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Collaborating with the Centers for Disease Control and Prevention's National Comprehensive Cancer Control Program to Increase Receipt of Ovarian Cancer Care from a Gynecologic Oncologist

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Abstract

Background: Treatment by a gynecologic oncologist is an important part of ovarian cancer care; however, implementation strategies are needed to increase care by these specialists. We partnered with National Comprehensive Cancer Control Programs in Iowa, Michigan, and Rhode Island in a demonstration project to deepen the evidence base for promising strategies that would facilitate care for ovarian cancer by gynecologic oncologists.

Methods: Five main implementation strategies (increase knowledge/awareness; improve models of care; improve payment structures; increase insurance coverage; enhance workforce) were identified in the literature and used to develop initiatives. Specific activities were chosen by state programs according to feasibility and needs.

Results: Activities included: (1) qualitative interviews with patients to determine barriers to receipt of specialized care; (2) development of patient/provider educational materials; (3) creation of patient/provider checklists to facilitate appropriate referrals; (4) expansion of a toll-free patient navigation hotline for ovarian cancer patients; (5) training of the health care workforce. The programs developed resources (educational handouts, toolkits, 2 webinars, 2 podcasts); trained 167 medical and nursing students during 8 Survivors Teaching Students[®] workshops; and conducted 3 provider education sessions reaching 362 providers in 45 states. Evaluations showed

Author Disclosure Statement

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increases in providers' knowledge, awareness, abilities, and intentions to refer ovarian cancer patients to a gynecologic oncologist.

Conclusion: The state program resources we discussed are available for other cancer control programs interested in initiating or expanding activities to improve access/referrals to gynecologic oncologists for ovarian cancer care. They serve as a valuable repository for public health professionals seeking to implement similar interventions.

Keywords

ovarian cancer; gynecologic oncologist; National Comprehensive Cancer Control Programs

Introduction

Each year, about 19,000 women are diagnosed with ovarian cancer, and about 14,000 die from the disease.¹ For women with ovarian cancer, receiving treatment from a gynecologic oncologist at a high-volume hospital or cancer center is a strong predictor of whether a woman with ovarian cancer will receive standard care.^{2–5} Access to specialized providers, such as gynecologic oncologists, and the receipt of guideline-based treatment improves probability of long-term survival.^{4,6} Despite recognized advantages of surgical treatment from a gynecologic oncologist, studies have shown that a considerable number of ovarian cancer patients do not receive treatment from a gynecologic oncologist.^{2,7} The goal of this study was to work within community-based programs to increase knowledge and awareness of gynecologic oncologists and their impact on ovarian cancer care.

The Centers for Disease Control and Prevention's (CDC) National Comprehensive Cancer Control Program (NCCCP) is a community-based public health program that aims to decrease the burden of cancer across the United States. Awardees of the NCCCP design and implement strategies to prevent and control cancer specifically in their local population.⁸ NCCCP awardees in Iowa, Michigan, and Rhode Island were selected to implement, disseminate, and evaluate strategies to increase receipt of care by a gynecologic oncologist for women with ovarian cancer.

Iowa, Michigan, and Rhode Island had varying degrees of prior experience in ovarian cancer program implementation. Iowa had participated in CDC's study titled "Patterns of Ovarian Cancer Care and Survival in the Midwest Region of the United States" and had conducted formative research work around gynecologic oncologist access in Iowa^{9–11}; Michigan had experience in ovarian cancer work through their longstanding activities around hereditary breast and ovarian cancer and cancer genomics¹²; and Rhode Island was newer to ovarian cancer work and in the process of pursuing partnerships to address this cancer in their state.

All three states had a strong desire to build capacity and infrastructure and address ovarian cancer in their populations. The overall goal of the demonstration project was to deepen the evidence base for strategies that have promise for increasing gynecologic oncologist treatment for ovarian cancer and provide a repository of methods and materials for other NCCCP awardees, as well as for other public health programs interested in using environmental and health system change strategies to address emerging issues in cancer

control.¹³ We describe each state's specific methodology, implementation activities, and the resulting resources that other community-based programs can use as a roadmap in adopting similar public health initiatives.

