Ovarian Cancer Podcast Series – Iowa Demonstration Overview Episode Transcript

[Announcer] This program is presented by the Centers for Disease Control and Prevention.

Announcer: Welcome to our podcast series on CDC's Ovarian Cancer Demonstration Project. I'm your host, Jake Lynn.
Did you know that ovarian cancer is the fifth leading cause of cancer death among women in the United States and the second most common type of female reproductive cancer?
This episode is part of a five-part podcast series that describes the activities, facilitators and barriers, lessons learned, and recommendations from the demonstration sites.
Today, I spoke with Katie Jones, Mary Charlton, and Jenny Patterson from Iowa about their CDC demonstration project to increase gynecologic oncologist involvement in the treatment for ovarian cancer While there is no simple and reliable way to screen for ovarian cancer in asymptomatic women, a woman's chances of survival increases if her treatment is given or directed by a gynecologic oncologist.
Let's meet our guests.

Katie: I can go first, I am Katie Jones, I am the Program Manager of the Iowa Comprehensive Cancer Control Program at the Iowa Department of Public Health, and I was basically the liaison between the Iowa Cancer Registry and ICF and helped with the application and the reporting, the budgeting, contracts, those types of things.

Mary: My name is Mary Charlton. I am Associate Professor in the Department of Epidemiology at the University of Iowa College of Public Health, and I am the PI and Director our Iowa Statewide SEER Cancer Registry. My role on the project was overseeing and directing the formative analysis that we did and just overseeing all components of the project.

Announcer: For our listeners, Mary is a principal investigator or PI who is responsible for directing the project. As Mary mentioned she is the Director of Iowa's Surveillance, Epidemiology, and End Results Program also known as SEER. SEER provides information on cancer statistics to reduce the cancer burden among the US population. Now, let's give Jenny an opportunity to introduce herself.

Jenny: Hi. I am Jenny Patterson and am a research specialist with the University of Iowa College of Public Health and I was working on the materials development and testing for this project.

Announcer: Excellent. So, what motivated you and the Iowa Department of Public Health to take on this work?

Katie: Well, I saw the opportunity was sent out to the comp cancer programs and I reached out to some of our partners including the Iowa Cancer Consortium and Mary is on the Board of the Iowa Cancer Consortium and we also work together since she is part of the Iowa Cancer Registry. We hadn't really worked on ovarian cancer for our comp cancer program. It hadn't been much of a focus but Mary

right away said, “Oh this actually aligns with a project we've already done, and we would like to apply.” So, I will let you take it away Mary if you want to talk about that at all?

Mary: Yea, it happened to be that I had a student, an MD/PhD student who helped a lot with this project and that was her main area of interest. So that was the first thing that perked my interest when Katie sent me that email asking for some information about ovarian cancer. And second, we had just participated in a CDC-funded project to do a special ovarian cancer patterns of care study along with Missouri and Kansas because mortality rates of ovarian cancer are quite high in the Midwest and I think there was some concern that people, especially in the Midwest were not getting treatment from a gynecological oncologist. So, we had started to analyze that data and were definitely seeing some issues that we had in Iowa. We knew we only had 6 gynecological oncologists in our state and 5 of them were at the University and only one of them was in Des Moines which is kind of in the middle of the state and nowhere else, so it seemed like a really important project to do.

Announcer: That’s great. Jenny, is there anything else you’d like to add?

Jenny: I reached out to Mary when I heard about the project. I've worked with CDC on a number of gynecologic cancer projects in the past and specifically ovarian cancer as well, so thought this would be a good fit and it was. I was happy to join the team.

Announcer: And what would you say was the overarching goal in participating in this demonstration project?

Mary: We really wanted to understand what the issues were that were driving the lack of either referrals or patients going to a gynecologic oncologist. We didn't really know what were the key issues. So, we appreciated that the project allowed us to do some formative research on determining that and selecting some strategies to address the barriers and issues that we found.

