Home Dialysis Quality Initiative Road Map

Goal
Establish a collaborative home dialysis quality initiative, a hub for patients, family members, researchers, and other stakeholders to learn, connect, and engage in patient-centered home dialysis research, education and mentorship.

Purpose
To improve home dialysis retention and uptake

Awareness & Education Projects

Home Dialysis Online Education Warehouse
Patient education and awareness has been identified as a major barrier to increasing U.S. home dialysis uptake. Home dialysis educational resources exist in many formats, and through many websites, making it difficult for patients and families to navigate. The goal of this project is to improve and standardize education on dialysis modality options; develop tools to measure the effectiveness of awareness and education programs; and make it easier for individuals to find education and resources on home dialysis and other modality options.

NKF plans to establish a web-based information and advocacy hub for patients, family members, care partners, researchers, and other stakeholders to engage and access up-to-date tools and resources to better understand the benefits and challenges of home dialysis.

Project Timeframe: Summer 2019 – Winter 2021

Action Items:
- Identify work group members, establish plan of action and assign tasks
- Take inventory of current education tools and resources
- Assess gaps in tools/resources and formats
- Identify any new resources to be developed
- Develop online warehouse to host all education, tools, and resources
- Raise awareness via LDOs, patients, professionals
- Official Launch
- Evaluate patient access to materials
- Measure effectiveness of warehouse, specific tools, etc.
Home Dialysis CME/CE Programs – National, Local, and Online

Expanded professional education is needed in order to close clinician knowledge gaps in patient selection, access and maintenance, infectious and non-infectious complications, and more. Providing focused continuing medical education in various formats will provide greater access to the education that healthcare professionals need.

This activity will educate clinicians on the efficacy of home therapies, recognizing and overcoming barriers to home modalities, and provide strategies to support patients and their families to make fully informed treatment choices. Educational formats include:

- 3-4-hour regional symposia held coordinated by NKF local offices and Medical Advisory Boards
- 3-4 online educational programs/modules
- 3-4-hour pre-conference course to be held at the NKF Spring Clinical Meetings

**Project Timeframe: Fall 2019 – Spring 2021**

**Action Items:**

- Establish a program committee who will conduct an in-depth needs assessment and develop program content
- Identify regions to host local symposia
- Identify speakers and confirm dates of regional symposia and module recordings
- Confirm program locals and logistics
- CME/CE accreditation
- Program marketing

**Mentorship Projects**

**Project ECHO**

There are currently a limited number of high-performing home dialysis centers and clinical experts in home dialysis in the United States, making the need for education and mentorship necessary in order to increase home dialysis uptake and retention. A Project ECHO (Extension for Community Healthcare Outcomes) model will provide an efficient and sustainable way to deliver clinical education and practice mentorship.

Project ECHO is a distance learning educational model, which uses telemedicine and conferencing technology to connect care providers across multiple geographical settings and expertise. High-performing home dialysis centers will act as “host” institutions and will provide clinical expertise using a multidisciplinary approach. The ultimate goal is to enhance knowledge base, care provider efficacy and promotion of team integration.

**Target Audience**

All healthcare professionals involved in the care of home dialysis patients
**Proposed Virtual Curriculum**

<table>
<thead>
<tr>
<th>Home Dialysis Knowledge</th>
<th>Clinical Scenarios</th>
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<tbody>
<tr>
<td>Home dialysis infrastructure</td>
<td>Patient selection</td>
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<tr>
<td>Dialysis access creation and maintenance</td>
<td>Training techniques and strategies for success</td>
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<td>Home dialysis training</td>
<td>Vascular access cannulation</td>
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<td>Home dialysis prescription</td>
<td>Treatment of peritonitis and hemodialysis access infection</td>
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<td>Infectious complications</td>
<td>Clinical effects of more frequent hemodialysis</td>
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<td>Non-infectious complications</td>
<td>Unique patient population for home dialysis</td>
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<td></td>
<td>• Pregnancy</td>
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<td></td>
<td>• Heart failure</td>
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<td>• Liver failure</td>
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<td></td>
<td>• Difficult to control blood pressure</td>
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<td></td>
<td>• Refractory hyperphosphatemia</td>
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<tr>
<td>Strategies to enhance home dialysis technique survival</td>
<td>The use of tele-medicine in home dialysis</td>
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<tr>
<td>Home to home dialysis transition</td>
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</tbody>
</table>

**Project Timeframe: Spring 2019 – Summer 2020**

**Action Items:**

- Establish a program committee to lead this project
- Outreach to dialysis organizations to assess interest in participation/establish end users
- Identify potential funding opportunities
- Establish steps and timeframe needed to become a Project ECHO Replication Center
- Develop CME accreditation process
- Identify outcomes to be tracked
- Market program
- Pilot testing
- Review of pilot results; program modifications (if needed)
- Official Program Launch

**Care Partner Peer Mentoring Program**

The goal of this project is to expand the National Kidney Foundation’s current Peer Mentoring Program to include support for care partners of home dialysis patients, as well as build a more robust experience for home dialysis patients.

A 5-hour mentor training program will be developed to teach essential skills in advocacy, empathic listening, role modeling, validating feelings and bridging the gap in psychological support. This training will be modeled after NKF’s existing NKF Peers program, but with modifications for the care partner and home dialysis patient experience. The training will be developed by NKF in collaboration with experts in home dialysis and care partner support. Tailored educational modules will also be created and accessible through NKF’s peer mentoring app, PeerStrong.
Peer mentoring and support will be provided through planned interaction between a trained peer mentor and a mentee in a reciprocal relationship with guidance and oversight from a master’s prepared expert clinician with experience in the field of nephrology. The overall role of the clinician is to provide leadership, oversight, expertise and professional guidance in all aspects of the NKF Peers program.

