

Ovarian Cancer Podcast Series – Partnerships

Podcast 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?
Today, I spoke with Katie Jones, Mary Charlton, and Jenny Patterson from Iowa and Kelly Smith and George Andoscia from Rhode Island about the partnerships they each developed as part of a 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 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, do you want to go next?
- 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 of 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 I am a research specialist the University of Iowa College of Public Health and I was working on the materials development and testing for this project.
- Announcer: And from Rhode Island.
- Kelly: I am C. Kelly Smith. I am the Comprehensive Cancer Control Program Manager under normal circumstances here in Rhode Island, but I am currently deployed full time, and so I wrote the original application, engaged our cancer coalition in the initial work, designed the project with our partners, helped them to do that and helped lead the planning process until I had to step aside during the pandemic due to COVID-19 deployment obligations.
- George: I’m George Andoscia. I am currently the acting Comprehensive Cancer Control Program Manager thanks to COVID. And previously, I was the Comprehensive Cancer Control Program’s Policy Systems and Environmental Change Specialist. So, like Kelly said, I stepped in to take over coordination of ovarian cancer related activities and worked with the task force when Kelly was pulled full time into her COVID-19 work.
- Announcer: Partnerships are integral to the work of the National Comprehensive Cancer Control Program, or NCCCP. Angela Moore, Lead Public Health Advisor with CDC’s Division of Cancer Prevention and Control, described for me the importance of partnerships in the context of the NCCCP program and for this demonstration project.

CDC: CDC's National Comprehensive Cancer Control Program brings together key partners and organizations to work together to reduce the number of community members who get or die from cancer. The NCCCP was built upon the premise that a coordinated and integrated approach to cancer control is much more impactful than individual efforts. Each Comprehensive Cancer Control program sets up a coalition who identified priorities as well as developed and carried out the state's cancer plan. Programs work with their coalition members to create formal agreements, review membership periodically to ensure the right community members and organizations are invited to participate, and ensure the coalition is a key partner in decision making. As with all NCCCP work, we encouraged the participating sites to identify, build, or enhance their partnerships within their communities and work with their state coalitions when planning, conducting, and evaluating their selected strategies for this demonstration project.

Announcer: Kelly, what do you think is the role of partners when it comes to planning, implementing, and evaluating strategies for your overall NCCCP work?

Kelly: So comprehensive cancer control is the art of connecting survivors, caregivers, providers, and advocates, and also sometimes businesses even to develop evidence-based strategies that help improve public health. When multi-disciplinary groups work together to create value-added education experiences, they are usually much better than they would've been had a small group of people with just one type of experience planned, implemented and evaluated them.

Announcer: Now I'd like to discuss some of the strategies you used to ensure your partnerships were successful for this demonstration. Tell us about bringing your partners on board. What was their role for this demonstration project?

Katie: Yes, 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. And then I work with Mary a lot too. I should also note Norma Leah also was a partner. The Norma Leah Ovarian Cancer Initiative. They have been working for a long time on ovarian cancer patient advocacy and they have been pushing to make sure that folks diagnosed with ovarian cancers are seen by a gynecologic oncologist early on. They really helped connect the project to patients for focus groups and look over materials and that sort of thing.

Jenny: We spoke with Norma Leah early on in the process when we were developing the patient education handout and got some feedback from early drafts and we're certainly grateful for that. And have absolutely made a point of mentioning them by name in the reporting that we've done back to CDC and ICF as part of this project. Hopefully they're happy with the relationship that was established, and we can continue to work together in the future. And they would be willing to do more with us and also reach out if they ever need help.

Announcer: It's really great to hear how you engaged and worked with your partners in Iowa. Thank you. Kelly, the Rhode Island Department of Health convened an ovarian cancer survivorship task force for this demonstration project. Can you describe the purpose of the task force, and their role for this project?

Kelly: Sure. So, our cancer coalition has, as I've mentioned, a few very active ovarian cancer survivors including one of its founders. We knew from past experience that this work would be strongest if the coalition of the willing planned it together and specifically a multidisciplinary coalition.

Announcer: Great, and how did you go about recruiting members to serve on the task force? I know you started with your state coalition, the Partnership to Reduce Cancer in Rhode Island.

Kelly: So again, we knew that there were people in our midst who were particularly engaged with the topic of ovarian cancer. One of the founders of the Partnership to Reduce Cancer who was still actively engaged in the organization is a long-time ovarian cancer survivor and

her husband was also very involved with the partnership to reduce cancer as a caregiver. And then there were a number of other people who identify as and are ovarian cancer survivors. And then there were some healthcare providers who the Cancer Coalition was working really closely with and so was the state with the Cancer Coalition who all kind of came together at first by design and then more organically and ended up planning these events and staging these events.

Announcer: Talk to me about the type of agreements that were established between the task force and the Rhode Island Department of Health? Was there any type of formal written agreement or memorandum of understanding?

