the treatment team at the facility level.
3. Take a positive approach to facility problems. Approach staff at the right time. Remember that although staff may not appear busy as you approach them, they may be in the middle of some other task. Make sure you always confirm they have time to engage in a discussion with you before you disclose the situation.
4. Reassure any patients who have concerns that they have a right to discuss their concern and they cannot be punished for speaking up. Patients are protected by government regulations when they speak up.

AT A GLANCE:

**ALWAYS
DEMONSTRATE
THESE TRAITS
WHEN
COMMUNICATING
WITH A PATIENT
ABOUT CONCERNS**

Respect
Integrity
Understanding
Acknowledgement
Acceptance
Awareness
Kindness
Diligence
Empathy
Dignity
Humor

PATIENT REPRESENTATIVE COMMITTEE

When you are a Patient Representative, you are also a member of a larger interactive group made up of all the other Network 4 Patient Representatives. This group is called the **Patient Representative Committee**. Like you, the patients in this group receive dialysis or have had a kidney transplant.

The Patient Representative Committee meets monthly by phone or webinar in order to gather support, ask questions, seek guidance or discover solutions for common patient concerns or problems. This meeting also serves as a communication portal for the Quality Insights staff to gather information about educational needs of both patients and dialysis staff.

Usually, the Patient Representative Committee meetings are held by telephone calls. But, sometimes the group talks through email or through Quality Insights social media sites.

The Patient Representative Committee appoints fellow patients to help run Patient Representative Committee meetings. An appointed patient can help run the meetings for up to three years.

The Patient Representative Committee may also give feedback that helps Quality Insights staff target annual improvement projects or assist with writing the Network 4 patient newsletter called *Network Notes*.

CONFIDENTIALITY

Our foundation is respect. Regardless as your role as either a Patient Representative or a Network 4 SME, you **MUST** keep all medical and personal patient information private. You **MAY NOT** discuss any **PATIENT-SPECIFIC** information you have learned while performing these roles with anyone other than the dialysis staff and the Quality Insights staff (*with the patient's permission*). You may not discuss any fellow patient's personal or medical information even with your family. We take patient confidentiality very seriously and so does the federal government. The United States government has enacted laws against sharing patient information with others. You may be prosecuted if you violate these laws. As a Patient Representative and a Network 4 SME, you must sign an agreement to keep all medical and personal patient information private and you agree to keep all materials and discussions confidential.

By agreeing to be a Patient Representative and by signing the Patient Representative forms, you pledge to **NEVER** repeat any patient medical or personal information to anyone without the patient's permission. You will not tell your family, friends or other patients about any information that a fellow patient tells you.

If you feel a patient wants you to talk to a staff member about a concern on his or her behalf, you must **ALWAYS** get the patient's permission to have this conversation first.

HOW TO GET STARTED

Now that you understand more about the roles of the Network 4 Patient Representative and Network 4 SME, please complete the required forms located at the end of this document if you would still like to get involved. When these forms are complete, please do one of two actions:

Fax documents to (610) 783-0374

or

Mail documents to:

Quality Insights Renal Network 4
610 Freedom Business Center, Suite 102
King of Prussia, PA 19406

We look forward to working with you and bringing your voice to the work that we do. Your voice will help engage patients in their own care and improve the experience of care for all patients in Network 4.

If you have any questions, or would like to discuss the Patient Representative or Network SME programs in more depth, please contact our *Patient Engagement Coordinator*. If you have any concerns about your facility, please contact our *Patient Services Coordinator*. You can reach both contacts by calling our toll-free patient number at **(800) 548-9205**.

NETWORK 4 SUBJECT MATTER EXPERTS (SMES)

You may decide you want to do more and become more involved in encouraging patients and spreading hope. Or, you may decide that being a Patient Representative is not exactly what you want to do, but you are still interested in encouraging new patients and spreading the concept of DML.

Network 4 has developed an engagement path for Patient Representatives to participate in activities with the Network staff. These are known as Subject Matter Experts (SMEs).