**Target Audience**

- Care Partners of patients considering home dialysis (Mentees)
- Care Partners of those currently on home dialysis (Mentors)
- Home dialysis patients (mentees & mentors)
- Healthcare professionals

**Approximate Launch Date: Spring 2019 – Summer 2020**

**Action Items:**

- Research and needs assessment with NKF’s Constituent Services and KLS departments
- Build out online management program/platform for peer mentors and mentees
- Develop self-help tools, online educational content, and training manual
- Recruit and train care partners for pilot test
- Pilot test of the program
- Review pilot results; make needed modifications
- Market program to dialysis centers, online, membership, etc.
- Official launch

**Research Projects**

**Building the Kidney Community’s Capacity for PCOR**

To address the gaps in patient involved-research as well as the barriers, lack of opportunities to participate, and engage in patient-driven kidney research, this project will provide research training to patients and researchers as well as build an infrastructure that equips the kidney community to collaborate throughout the research process from planning to dissemination of findings. This project has the potential to significantly impact the number of kidney-focused PCOR projects, increase the development of research that answers questions most important to patients and those who care for them, as well as serve as a communication channel to support the dissemination of PCORI-funded kidney study results.

The project’s objectives will be guided by an advisory committee of patients and researchers, who have actively engaged in the development of PCORI-funded kidney research projects. The advisory committee will:

1. guide the development of training content including interactive activities and exercises for both patient and researcher audiences;
2. serve as master trainers to deliver the training content to both patients and professionals via live webinar and two (2) in-person educational events hosted by NKF’s local offices; and
3. provide insights on the design and implementation of the online patient-researcher network.
Project timeframe: Fall 2019 – Fall 2021

Action Items:

- Identify project advisory committee
- Develop training curriculum for both patients/care partners and researchers
- Develop data collection instruments
- Develop Partners in Kidney Disease Research Guide
- Online platform development – website design, framework, test functionality
- Conduct live training webinar for patients and professionals
- Post recording of living training on online platform
- Conduct 2 in-person trainings

Pilot Project to Validate & Implement a Care Partner Self-Assessment Tool

The goal of this project is to support persistence of home dialysis through regular check-ins using a Care Partner Burden Inventory Self-Assessment tool developed by a working group of conference participants. The tool assesses signs of burnout, depression, and other aspects of burden in care partners of patients on home dialysis. A pilot program would include formally validating the tool, assessing its impact in identifying potential burnout, and ultimately improving home dialysis abandonment rates.

Questions from the Care Partner Burden Inventory Self-Assessment Tool

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<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
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<tbody>
<tr>
<td>1.</td>
<td>I often feel physically exhausted.</td>
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<tr>
<td>2.</td>
<td>I often feel emotionally exhausted.</td>
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<td>3.</td>
<td>Sometimes I wish I could “run away” to take a break.</td>
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<td>4.</td>
<td>Our relationship is good.</td>
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<td>5.</td>
<td>My finances suffer.</td>
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<td>7.</td>
<td>My other relationships suffer (family, friends, coworkers).</td>
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<td>8.</td>
<td>There are people I can turn to for help.</td>
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<tr>
<td>9.</td>
<td>My sleep suffers.</td>
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<tr>
<td>10.</td>
<td>I feel torn between providing care and my other demands.</td>
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<tr>
<td>11.</td>
<td>I am overwhelmed by managing supplies.</td>
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<tr>
<td>12.</td>
<td>I find ways to feel satisfied with my life.</td>
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<tr>
<td>13.</td>
<td>I don’t think I can do this for more than one year.</td>
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<tr>
<td>14.</td>
<td>Sometimes I feel depressed and/or anxious.</td>
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</tbody>
</table>
15. I feel frustrated when he/she doesn't follow their diet, take medicine, or do their dialysis as they should.

16. The thoughts and feelings I have about being a care partner make me feel guilty.

**Project timeframe: Winter 2020 – Fall 2022**

**Action Items:**

- Establish a project lead and team
- Identify steps needed to validate and test tool
- Identify partner for tool testing
- Develop outcome measures
- Pilot test tool

**Policy Change Recommendations**

Among the current leadership at the U.S. Department of Health and Human Services (HHS) there has been a new focus on prioritizing transplantation and home dialysis as the first-line treatments for End-stage Renal Disease (ESRD) by leveraging changes to Medicare reimbursement to kidney care providers. During the Home Dialysis Controversies Conference, Amy Bassano, Deputy Director of the Centers for Medicare & Medicaid Innovation (CMMI), spoke about HHS and CMMI leadership’s vision to shift misaligned reimbursement incentives in order to increase the number of ESRD patients who receive a transplant or home dialysis. A small work group of conference attendees discussed and recommended that initial efforts to increase home dialysis uptake should include the following policy changes:

- Increase uptake of the Medicare KDE benefit by increasing the reimbursement to providers and allow for other types of providers to bill and oversee the delivery of the education, expand the benefit to include CKD stage 5 patients who are not already on renal replacement therapy, remove the co-insurance obligation for patients and allow for the patient’s home to be the site of service so that KDE can be offered virtually.
- Modify the Medicare Capitated Payment (MCP) to equalize the payment to nephrologists to treat home patients at the highest level of the MCP.
- Clarify contradictory requirements of the face to face visit for vascular access inspection and the allowance of telehealth visits for home dialysis by clarifying in regulatory guidance that the monthly inspection is only required for vascular access and not peritoneal dialysis catheter sites OR that peritoneal dialysis catheter sites can be inspected monthly via telehealth with the right video equipment.