Announcer: That's a great tee up! Next, I’d like to go into the strategies you implemented and the formative research you conducted to help you select those strategies. So, if you could, please describe first the formative research you conducted, and then describe the strategies you selected for implementation based on the findings from the formative research.

Mary: We were really trying to learn what the root causes of some of the problems were in Iowa so that we could best address them. And we really heavily relied on the Iowa Cancer Registry data. It was nice to have that as a starting place.

And we could see that there were some places in Iowa, a handful where it looked like they were referring less than others. So, we wanted to make sure to try and reach out to providers in those areas to see if we could kind of figure out what was happening.

So, when we did the formative research, we started with interviewing providers and then also decided that we needed to interview patients too. Thankfully with the Iowa Cancer Registry being part of the project, we could use that data to determine if there were some people we could talk to who looked like they never went to a gynecologic oncologist according to our records and focus on them and just ask them about the process that they used to decide where to receive care.

That was probably the most illuminating set of interviews because it didn't really say, I couldn't travel somewhere or there were financial barriers, transportation barriers. They did not say those things. They said, “my doctor, I trusted my doctor and they said they could take care of it.” So essentially, we learned from them that some people are just not getting referred because of that trust-based relationship with their physician. They're not seeking second opinions. They're not doing a lot of online research. They're just sort of going where they're told to go and assuming that person offered treatment is the most qualified person to take care of them. And unfortunately, that assumption is not actually always true. So that was the big, an impetus for selecting patient education materials as one of our strategies to help make them aware of the importance of seeing a gynecologic oncologist and some questions to ask their providers.

Announcer: That’s great. So now I want to talk about each of the strategies you implemented based on these findings. Let’s start first with the patient and provider education materials.

Mary: So again, the goals of the patient education materials were really awareness to help patients make informed decisions, ask the right questions. This is hard to do. You certainly don't want to undermine that trust-based relationship with providers. But with something like ovarian cancer, which is the most deadly of the gynecologic cancers, it is particularly important for one for them to at least seek consultation with a gynecologic oncologist. We worked with a patient advocacy organization called NormaLeah. And they had a number of materials that we could start with and incorporate and then test. That was the other thing. We just wanted to make sure the messages we were trying to get across were resonating with our target population, so that organization helped us to recruit people, to test the materials and go over those and make sure they were picking up what we were putting down in terms of messaging.

Similar process with the providers too, where we wanted to test that out. That's a little trickier. Patients are a little bit easier to recruit to do things like that, to spend the time with you and go through things like that. So, it's a little trickier to get OB/GYNs and other providers to do that but we really tried to take what we learned through that and make it a clear messaging on information for them. And then we also wanted to arm the providers with information to give to their patients also. So, we wanted to get those patient education materials in the hands of the providers, because they're the ones who can give those out at the time of the diagnosis when the patient is really overwhelmed and probably can't process everything right then when they're learning about their cancer diagnosis.

Announcer: Great, thanks Mary. Looking back, were there any questions or issues you wish you had explored during the formative research process?

Mary: One thing we weren't able to do was get the physicians together. We did talk to some gynecologic oncologists about their perspective on getting the referrals. And one mentioned his hypothesis. Once a physician tries to make a referral for something, whether it's last week, last year, 10 years ago it stuck in their mind for a long time. When that goes bad for whatever reason they are angry, and it can like predate even the people that are even working there now. So, what we really wish is that there was a way to do some sort of focus group, or even just an

informal conversation, between some of the providers who were not referring and the people who are there now just to sort of hash it out and reformulate those relationships.

Announcer: Okay, thanks. Let's turn to partnerships next. Can you talk a bit about the partnerships you established for this demonstration project?

Katie: So, partners are a huge part of our work. You know we work with the Iowa Cancer Consortium a lot. They're our main contractor and then also the American Cancer Society. A variety of other partners too.

Announcer: I see that you also partnered with Brown University's Office of Continuing Medical Education. Can you describe that partnership?

