Kidney Community Emergency Response Program
National Patient and Family Engagement
Patient/Caregiver Subject Matter Expert

2019 Guidebook
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“Believe in yourself. You are braver than you think, more talented than you know, and capable of more than you imagine.”

—Roy T. Bennett
Welcome Subject Matter Expert (SME),

Thank you for agreeing to volunteer as a member of the National KCER Patient and Family Engagement Learning and Action Network (N-KPFE-LAN).

The role of a SME is an important one. This guidebook will explain more about what your role as a patient or caregiver SME will be, including:

- How you can help.
- What is expected of you.
- Who KCER is.
- What KCER, with your help, strives to achieve.

After you have had a chance to read this guidebook, please let us know if you have any questions. Your time and effort are greatly appreciated. We welcome every opportunity to connect with you and look forward to your input and partnership.

Sincerely,

The KCER Team
What is KCER?

KCER serves as the leading authority on emergency preparedness and response for the end stage renal disease (ESRD) community. The KCER Program provides organization and guidance to seamlessly bridge the needs of emergency management stakeholders and the ESRD community nationwide. The goals of the KCER Program are to:

- Raise public awareness of:
  - The critical needs of people with kidney failure.
  - The need to plan ahead to ensure that life-saving dialysis services are obtainable in the event of an emergency and/or disaster.

- Promote and distribute tools and resources to:
  - Individuals with kidney failure.
  - Dialysis facilities.
  - Federal, state, and emergency workers.
  - ESRD Networks

- Test and refine the existing national response strategy to assist federal, state, and local efforts in the event of an emergency and/or disaster.

“One emergency resource I wish I had when starting dialysis was the emergency preparedness tools that KCER has created. Such resources would have taught me how to prepare for a disaster.”

-2018 N-KPFE-LAN SME
What is a LAN?

A LAN brings people together to solve a shared problem on a large scale. The N-KPFE-LAN is a group of patients, caregivers, healthcare professionals, other interested groups of people who work together to improve emergency preparedness for ESRD patients. LANs value the knowledge that members bring to the group. LANs use the information and ideas shared by members, like you, to make improvements quickly through many small changes. These small, quick improvements can add up to make a big difference in the lives of ESRD patients.

Your Role

You were nominated to be a SME by your ESRD Network. Your Network staff believes you have a lot to contribute about the patient/caregiver experience. Your input will add greatly to the ESRD community emergency preparedness improvement efforts and to meeting national goals set by the Centers for Medicare & Medicaid Services (CMS). We agree.

Your role may include:

- Helping with the creation and development of educational resources for patients and caregivers.
- Reviewing KCER materials to make sure they are meeting the needs of patients and are “patient-centered.”
- Joining bi-monthly conference calls.
- Providing the patient/caregiver perspective on KCER activities.
- Spreading the work of KCER and increasing overall awareness.

SME Participation Guidelines

As a volunteer for the N-KPFE-LAN there are requirements for your participation:

- Sign and return the N-KPFE-LAN agreement, if you have not already done so.
  - The agreement form includes a waiver that permits us to share your voice through pictures, writing, and video/photographic formats.
- If you have any changes in your contact information (phone number, email, or mailing address), please let a KCER staff member know as soon as possible.
  - This ensures we can stay in touch with you.
- Actively participate during the bi-monthly conference calls and Webex® meetings.
Your perspective makes a difference, so we ask that you attend the calls regularly.

If you are unable to attend a call, please let a KCER staff member know as soon as possible. A staff member will provide you a summary of the call to allow you to give input if you choose to do so.

Recommendations for Participation in LAN Meetings

You were nominated to be a SME because you are an expert in understanding the patient or caregiver perspective and want to make meaningful change. The information below will assist you in this role.

- **Before the meetings/calls, whenever possible:**
  - Prepare to join the meeting in a quiet location and keep your phone on mute unless you are speaking.
    - Background noises are easily heard during phone conferences.
  - Please read the materials sent to you prior to the meeting.
    - Your meeting information will arrive at least three days before the meeting.
  - Plan for what you will share during the meeting.
    - Because all SMEs will have an opportunity to share their ideas, it is helpful to plan for what you will share.

- **Sharing during the meetings:**
  - N-KPFE-LAN meetings are unique because they give SMEs the opportunity to share their experiences.
    - Collectively those experiences are shared with CMS.
  - There may be times when you decide to share your personal experiences.
    - Remember, only share what you are comfortable with others knowing about you and your situation.
  - If you share about something that did not go well, it’s helpful to offer suggestions on what would have made it better for you.
  - Think about the words you use to tell your story.