Some patient may become more involved by being a Network 4 SME.* Network 4 SMEs volunteer to provide a patient voice to the work done in Network 4. All patient SMEs are part of the Network 4 Patient Advisory Council. Some Network 4 Patient SMEs sit on the Network 4 Board of Directors or the Medical Review Board, represent Quality Insights at national patient engagement activities, or may even attend national conferences.

If this is for you, please fill out the form at the end of this document and fax it to the number provided or mail it to the address provided. If you have any questions, contact us by calling (800) 548-9205. Ask for the Patient Engagement Team Leader.

**The Subject Matter Expert (SME) group is limited to 30 patients. If we are at capacity, you will be placed on a waiting list.*

● ● ● AT A GLANCE: PATIENT INVOLVEMENT

A Patient Representative Committee (PRC) is made up of Patient Representatives from dialysis facilities and transplanted patients

Some Patients become Network 4 SMEs and sit on the Quality Insights Renal Network 4 Board of Directors and Medical Review Board.

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ADDITIONAL RESOURCES

Network-Related Organizations

Quality Insights Renal Network 4 website

www.qirn4.org

Centers for Medicare & Medicaid Services (CMS)

(800) MEDICARE (1-800-633-4227)

www.medicare.gov

Dialysis Facility Compare: www.medicare.gov/dialysis

Kidney End of Life Coalition

www.kidneyeol.org

Fistula First

<http://esrdncc.org/ffcl/for-ffcl-patients/>

Forum of End Stage Renal Disease Networks

www.esrdnetworks.org

Support Groups

National Kidney Foundation (NKF) Peers

(855) 653-7337

Nephcure Kidney International (NKI)

www.nephcure.org/peer-to-peer-connections-request

Renal Support Network

HOPEline: (800) 579-1970

www.facebook.com/RenalSupportNetwork

Western PA Kidney Support Groups

www.wpakidneysupport.org

Kidney Patient Organizations

American Association of Kidney Patients (AAKP)

(800) 749-2257

www.aakp.org

Renal Support Network (RSN)

(866) 903-1728

www.rsnhope.org

Rehabilitation

Life Options

www.LifeOptions.org

Social Security

(800) 772-1213

www.ssa.gov

Ticket to Work: www.ssa.gov/work

Department of Rehabilitation Services (DRS)

Delaware Phone: (302) 761-8275

Division of Vocational Rehabilitation

4425 N. Market Street, P O Box 9969, Wilmington, DE 19809

<http://dvr.delawareworks.com/>

Pennsylvania Phone: (800) 442-6351

Office of Vocational Rehabilitation

1521 N. 6th Street, Harrisburg, PA 17102

http://www.portal.state.pa.us/portal/server.pt/community/vocational_rehabilitation/10356

Disability Resources

www.disabilityresources.org

Kidney Education Resources

American Kidney Fund (AKF)

(800) 638-8299

www.kidneyfund.org

American Society of Nephrology (ASN)

(202) 640-4660

www.asn-online.org

Dialysis Patient Citizens (DPC)

(866) 877-4242

www.dialysispatients.org

Home Dialysis Central

www.homedialysis.org

Home Dialyzors United (HDU)

www.homdialyzorsunited.org

IgA Nephropathy Foundation of American, Inc.

(732) 770-7377

www.igan.org

Kidney and Urology Foundation of America

(800) 633-6628

www.kidneyurology.org

Kidney School

www.KidneySchool.org

National Kidney Foundation (NKF)

(800) 622-9010

www.kidney.org

Nephcure Kidney International (NKI)

(866) 637-4287

www.nephcure.org

CONTACT US

As always, please contact us if you need to file a grievance.

Quality Insights Renal Network 4
610 Freedom Business Center, Suite 102,
King of Prussia, PA 19406
www.qirn4.org

Patient Services Department
www.qirn4.org/Contact-Us

Toll-Free Patient Phone
(800) 548-9205
(Patients only)



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Forms for Participation

CONFIDENTIALITY AGREEMENT

As a Patient Representative of Quality Insights Renal Network 4, I recognize that I have an obligation to act prudently, in good faith, and in a manner I reasonably believe to be in the best interest of my fellow patients, the Network and the dialysis facility regarding confidential information which I may learn, or to which I have access to the Patient Representative or Network SME role.

