

Network 15 Podcasts

Learning About Learning and Action Networks (LANs)

Moderator

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Guest

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Hello. Thanks for joining us today. My name is Justin Carr. I'm the patient services manager for ESRD Network 15. I'd like to welcome you to the first in a series of podcasts. The goal of this podcast series is to help get information to patients that we feel is beneficial. We try to do this from the patient perspective, and always with an eye towards improving patient understanding and patient quality of care.

Justin

Today we're going to be talking about the Learning and Action Networks, or LANs. We hope to provide you with information about what they are, and how they do what they do.

Joining me for this discussion will [be] Mr. Jeff Needham. Mr. Needham is the co-chair of the Network's Patient Advisory Committee, or PAC. The PAC gets together about once a month and talks about issues relating to them. [PAC members] talk about their care. They talk to each other about being on dialysis, and they also give their input on some of the important work we do with the Network. If you're interested in learning more about the PAC, please reach out to one of your clinic staff members for more information.

Hey Jeff, are you there, sir?

Jeff

I'm here all right!

Justin

Great! That was almost too easy. Okay, so Jeff, I apologize. I realized before we got started on this it might be good for you and I to introduce ourselves.

My name is Justin Carr. I'm the patient services manager for Network 15 and the Network is basically a quality improvement organization under contract to

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the Centers for Medicare & Medicaid Services. We help oversee quality at dialysis clinics.

And Jeff, if you don't mind, can you just say hi, and your name, and that you're our PAC co-chair, and you're awesome.

Sure, I can probably do most of that.

Jeff

My name is Jeff Needham. I'm the co-chair, with Maile Robb, of the Network Patient Advisory Committee (PAC). And essentially, what we do is what it sounds like; we advise the Network on issues that are related to our care so that they have an opportunity to hear the patient voice.

Justin

Perfect! Wonderful! Jeff thank you so much for being here again, and today we're going to talk about the LANs. And so I thought we would start by me kind of defining that real quick, and then you and I can maybe have a short conversation about that. Okay?

Jeff

Sure.

Justin

Great! So, LANs—because Networks love acronyms—stands for Learning and Action Networks. And what that basically means is, it's a group of people who are brought together under the auspices of the National Coordinating Center, the NCC. That's a group under contract, again, to the Centers for Medicare and Medicaid Services. Basically, [a LAN is] a group that comes together—it brings together patients from across the nation, and they talk about certain topics—transplant, bloodstream infections, vocational rehab. It can be just a whole bunch of issues, but the idea is that patients come together from across the country and work on developing tools and work on improving various aspects of the patient experience on dialysis.

So, it's a very cool thing, and like I said, their kind of end goal is, at times, to develop tools at times, to develop interventions. But they're just looking to improve the quality [of care] for folks. And Jeff has been good enough, not only to be involved on our PAC, but also to be involved in the past on several LANs. So, I thought he'd be a great expert to talk about this.

So, Jeff, if you don't mind, now that I've kind of just given a whole bunch of word salad out there about LANs, maybe you could tell us a little bit about what exactly a LAN does for, from your perspective.

Jeff

Sure.

Depending on the group itself, it's going to be comprised of people from around the country, people who are renal patients, and they'll meet once a month, perhaps every other month on the phone, generally [for] an hour to an hour and a half and discuss issues related to care. Again, like you mentioned, things like

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bloodstream infection, transplant, home modalities—you know, issues that that are directly related to patients and much in the way of their network PAC. You know, the job, I suppose, you could say of the patient volunteers, is to provide their individual expertise at being dialysis patients to advise the NPFE-LAN [National Patient and Family Engagement Learning and Action Network] and those who, you know, pay attention to it—what patients are thinking about any given issue. Because ultimately, what decisions are made are going to affect patients.

Justin Holy cow! I'm glad I invited you on this. That was awesome. So, what exactly, like if you recall back on your kind of experience, if you just called in to a LAN meeting, do you remember kind of briefly maybe, how that meeting would go?

Jeff Yeah, I mean structurally, you're gonna start off with a roll call, you know, perhaps, say, an acceptance of the previous minutes of the previous meeting, and there's going to be an agenda. There will be topics, for instance, let's say, one agenda is related specifically [to] the bloodstream infection, the Networks, and the NPFE-LAN, and the NCC. You know, they come up with quality improvement activities for the individual dialysis facilities, and so the topic might be, you know, what can we do to reduce bloodstream infection. Sometimes it might be posters; sometimes it might be awareness of [treatment] times; might be hand-washing. So, for instance, I participated in probably a half dozen hand-washing audits at my facility, sometimes in conjunction with the NPFE-LAN and sometimes in conjunction with the Network.

Justin That's great. So, you would have this agenda, you would call in, and then you guys would kind of eventually get down to discussing these various topics, right?

Jeff Exactly. And some of them could be very specific you know? For instance, another topic was the issue of what to do when patients get transplanted; what to do when patients pass away; what to do when patients move or [are] hospitalized. And so, one of the LANs this past year, it came up with several forms that could celebrate transplant, [another form] where LAN patients could allow their information to be shared with a small group of people they might know at the facility. And you know, [the form] gave their okay. Perhaps if they passed away, you told my people about it so that, you know, people could pay their respects. So that was some of the specific things that the LAN did last year.

