

CREATING A CULTURE OF QUALITY

WEBINAR #3 ~ NOVEMBER 9, 2016

PATIENTS & PROVIDER ENGAGEMENT:

Forging True Partnerships and Changing the Culture

QUESTIONS & ANSWERS DOCUMENT

*The Q&A below represents general questions to the presenters.
Questions were answered by the presenters and webinar co-chairs.*

General Questions	
Are the previous webinars available by recording?	Yes – recording, slides, Q&A – see the Forum website at: http://esrdnetworks.org/education/quality-conference/quality-conference-2016-2017
Questions for Jennifer Flythe and Jennifer Russell:	Answers/Responses from Presenters: Jennifer Flythe (JF), Jennifer Russell (JR), Dori Schatell (DS) and Planning Committee Co-chairs
As a Social Worker, I would like to do a support group or activity with the patients but my administration sees my role as more of a financial/insurance expert. Any suggestions on how to change this perspective at the administrative level?	<p>JF: Our study results suggest that patients who are involved in advocacy activities are more likely to be engaged or activated in their own health care. The potential advocacy by-product of better self-health may be of benefit to the individual as well as to the dialysis clinic’s overall performance. Thus, encouragement of patient engagement has the potential to improve individual and clinic outcomes. Social workers may be able to affect change for patients and the clinic by encouraging advocacy and engagement among patients in addition to assisting with their financial and insurance needs.</p> <p>Co-chairs: The social worker could offer to administration a trial “short term experiment” of hosting a couple of support groups or focused educational sessions to see if patients respond and/or attend. Have patients evaluate the sessions on a brief evaluation form to learn if patients do or do not want these sessions. Alternatively, the social worker could host informal sessions in the waiting room; patient feedback can be shared with administration.</p> <p>A word of caution regarding support groups. They may have limited success, as judged by anecdotal experience, literature review and interviews with organizations. Success may depend on the format or content. They need to be topic focused and engaging experiences. Occasionally, off-site groups conducted solely by patients may have better luck. That said, there are multiple approaches to everything and no one approach works for all.</p>

Questions for Jennifer Flythe and Jennifer Russell:	Answers/Responses from Presenters: Jennifer Flythe (JF), Jennifer Russell (JR), Dori Schatell (DS) and Planning Committee Co-chairs
<p>I'm sure some patients would be motivated by incentives but Medicare doesn't allow us to provide patients transportation or gift cards for meals, etc. so how did you get around that?</p>	<p>JF: For our study, we asked patients what types of things would make patient interested in participating in advocacy educational events. Patients suggested transportation and incentives. We did not offer them and did not suggest these ourselves. These were patient-identified ideas.</p> <p>Co-chairs: We recommend that providers confer with their own compliance officers and/or review clinic policies about offering complimentary services or goods to patients, such as transportation or meals. See a 2002 advisory bulletin from the Office of the Inspector General https://oig.hhs.gov/fraud/docs/alertsandbulletins/SABGiftsandInducements.pdf. Small nonmonetary inducements (under \$10 per person and cumulatively under \$50 annually per person) are acceptable per this bulletin. Certain government-sponsored clinical trials are exempt from the prohibition of inducements.</p> <p>Of note is that there are different views even among professionals about incentives. One is that external incentives may reduce intrinsic motivation. Ideally, patients should engage in self-care because it makes them feel better. Rather than offering incentives, a clinic could create a “cheer board” where people put up notes to encourage each other. Another view is that sometimes “you have to lead with a carrot” so that patients can see the bigger picture, have better outcomes and become intrinsically motivated.</p>
<p>You had mentioned that transportation had been supported by the clinic so that patients could attend meetings. How did you go about that?</p>	<p>JR: The <i>Peer Up!</i> Program worked with the facility social workers who connected us with the local aging program. They were able to provide transportation to key events.</p>
Questions for Jennifer Flythe	
<p>When you talked about dialysis 'advocacy,' were you including dialysis support groups in this concept (or meaning?)</p>	<p>We defined advocacy as the act of speaking out on behalf of persons with chronic kidney disease or on behalf of a chronic kidney disease-related cause. We classified advocacy on the dialysis clinic, community and national levels. Participation in a dialysis support group was included in the dialysis clinic level classification of advocacy. Thus, dialysis support groups were included in this concept.</p>
<p>Any suggestions for developing skills for people with kidney disease to talk to their legislators about needs of people with kidney disease?</p>	<p>Participants in our study suggested that example letter templates would be helpful as well as examples of past advocacy efforts that led to success on the legislative/ policy front.</p> <p>Co-chairs: There are many kidney patient organizations that advocate for dialysis patients. For example, the American Association of Kidney Patients (AAKP) provides an excellent avenue for patients and providers to participate in advocacy. There is a wealth of information on their website https://aakp.org/</p>