Methods

In 2018, CDC conducted a tailored search of published and gray literature to identify facilitators and barriers to receipt of care by a gynecologic oncologist among women with ovarian cancer. The results of the search were used to recommend strategies that have the potential for increasing receipt of ovarian cancer care from a gynecologic oncologist.¹⁴ During April 2019 to December 2020, Iowa, Michigan, and Rhode Island conducted and evaluated activities in line with five strategies: (1) increasing knowledge/awareness of the role and importance of gynecologic oncologists; (2) improving models of care; (3) improving payment structures; (4) improving/increasing insurance coverage for gynecologic oncologist care; and (5) expanding or enhancing the gynecologic oncology workforce. Specific strategies were chosen by each state program according to their population needs and program/partnership feasibility and readiness.

Each state had a different starting point for their implementation, and the rationale for their chosen activities varied. Iowa, for example, chose to expand prior work in ovarian cancer. The Iowa state central cancer registry was one of three states previously funded to examine ovarian cancer treatment patterns of care.^{9–11,15} According to analyses of data collected from the study, almost one in five Iowans diagnosed with ovarian cancer in 2011 and 2012 was not referred to a gynecologic oncologist.^{9,16} Michigan had longstanding partnerships with the Michigan Oncology Quality Consortium (MOQC) and the Michigan Ovarian Cancer Alliance (MIOCA) and worked with these two groups and other key partners to identify needs and feasibility. Rhode Island, being relatively new to ovarian cancer implementation work, focused on building a multisector Ovarian Cancer Survivorship Task Force to help guide the selection and implementation of strategies and activities. The demonstration project was reviewed by the CDC's Human Subjects Review Coordinator and Institutional Review Board approval was not required.

Results

Strategic approaches selected by each state

Table 1 shows the strategic approaches implemented by each state. Iowa engaged patients and providers in qualitative interviews to determine barriers to treatment receipt from gynecologic oncologists and promoted a referral system to gynecologic oncologists. Michigan created provider checklists (and complementing patient checklist) to assist with making appropriate referrals to gynecologic oncologists for suspected ovarian cancer cases, developed an informational podcast for patients and providers, and added to an existing toll-free patient navigation hotline so as to serve ovarian cancer patients. Rhode Island worked with medical schools to implement the Survivors Teaching Students[®] program and convened a roundtable of experts and survivors for a continuing education module for providers. They invited the other sites (Iowa and Michigan) to participate in this effort. All three states used

strategies targeting education/awareness for provider, patient/general public, and partners. Additional state-specific activities are discussed below.

lowa.—Iowa and its partners, including the Iowa Cancer Registry, the Iowa Department of Public Health, and the Iowa Cancer Consortium, conducted formative studies and telephone interviews with 10 health care providers (primary care physicians, OB/GYNs, general surgeons) and 16 ovarian cancer survivors who were not treated by a gynecologic oncologist to understand patient and provider barriers to treatment by and referrals to gynecologic oncologists in Iowa.¹⁰ Iowa and its partners used findings from these interviews to select a strategy to educate women about the importance of seeking care from a gynecologic oncologist. The interviews showed that patients were not aware of the importance of and did not have the confidence to request a referral to a gynecologic oncologist for ovarian cancer care and treatment. None of the survivors who were interviewed received such a referral when they were diagnosed.¹⁰ To meet these identified needs, Iowa developed patient education handouts and conducted cognitive interviews with survivors to refine the handouts (Fig. 1).