Accordingly, I hereby agree not to release, discuss or otherwise disclose any confidential information which I may learn or to which I have access to through my voluntary role as a Patient Representative or Network SME.

In particular, but without limiting to the above, I agree not to share information regarding patients or facilities with any person other than my fellow board or committee members; provided, however, that my fellow members do not have a conflict of interest regarding such confidential information that would preclude my discussing such information with them.

I recognize that breach of confidentiality by me may result in my removal from any or all boards or committees of Quality Insights Renal Network 4 on which I am presently serving and such breach may expose me to personal liability to third parties.

ACCEPTANCE OF APPOINTMENT

My signature on the Patient Representative form and/or Network SME form indicates I have acknowledged my agreement with the above policies and accept the role of Patient Representative and/or Network SME.

PATIENT REPRESENTATIVE FORM

Name of Current Dialysis Unit: _____ CMS Certification Number (CNN): _____

Facility Social Worker: _____ Social worker Phone: _____

Social Worker Email: _____

Social Worker Acknowledgement Signature: _____

Patient Representative Name: _____

Address: _____

Home Phone: _____ Cell Phone: _____

Patient or Patient Families Email: _____

Patient Treatment Information: ☐ Home-Hemo ☐ In Center -Hemo ☐ Peritoneal Dialysis
☐ Transplanted (Date of Transplant _____)

Dialysis Schedule for In Center: M/W/F Shift: _____ T/T/S Shift: _____

Is Patient on a transplant list? Yes ☐ No ☐ In process of work-up for list ☐

Patient to read, check each statement below and sign this referral form:

- ☐ I have read the Patient Representative Handbook
- ☐ I have read the Quality Insights Renal Network 4 confidentiality Agreement and with my signature below, I acknowledge the Patient Confidentiality Agreement policies and accept the role of Patient Representative.
- ☐ I authorize Quality Insights to utilize my name and email address for specific Patient Representative communications.
- ☐ I further authorize Quality Insights Renal Network4 to use my name where necessary in listing Patient Representatives in reports to The Centers for Medicare and Medicaid Services (CMS).

Signature of Candidate: _____ Date: _____

Fax completed form to Network 4 office at (610)783-0374 OR Mail to

**Quality Insights Renal Network 4 – Attention Patient Engagement Coordinator
610 Freedom Business Center Dr. Suite 102
King of Prussia, PA 19406**

NETWORK 4 SUBJECT MATTER EXPERT (SME) FORM

Background

Who is Quality Insights Renal Network 4? Quality Insights Renal Network 4 is a health care company who has been contract by the Centers for Medicare and Medicaid Services (CMS) to support achieving national quality improvement goals and statutory requirements as set forth in Section 1881 of the Social Security Act and the Omnibus Budget Reconciliation Act of 1986. The term “Network” is a term used to refer to the End Stage Renal Disease (ESRD) Network contractor. QIRN4 participates in assigned activities that are selected to align with the Department of Health and Human Services (HHS) [National Quality Strategy \(NQS\)](#), the CMS Three-Part Aim (Better Care, Better Health, Lower Cost), and other CMS priorities designed to result in improvements in the care of individuals with ESRD.

What is End Stage Renal Disease Quality Improvement? The End Stage Renal Disease (ESRD) Quality Initiative promotes ongoing CMS strategies to improve the quality of care provided to ESRD patients. This initiative supports quality improvement efforts among providers and makes available quality information that will enable patients to participate in making health care decisions.

What is the ESRD Network Program? Under the direction of CMS, the End-Stage Renal Disease (ESRD) Network Program consists of a national network of 18 ESRD Networks, responsible for each U.S. state, territory, and the District of Columbia. ESRD Networks service geographic areas based on the number and concentration of ESRD beneficiaries. ESRD Networks work with consumers/patients and ESRD Dialysis Facilities and other providers of ESRD services to refine care delivery systems to make sure ESRD patients **get the right care at the right time**. The Program's responsibilities include but are not limited to:

- Improving quality of care for ESRD patients
- Collecting data to measure quality of care
- Providing assistance to ESRD patients and dialysis providers

What is achieved with quality improvement activities? To achieve the vision of the ESRD Network Program, *the right care for every person every time*, quality improvement activities assists dialysis providers in transforming quality to make healthcare:

- Safe
- Effective
- Patient-Centered
- Timely
- Efficient
- Equitable

Thus, ultimately in transforming healthcare and improving the quality of care and quality of life for ESRD patients. Because of that, CMS is committed in having the patient's voice and input part of the Quality Improvement activities at the ESRD Networks.