Kelly: So initially, it was a group of stakeholders who were given a set of proposed interventions to work with and modify and a budget, but the budget was a project budget. It wasn't payment to each of them. And later we subsidized the work by adding to the contract of the Partnership to Reduce Cancer in Rhode Island which is our cancer coalition. They agreed to help take on an organizing role and some of the logistics in support of the events.

Announcer: George, in the context of the demonstration project, could you maybe describe what you view as the success of this partnership with the Task Force?

George: Sure. Kelly had touched upon it but pulling together the Task Force to work on the project in the first place and the fact that it really has such a survivor-oriented focus which has helped to drive a lot of experientially shaped work that they've taken on. And the fact that it did wind up becoming a part of our statewide cancer coalition, which really has quite the infrastructure built out now as a nonprofit themselves. I think really again the survivor engagement and the provider education has really gone a long way in reshaping the conversation around care, not just for ovarian cancer patients but for a whole array of other issues in comprehensive cancer control and survivorship, and especially within the realm of primary care.

Announcer: For this demonstration, you collaborated primarily with the Ovarian Cancer Task Force to plan and implement and evaluate your strategies but also with the Partnership to Reduce Cancer, Brown University's Office of Continuing Medical Education, as well as several other colleges and universities in Rhode Island. If you could tell us how you came to partner with these organizations and about each of their roles in this project, that would be very helpful to our listeners!

George: Sure. I can start by sharing a bit about what we did with Brown CME. The Rhode Island Department of Health has been contracting with the Brown Office of CME for quite some time. But this was particularly vital this time around in that they were quickly able to kind of pivot away from in person events and help us as a project adapt to kind of a live virtual delivery of webinar and round table events. That involved, again, recording and archiving of the webinar and the round table. So far as their role goes, Brown CME worked to, like I said get accreditation for both events, which sometimes is kind of the carrot at the end of the stick to get people in the room and participating. They developed and facilitated the registration for the events on their website. And they really actually helped us to develop the evaluation for both of the events.

Announcer: Are there any other partnerships you established, or built upon, for this demonstration project?

Kelly: So, I would be remiss if I didn't point out that the University of Rhode Island's College of Nursing was very involved in this project. One of the Partnership to Reduce Cancer's Board Members is a Professor of Nursing there and was able to participate in the planning of these events on behalf of the College of Nursing. And actually, she did a huge amount of work to get the Ovarian Cancer Research Alliance's survivors teaching students program incorporated into nursing curricula in other colleges throughout the state.

Announcer: Your state also partnered with the Ovarian Cancer Research Alliance, or OCRA, to implement Survivors Teaching Students in universities and medical programs in Rhode Island. The sessions began in-person but transitioned to virtual sessions due to the COVID-19 pandemic. Tell us a bit about this workshop.

Kelly: So, it's an evidence-based curriculum. It was something that the nursing professor in our midst thought would be very appealing to at least nursing students. But we were also successful in getting it in front of physician assistant students, advance practice nursing students and social work students. One of our committee members had experience as a presenter through that program in other states. So, their role in the work was to explain to us what their program was and how it worked. And then to actually organize presentations of survivors teaching students working with ovarian cancer survivors in the colleges and universities that wanted to host it. So, I know Rhode Island College, the University of Rhode Island, Johnson and Wales I believe hosted one.

Announcer: Okay, I want to shift our conversation a bit. Tell me what made it easier or perhaps more difficult to develop and sustain your partnerships for this demonstration. Let's start with you, Mary.

Mary: I would say the biggest challenge, the Norma Leah Foundation. And they're so helpful but it is kind of when you first start working with an organization like that, I was sort of new to the area. Obviously, I have a lot of expertise in cancer surveillance and cancer research but my whole life's work has not been around ovarian cancer. And so here's this organization where that is their life's work. They're so passionate; most people have had ovarian cancer, lost somebody to ovarian cancer and they're kind of like hey who are you? How did you get this contract? Why isn't it us? We're the ones who have been doing this. So, she was very sweet and very kind but sometimes, when you meet new partners you just really have to honor what they've done and make sure they feel really valued. But I think mostly to really acknowledge their help and really go into it, like we want to learn from you. We want to be partners and we want this to be a sustained relationship.

Announcer: George, anything to add?

George: I think really all the work that was done and the Partnership to Reduce Cancer's involvement in this project really helped to enhance their engagement in a lot of the different work that we do as a health department but also other partners too around the state.

Announcer: Wonderful. It sounds like both states have really developed a strong relationship through this experience. Thank you to Kelly, George, Katie, Mary, and Jenny, for joining me today and for discussing your experience developing and establishing partnerships 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 at www.cdc.gov/cancer/ovarian.

Thanks again for joining us. 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. Check out the other episodes in this podcast series on the CDC webpage.

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