Katie: I know we basically just were having trouble finding an affordable provider for CMEs or for physicians for the webinar. And since ICF had connected us with the other ovarian cancer demonstration sites, one of which was Rhode Island. And they were working with Brown University for a webinar. And with Covid we had decided to switch to doing a webinar as well. So, then we were just able to work with Brown University. And they were great to work with.

I should also note NormaLeah was a partner, the NormaLeah Ovarian Cancer Initiative. They have been working for a long time on ovarian cancer patient advocacy and they have been pushing for making sure that folks diagnosed with ovarian cancers are seen by a gynecologic oncologist early on before this project. And they really helped connect the project to patients for focus groups and look over materials and that sort of thing.

Announcer: Tell me what made it easier or more difficult to plan, implement, and evaluate your strategies for this demonstration. Let's start with you, Mary.

Mary: I would say probably the biggest facilitator is just the sort of fact that I am with the cancer registry and so we have so much data. I think that's probably very different depending on the state. One, how much access you have to your state's cancer registry or your relationships that you have there. And two, what the registries analytic capabilities are, and I think that's highly variable. But we were fortunate to have full access and a lot of analytic capabilities at ours, so we could really start from a data driven approach.

I think the barriers were really mostly in the recruitment of providers to participate. We had NormaLeah and heavily relied on them for access to survivors, ovarian cancer survivors; we didn't have anything that mirrored that on the provider side. There wasn't like one place we could go to recruit providers. And it was during the pandemic so who knows how it would've gone otherwise. But during that time, it was pretty difficult to recruit them to participate in interviews or kind of the testing of our subsequent materials. So that was probably hardest.

The thing that helped that is the Iowa Cancer Consortium has a lot of providers that are involved. Also, our connection with having a gynecologic oncologist on our team. She could reach out to people and recommended people who we could interview. So, we kind of relied on some of those relationships between our partners and it comes back to having a broad set of partners who can reach out to hard-to-get groups like providers when you need some of their time to talk to them.

Announcer: Great. Katie, anything to add on that?

Katie: So, there was just some barriers with some of the providers referring, thinking that the referral process is complicated. But then when we talked to the gynecologic oncologists they said no, we've streamlined it. We get patients in, so just helping to connect the dots there. Again, focusing on that provider education component.

Announcer: And Jenny, how about you?

Jenny: Yes, I think with the goal of educating providers we knew that CME was the way to go. That's the way to get them to participate and so we were able to do that again with the partnership with Brown and we were grateful for that.

Announcer: Excellent. Any plans for continuing or sustaining these strategies, or any changes that you envision would be needed to continue implementing these strategies?

Mary: It wasn't something we were tracking before the registry—to look at proportion of people with ovarian cancer who it appears from our records were treated or at least had an opportunity to see a gynecologic oncologist. So that's something that we plan to implement on an annual basis to see what's happening with that. And if it's not going in a good direction, then revisit some of our strategies again. And maybe send out the materials again; maybe facilitate some conversations between providers, really trying to break down any interpersonal barriers there.

Katie: So, I think we will, definitely. The cancer program and our partners are trying to address how do we improve cancer care. You know and just reduce disparities. . I feel like there's always been an interest in health disparities but now there's so much more energy behind it, and some people who weren't necessarily as involved in it before now realize this is something that we need to prioritize.

Announcer: It sounds like you did some great work planning and implementing strategies aimed at increasing receipt of care by a gynecologic oncologist among women diagnosed with ovarian cancer in Iowa. Thank you to Katie, Mary, and Jenny for joining me today and for discussing your experience collaborating on this demonstration project.

For more information, please take a look at the resources developed by Iowa, Rhode Island and Michigan, for this demonstration. You can access these resources as well as the action plan, which describes the promising strategies identified for this demonstration project, and the accompanying toolkit which is a compilation of tools and resources addressing planning, implementation, and evaluation of the strategies included in the action plan. These can all be found at www.cdc.gov/cancer/ovarian.

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[Announcer] For the most accurate health information, visit cdc.gov or call 1-800-CDC-INFO.