Justin That's a wonderful example. I know we've had a lot of patients asking about information very similar to that sheet that was generated, so I know that was kind of a good thing that you guys made. Do you, on that topic, do you find it rewarding working with the LAN? Do you like it?

Jeff I do. You know, part of the reason I originally volunteered [was that] I knew nothing about the Network system. You know, it was brought to me, brought to

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my attention by the social worker at my facility [that] the ESRD networks had sent out, you know, one of their emails, and he brought it to my attention. And I had been looking to find a way to give back. You know, I feel that I just, by virtue of my care, I'm granted a second lease on life, and I personally feel obligated to do what I can, I guess you could say, to earn my keep. You know, I certainly can't pay for my care, but I can give back in a lot of ways, and so that was originally why I volunteered for the Network without even knowing what it did. But through the course of, you know, volunteering for the Network, for the NCC, working with the NPFE-LANs, yeah, it's extremely rewarding to see something come to fruition that started off as an idea and to see that become something concrete—you know, that patients can hold in their hand, can see with their eyes, but that will affect somebody's life? Yeah, it's extremely rewarding.

Justin

And one thing I've heard talking to patients who have been on the LAN is that experience being able to create these things, then go out and help people, can be kind of empowering. Did you ever have that feeling?

Jeff

Very much so. I don't know what the science behind it is, but I'm firmly convinced that the more involved people are with their own care, the better outcomes they're going to have. You know, not just from the standpoint of “oh I feel better”, but, you know, clinically, scientifically better outcomes; the more we are involved in our care, the more engaged [we are] with our care. And I think that means being engaged with others as well. And also, one of the benefits of being part of the NPFE-LAN and being part of the Network system is, you do need people from around the country who have, on the one hand, a shared interest, but also, if you meet a hundred people, you're going to find a hundred different perspectives on how to live life. And I think that has a great deal of value as well.

Justin

Yeah. So, it sounds like you kind of started off, [and] this has been rewarding for you. Would you recommend this to other folks who are maybe interested?

Jeff

Oh, by all means, yes! I would. Yeah. Yeah. And I know sometimes, you know, the LAN recruits at different points of the year, but there's always a way to get involved, if not in the LAN, maybe their own Network's PAC.

Justin

We talked about that you're the co-chair of [our PAC], but it's really good to hear that. You know, people talk about how good it is to get involved, but it's good to hear that that kind of carries out for you, and you've seen that. So, thank you for sharing that.

So, great. One thing I'd like to talk about is, you know you guys generate these tools, and that sounds really cool, but how do we get the things you guys generate or the information you guys get and get it to folks at the individual

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clinic level? And that's something that's kind of an ongoing discussion. Do you have any ideas or thoughts on how that might work?

Jeff

I think truly, a multi-pronged, ongoing effort. You know, for instance, there's always turnover at clinics, so there's always going to be new patients coming in, new patients, you know, other patients leaving for whatever reason. So, from that standpoint, I think things have to be ongoing. The other [thing], you'll have dialysis patients in my clinic anywhere from “years old” to about “*years* old,” so I think it's necessary to have a variety of ways to reach them. You know, and understand generationally, in general, younger folks are going to be more in tune with social media, like Facebook and Twitter and other platforms like that. Whereas, perhaps, you know that the other end of the spectrum, you'll want to have, you're going to want to do something more personal, more one-on-one as possible, about issues that are related directly to the patient. So, a multi-prong [approach], I think, is the best. I think one way or another, is going to resonate with different people, because again, in my facility, there's patients, and so I can't write a template over [their] lives and say just, I'm going to communicate with you. You can get a representative within a facility that might [think they] know the patient's better than [the patients] can, [and then this facility representative may] decide which way to communicate with any given group of patients. And honestly, because this is obviously part of a discussion we've all been having in the PAC, but I know we've talked about [making more personalized efforts], making a series of possible videos. We've talked about, like this podcast here, do any sorts of recordings. Doing, you know, fliers, which I know show up [in] a lot in clinics, but doing maybe, some kind of a unique spin on that, so that it's clear this is coming from other patients to other patients. And in that individual approach, where we're lucky enough to have patients in clinics who are in the LAN, or PAC members who were able to interact with LAN members in the PAC and having them kind of be representatives and advocates at their clinic.

Justin

I think those are all real world, practical ways to do what you just said, which is, in a multi-prong way, disseminate this information out. I think it, as a whole, it is really useful stuff you guys are doing. So, yeah, I totally agree. So, Jeff, do you have any kind of final thoughts on the LAN, or anything we've talked about, or anything else you want to mention here?

Jeff

I would say, again, if somebody's wondering if it is worthwhile— yeah, yeah, it is. So far that I know, it's the best way to start to meet people from around the country, start to understand how care is provided to us, and start to understand that there are things we can do to improve our own lives and to improve the lives of others. And it's a good avenue and a good opportunity to do that.

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Justin Well, Jeff Needham, it's always a pleasure talking to you, sir. I'm so grateful that we have you as part of our PAC, and I really appreciate your time. Thank you, thank you, thank you.

Jeff You're very welcome.

Justin We hope you found this discussion of the Learning & Action Network's helpful. Please be on the lookout for future episodes in this series.
We'd like to thank you for listening to the podcast today. This is Justin Carr for Network 15. Take care.