Iowa also coordinated with partners to develop and disseminate provider- and public health professional-focused handouts titled Patients with Ovarian Cancer: Improving Health Outcomes [PDF-310KB] (https://canceriowa.org/wp-content/uploads/2021/02/Ovarian-Cancer-Handout-for-Providers.pdf) (Fig. 1) containing information on referral centers. They also developed and disseminated a report, *2020 Cancer in Iowa*, to increase knowledge and awareness among patients and the general public of ovarian cancer, including staging, screening, prevention, ongoing research, and treatment for ovarian cancer and the importance of receiving care from a gynecologic oncologist (2020 Cancer in Iowa Report [PDF-1.1MB] (https://shri.public-health.uiowa.edu/wp-content/uploads/2020/03/2020-SHRI-Annual-Report.pdf) (Fig. 1).

For provider education, Iowa worked with Brown University Office of Continuing Medical Education (Brown CME) to produce and host a webinar and provide CME credit for participants; there was no cost to its participants. They incorporated findings from formative study focus groups and interviews with patients and health care providers, published by Weeks et al¹⁰ to create the webinar content. The webinar is archived on the Brown CME site: [Ovarian Cancer in Iowa (https://cme-learning.brown.edu/IowaOC)]. Additionally, Iowa conducted formative research and organized a systems-level approach to explore options and promote processes for referring patients to a gynecologic oncologist for ovarian cancer treatment within the University of Iowa Hospitals and Clinics (UIHC) system. During formative evaluations, Iowa identified lengthy phone wait times as a barrier to referral for some providers. However, multiple UIHC providers perceived making referrals by phone to be more efficient than the online system. Iowa plans to continue to explore how best to make a referral to a gynecologic oncologist and to assess satisfaction with the UIHC referral number.

Michigan.—Michigan created a Provider Checklist [PDF-524KB] (https://moqc.org/wpcontent/uploads/Final-Physician-MOQC-OvarianCancerChecklist.pdf) (Fig. 2) to increase providers' knowledge and awareness related to ovarian cancer risk and the importance

of referrals to a gynecologic oncologist, when necessary, for ovarian cancer treatment. The team worked closely with the MOQC and the MIOCA to plan, implement, and evaluate strategies in the planning process. Specifically, Michigan convened a team of 16 providers from gynecologic oncology practices to develop content for and provide feedback on iterative versions of the checklist. They marketed the checklist to providers attending MOQC Quality Initiative meetings and the Michigan Surgical Quality Collaborative meeting and solicited feedback and conducted social media campaigns through Facebook and Google text-based advertisements to promote resources and tools developed from this demonstration project. The advertisements directed readers to the Michigan Department of Health and Human Services ovarian cancer webpage, where materials were available for download.⁵

Michigan also developed a complementary patient checklist for newly diagnosed ovarian cancer patients, using a similar feedback process: Ovarian Cancer Patient Checklist [PDF-710KB] (www.moqc.org/wp-content/uploads/Final-Patient-OvarianCancerChecklist.pdf) (Fig. 2). During May to August 2020, 20 ovarian cancer survivors participated in a series of focus groups to discuss their pathways to diagnosis, encounters with providers/health care system, navigating treatment, and key points for someone who might suspect they have ovarian cancer. Themes from the focus groups are highlighted in A Roadmap for Ovarian Cancer: Know the Signs and Symptoms, Work with a Gynecologic Oncologist [PDF-193KB] (www.michigan.gov/documents/mdhhs/ ARoadMapforOvarianCancer_707815_7.pdf) (Fig. 2). The patient checklist and the roadmap are intended to be helpful throughout the cancer journey and a resource for discussions with the health care provider.

Michigan also developed two podcasts that showcased a dialog between patients and providers; while survivors detailed their experiences from diagnosis through treatment, gynecologic oncologists provided additional clinical information about the cancer. The first podcast is called *New Diagnosis* and focuses on ovarian cancer symptoms, diagnosis, when to seek a referral to a gynecologic oncologist, and advice to ovarian cancer patients and their loved ones. The second podcast, called *Treatment Options*, focuses on treatment options for ovarian cancer, including surgery and chemotherapy. Podcasts are available online at Patient Podcasts (https://moqc.org/initiatives/gynecologic-oncology/ovarian-cancer-resources).