Requirements for patient SME volunteer participation in Quality Insights Renal Network 4 Activities and Quality Improvement projects:

- Have an interest in improving the quality of dialysis care patients receive in Network 4
- Be willing to participate in monthly telephone meetings that take place throughout the year, usually no more than monthly.

Next Steps

Please check any QIA projects you wish to participate in. *Please note: you will not be selected for more than one QIA project.*

If you are interested in several, please indicate which project you prefer by assigning **number 1** to the project you are most interested in, followed by number 2, 3, 4 etc. These projects will be conducted at selected facilities in Pennsylvania and Delaware:

- ☐ Improve the patient experience of care by decrease patient complaints and grievances
- ☐ Increase Transplant Referrals
- ☐ Reduce the use of dialysis catheters
- ☐ Increase dialysis patient's immunizations rates
- ☐ Reduce Blood Stream Infections for dialysis patients
- ☐ Reduce the number of patients with high Calcium levels in their blood
- ☐ I do not have a preference

Additional opportunities you would like to participate in:

- ☐ Participate in Monthly CMS Calls
- ☐ Participate in National Patient Calls
- ☐ Participate in Network Board Meetings (Board of Director or Medical Review Board)

Fill out the information below, sign the bottom of the form, and return to Quality Insights Renal Network 4

First and last name: _____

Mailing address: _____

Telephone number(s): _____

Email address we can contact you at: _____
_____ (Required – can be your social worker, family or friend)

Name of Current Dialysis Unit: _____

Location of Current Dialysis Unit: (street name and city): _____

Please indicate your current dialysis situation:

- ☐ In center Hemodialysis
- ☐ In center Peritoneal Dialysis
- ☐ Home Hemodialysis
- ☐ Home Peritoneal Dialysis
- ☐ Transplanted: Year _____

In center Dialysis Schedule (if indicated): M/W/F Time: _____ T/T/S Time: _____

Are you on a transplant waiting list?

- ☐ Yes
- ☐ No
- ☐ Informed not a candidate

Please tell us about yourself:

Provide a brief statement of why you are interested in volunteering to partner with the staff at Quality Insights Renal Network 4.

Please list any additional information you would like the network to know about you. You may want to include experiences you have had or educational degrees or relevant work experience (not required to be selected to participate but used for project assignment).

Please read each statement and check the box if you agree to these statements; then please sign this form

- ☐ I have read the Network 4 Patient Representative Handbook.
- ☐ I agree to participate as a SME for Quality Insights Renal Network 4.
- ☐ I authorize Quality Insights to utilize my name and email address for specific QIA communications.
- ☐ I authorize Quality Insights Renal Network 4 to use my name where necessary in QIA meeting minutes and in listing QIA members in reports to The Centers for Medicare and Medicaid Services (CMS).
- ☐ I (including my family members) do not have a financial interest, arrangement, or affiliation with any corporate organizations that may create a potential conflict of interest.
- ☐ If at any time during my service as a Patient SME, my conflict of interest status changes, I will notify the Quality Insights Renal Network 4.
- ☐ If I am unable to continue to be a Quality Insights Renal Network 4 patient SME, I will contact Quality Insights Renal Network 4 to inform them of my resignation
- ☐ If selected to participate as a patient SME, I will keep patient information, materials and discussions confidential at all times

Applicant/Nominee's Agreement

I have read the above and agree to these statements:

Signature: _____ Date: _____

Fax completed form to Network 4 office at (610)783-0374

OR Mail to

**Quality Insights Renal Network 4 – Attention Patient Engagement Coordinator
610 Freedom Business Center Dr. Suite 102
King of Prussia, PA 19406**