- **After the meetings:**
  - Please complete the post-meeting evaluation.
    - Your feedback is essential.
  - You are encouraged to talk with fellow patients, friends, community members, and healthcare professionals regarding your work with KCER.
    - The feedback you receive from others could assist with the development of KCER resources.
When the KCER resources are finalized, you will be invited to share the resources with fellow patients, friends, community members, and healthcare professionals.

Sharing Your Input Outside of the Meetings

Your role as a SME goes beyond the monthly meetings and providing input during the calls. Below are a few suggestions to help make sure your perspectives are spread beyond the KCER meeting discussions.

• Meeting Pre-Work:
  o You may be asked to share your thoughts as part of meeting prework.
  o Pre-work questions are valuable and the information you provide is included in meeting minutes.

• Document Review:
  o You may be asked to review documents and provide feedback through emails or electronic communications.
  o Sharing your perspective on these documents can make an impact.
    ▪ If you are able, take part in any email or electronic forums conducted by the N-KPFE-LAN.
  o If you miss a meeting, review the meeting minutes and share your thoughts about what was discussed with the KCER staff.

“I wasn’t sure at the beginning of the year where all this was going. But real progress got made and positive improvements achieved. Satisfied. I would do it again.” - 2018 N-KPFE-LAN SME
Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the Privacy of Medical Information

You are receiving information about HIPAA because, as a SME, you might hear health information about other patients. It is important to know how that information should be protected and why.

What is HIPAA?
HIPAA is the legislative act that protects the healthcare privacy of all Americans. Basically, HIPAA ensures that all information about your health is private and should be kept private.

Sharing Your Medical Information with Other Patients
You may choose to share your health information with others, but that is up to you. If someone shares their health information with you, you must keep it confidential.

Don’t Give Medical Advice
As ESRD patients, you have a lot to teach each other; and you are free to share your own experiences. But be careful! Never act as an authority regarding medical information. Never give medical advice. Medicines or a diet that works for you may be dangerous or even deadly to another patient. Even a tiny difference in a person’s medical condition can make a difference. Remember, you are the expert on being a patient or caregiver. Medical professionals are the experts on healthcare. The best medical help you can give to another patient is to send them to the right staff member.
## Acronym Guide

There are many acronyms or abbreviations used in healthcare discussions. Below is a list of common abbreviations that may be used during meetings.

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AAKP</td>
<td>American Association of Kidney Patients</td>
</tr>
<tr>
<td>AKF</td>
<td>American Kidney Fund</td>
</tr>
<tr>
<td>AVF</td>
<td>Arteriovenous Fistula</td>
</tr>
<tr>
<td>AVG</td>
<td>Arteriovenous Graft</td>
</tr>
<tr>
<td>BMI</td>
<td>Body Mass Index</td>
</tr>
<tr>
<td>BP</td>
<td>Blood Pressure</td>
</tr>
<tr>
<td>BSI</td>
<td>Bloodstream Infection</td>
</tr>
<tr>
<td>CAPD</td>
<td>Continuous Ambulatory Peritoneal Dialysis</td>
</tr>
<tr>
<td>CCPD</td>
<td>Continuous Cycling Peritoneal Dialysis</td>
</tr>
<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
</tr>
<tr>
<td>CKD</td>
<td>Chronic Kidney Disease</td>
</tr>
<tr>
<td>CM</td>
<td>Clinic Manager</td>
</tr>
<tr>
<td>CMS</td>
<td>Centers for Medicare &amp; Medicaid Services</td>
</tr>
<tr>
<td>EMR</td>
<td>Electronic Medical Record</td>
</tr>
<tr>
<td>ESRD</td>
<td>End Stage Renal Disease</td>
</tr>
<tr>
<td>ESRD NCC</td>
<td>End Stage Renal Disease National Coordinating Center</td>
</tr>
<tr>
<td>FA</td>
<td>Facility Administrator</td>
</tr>
<tr>
<td>HAI</td>
<td>Healthcare-Associated Infection</td>
</tr>
<tr>
<td>HD</td>
<td>Hemodialysis</td>
</tr>
<tr>
<td>HHD</td>
<td>Home Hemodialysis</td>
</tr>
<tr>
<td>HIPPA</td>
<td>Health Information Portability and Accountability Act of 1996</td>
</tr>
<tr>
<td>HSAG</td>
<td>Health Services Advisory Group, Inc.</td>
</tr>
<tr>
<td>ICHD</td>
<td>In-Center Hemodialysis</td>
</tr>
<tr>
<td>Acronym</td>
<td>Definition</td>
</tr>
<tr>
<td>-----------</td>
<td>----------------------------------------</td>
</tr>
<tr>
<td>ICH CAHPS</td>
<td>In-Center Hemodialysis Consumer Assessment of Healthcare Providers and Systems</td>
</tr>
<tr>
<td>K</td>
<td>Kidney Disease Outcomes Quality Initiative</td>
</tr>
<tr>
<td>KDQOL</td>
<td>Kidney Disease Quality of Life Survey</td>
</tr>
<tr>
<td>LAN</td>
<td>Learning and Action Network</td>
</tr>
<tr>
<td>LDO</td>
<td>Large Dialysis Organization</td>
</tr>
<tr>
<td>N</td>
<td>National Coordinating Center</td>
</tr>
<tr>
<td>NKF</td>
<td>National Kidney Foundation</td>
</tr>
<tr>
<td>NPFE LAN</td>
<td>National Patient and Family Engagement Learning and Action Network</td>
</tr>
<tr>
<td>PA</td>
<td>Physician Assistant</td>
</tr>
<tr>
<td>PCP</td>
<td>Primary Care Physician, Primary Care Provider, Primary Care Practitioner</td>
</tr>
<tr>
<td>PD</td>
<td>Peritoneal Dialysis</td>
</tr>
<tr>
<td>PFE</td>
<td>Patient and Family Engagement</td>
</tr>
<tr>
<td>QAPI</td>
<td>Quality Assessment and Performance Improvement</td>
</tr>
<tr>
<td>QI</td>
<td>Quality Improvement</td>
</tr>
<tr>
<td>QIA</td>
<td>Quality Improvement Activity</td>
</tr>
<tr>
<td>RCA</td>
<td>Root Cause Analysis</td>
</tr>
<tr>
<td>SME</td>
<td>Subject Matter Expert</td>
</tr>
<tr>
<td>UNOS</td>
<td>United Network of Organ Sharing</td>
</tr>
</tbody>
</table>
Here’s What KCER SMEs are saying about sharing the patient created resources:

**Emergency Preparedness Checklist and Tips**

*An emergency can happen at a moment’s notice. Act now and prepare before disaster strikes!*

**Take checklist and have you got prepared?**

- You’re not prepared? If you can’t check these items on your plan:
  - Make a list of emergency use shelter.
  - Check the current address and phone number you’ve used to contact your doctor.
  - Make an extra copy of your emergency plan.
  - Make a plan for what to do if you’re unable to return home.
  - Have a plan for how you’ll communicate with your doctor.
  - Have a plan for where you’ll stay during an emergency.

**2018 KCER SME**

“We have a lobby day coming up in about emergency preparedness, and I will share these resources during that time.”

“I provided copies of the materials to the dialysis clinic manager.”

**2018 KCER SME**

“I shared the checklist with several patients. Each of them realized that they were not as prepared as they thought they were. The checklist is something that will be useful to everyone, particularly the information regarding prescriptions and packing an emergency kit.”

**2018 KCER SME**

“I’ve been in contact with my former dialysis clinic, and I plan to share these resources with the social worker at the clinic.”

**2018 KCER SME**

“I host a support group at my former transplant center and I will be sharing the resources with the group members.”

**2018 KCER SME**
Below is a listing of kidney-related websites that provide information for patients and families.

<table>
<thead>
<tr>
<th>Website</th>
<th>Website Link</th>
</tr>
</thead>
<tbody>
<tr>
<td>American Association of Kidney Patients (AAKP)</td>
<td><a href="http://www.aakp.org">www.aakp.org</a></td>
</tr>
<tr>
<td>American Kidney Fund (AKF)</td>
<td><a href="http://www.kidneyfund.org">www.kidneyfund.org</a></td>
</tr>
<tr>
<td>Dialysis Patient Citizens (DPC)</td>
<td><a href="http://www.dialysispatients.org">www.dialysispatients.org</a></td>
</tr>
<tr>
<td>ESRD NCC</td>
<td><a href="http://www.esrdncc.org">www.esrdncc.org</a></td>
</tr>
<tr>
<td>ESRD NCC NPFE LAN</td>
<td><a href="http://www.esrdncc.org/npfe-lan">www.esrdncc.org/npfe-lan</a></td>
</tr>
<tr>
<td>Forum of ESRD Networks</td>
<td><a href="http://www.esrdnetworks.org">www.esrdnetworks.org</a></td>
</tr>
<tr>
<td>Kidney Community Emergency Response Program (KCER)</td>
<td><a href="http://www.kcercoalition.com">www.kcercoalition.com</a></td>
</tr>
<tr>
<td>National Kidney Foundation (NKF)</td>
<td><a href="http://www.kidney.org">www.kidney.org</a></td>
</tr>
<tr>
<td>ESRD NCC QIA LAN</td>
<td><a href="https://www.esrdncc.org/en/qia/">https://www.esrdncc.org/en/qia/</a></td>
</tr>
<tr>
<td>United Network for Organ Sharing (UNOS)</td>
<td><a href="http://www.unos.org">www.unos.org</a></td>
</tr>
</tbody>
</table>

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