Questions for Jennifer Russell	
What tools were used to measure the results? Was it quantitative or qualitative? (I believe this was directed to Jenn Russell).	A combination of instruments were used. Where possible, validated scales were used. All instruments are available via the <i>Peer Up!</i> toolkit (Assessment & Evaluation Section) at: http://www.esrdnet5.org/Special-Initiatives/Peer-Up!-Program.aspx .
Can I get copies of the Peer Program brochure?	See the <i>Peer Up!</i> website: http://www.esrdnet5.org/Special-Initiatives/Peer-Up!-Program.aspx . There is a patient brochure here: http://www.esrdnet5.org/Files/PeerUp!/Recruit-Retain-Brochure.aspx
Who trained the peer mentors? How long did this take, and how was the training structured?	Network 5 staff conducted the training for the program since this was a pilot. A comprehensive curriculum was created as part of the <i>Peer Up!</i> toolkit so that facility staff can train patients. Please see: http://www.esrdnet5.org/Special-Initiatives/Peer-Up!-Program/Mentor-Training.aspx for the training manual and demonstration video. The training is designed to take approximately 5 hours, but could be broken into two 2.5 hour sessions or adapted to be delivered chair-side, if necessary.
Do you feel the patient mentoring can only be successful if it's one on one? Do you have any thoughts on how to make patient to patient mentoring effective when there is one patient champion and maybe 3-5 patients that they are mentoring?	There is currently a randomized controlled trial examining this question along with modality of mentoring (face-to-face or online). Please see: http://www.pcori.org/research-results/2014/improving-patient-quality-life-and-caregiver-burden-peer-led-mentoring-program The <i>Peer Up!</i> Program was one-on-one so that patients could develop a deeper relationship and receive social support from another patient. Because this was a new program and no participants had prior mentoring experience, we thought it best to start with one-on-one. In our program and experience, multiple patients might have been challenging; however, it likely depends on the patient population and time availability.
How are HIPPA issues addressed with peer mentoring? Did you prepare forms to fill out? Can you speak to the tension we as providers feel for adhering to HIPPA policy and yet encouraging a culture of community?	This was a concern, but the facility and <i>Peer Up!</i> Program shared no patient information with participants. Topics for discussion and how much a mentee or mentor disclosed was up to each individual. The mentor training did address the importance of confidentiality and this was also discussed during the kick-off mixers so that mentees were also aware. All participants reviewed and signed a confidentiality agreement and instances where confidentiality might need to be broken (e.g., danger to self or others, medical emergency, etc.) were reviewed. Please see training manual and confidentiality agreement at: http://www.esrdnet5.org/Special-Initiatives/Peer-Up!-Program/Mentor-Training.aspx
How can we connect or refer patients without violating privacy policies?	The <i>Peer Up!</i> Program paired individuals based on the responses provided on a member application: http://www.esrdnet5.org/Special-Initiatives/Peer-Up!-Program/Recruitment-Retention.aspx This information was not shared with the participants. We simply introduced the mentee/mentor and encouraged them to talk. A sample meeting agenda (Guide for Mentors) was given to mentors as a suggested meeting format: http://www.esrdnet5.org/Files/PeerUp!/Mentor-GuidePocket.aspx
Comment: Good ratio of mentors to pts would be workable.	We did not examine this in our pilot study. It likely would depend on a variety of factors, including patient time, willingness to engage with multiple mentees, format (phone, face-to-face, email), previous mentoring experience, training, etc.

Questions for Dori Schatell

<p>After you help a patient identify their goals, does the process of starting to work on the goals automatically help the patient have more hope, or is there more that the staff needs to do? Do you see the dietitian as being as important in this as the social worker?</p>	<p><i>Succeeding</i> in a step toward a goal can help patients have more hope—which is one reason that it's vital to break down goals into SMALL steps. The staff can cheerlead—which takes no extra time. Express interest in the goal the patient has set, and enthusiasm over any progress, however tiny. If a patient seems frustrated and stuck, see if the social worker can help, or perhaps brainstorm while putting the patient on or taking him/her off. I see the entire team being important, and who specifically will depend on what the goal is.</p>
<p>Any suggestions for developing skills for people with kidney disease to talk to their legislators about needs of people with kidney disease?</p>	<p>The most important thing a patient can do to talk to a legislator is tell his or her own story. Patients often feel that they need to spout statistics and studies. They don't. Knowing what a bill would do and being able to say why it would matter is enough.</p>
<p>Can you give a list of good social media sites to refer patients to?</p>	<p>Our Home Dialysis Central Facebook discussion group for people who do, support, or are interested in PD or home HD is: https://www.facebook.com/groups/HomeDialysisCentral/.</p> <p>Another good PD group with solid information is here: https://www.facebook.com/groups/peritonealdialysissupportgroup/</p> <p>There are some large groups for dialysis in general; please note that these are more likely to have inaccuracies, because it is impossible for anyone to monitor all of the posts. https://www.facebook.com/groups/DialysisUncensored/ https://www.facebook.com/groups/2229039880/</p>
<p>I am a dietitian and would like more on how we can be a part!</p>	<p>Get to know your patients and what matters to them. Help them see how following their diet and keeping their labs in range will get them where THEY want to go. Be cheerleaders for even tiny improvements. Support their progress, even when they are not perfect. Tell them that they can have fewer dietary and fluid limits with home treatments.</p>