Michigan's approach to addressing models of care was to focus on improving an existing patient navigation infrastructure. They developed a patient navigation manual with resources specific to ovarian cancer to connect patients diagnosed with or those suspected to have ovarian cancer to a gynecologic oncologist. As part of this process, Michigan conducted a scan of community resources, developed the patient navigation manual, and promoted the toll-free hotline through partners' listservs, newsletters, and social media campaigns. They relied heavily on their existing partnerships with MOQC and MIOCA. Launching the navigation phone line proved challenging, but the toll-free line and patient navigation process are intended to remain live for as long as they have the funding to operate the hotline and will continue to be evaluated.

Rhode Island.—Rhode Island's efforts largely centered around education and partnerships. Rhode Island developed an Ovarian Cancer Survivorship Task Force composed

of survivors, caregivers, advocates, and health care professionals to help Rhode Island plan and implement activities. Subsequently, Rhode Island and its partners convened a multidisciplinary panel of health care provider experts to review current practices and share information on the benefits of referrals to a gynecologic oncologist.

The CME event, Making a Difference: Expediting Diagnosis of Ovarian Cancer: A Virtual Roundtable Discussion (https://cme-learning.brown.edu/DifferenceOnDemand), used a case study approach for panelists to examine and discuss practices that could facilitate earlier diagnoses of ovarian cancer, motivate more rapid referrals for appropriate care, and describe how timely differential diagnosis can improve overall patient outcomes.⁵ Additionally, Rhode Island developed several materials to aid providers and patients with resources; they are in Rhode Island's Ovarian Cancer Resources Toolkit [PDF-243KB] (https://health.ri.gov/publications/toolkits/2020RI-Ovarian-Cancer-Resources.pdf) (Fig. 3). These materials covered a range of topics, including identifying signs and symptoms of ovarian cancer, evidence-based guidelines for effective symptom workup and indication for referral to a gynecologic oncologist, and national protocols for genetic counseling and testing eligibility.

Rhode Island also worked with students from in-state colleges and universities studying to become health care professionals who were likely to interact with women in a health care setting (physicians, physicians' assistants, nurses) to implement the Survivors Teaching Students workshops. Survivors Teaching Students is a trademarked, proprietary curriculum developed by the Ovarian Cancer Research Alliance independent of this demonstration project or any CDC affiliation. Throughout the implementation period, Rhode Island conducted eight 60-minute workshops at five colleges and universities as part of their Survivors Teaching Students work. Each workshop delivered the following five key messages: (1) ovarian cancer has the highest death rate of all gynecologic cancers; (2) diagnosis for most women occurs at late stages after the disease has metastasized; (3) there is no reliable and regularly recommended screening test for ovarian cancer; (4) survival rates improve dramatically for women diagnosed in early stages; (5) ambiguous symptoms and common referrals to gastrointestinal specialists and other health care professionals who are not gynecologic oncologists can delay diagnosis and may lead to worse prognoses for patients.

Overall, 167 students participated in the workshops. Of the proportion of respondents (n = 135), there was about a 30% point increase in knowledge of risk factors and signs/ symptoms and about a 60% point increase in knowledge of diagnostic protocols following the workshops. Rhode Island and the Ovarian Cancer Survivorship Task Force expect to continue working with the Ovarian Cancer Research Alliance to offer Survivors Teaching Students workshops in colleges and universities throughout the state and sustain this collaboration in years to come.

All work performed by Iowa, Michigan, and Rhode Island was combined and described in depth in CDC's Action Plan [PDF] (https://www.cdc.gov/ cancer/ovarian/gynecologic-oncologist/pdf/ovarian-cancer-action-plan-v2-508.pdf) and Toolkit [PDF] (https://www.cdc.gov/cancer/ovarian/gynecologic-oncologist/pdf/ovarian-

cancer-toolkit-508.pdf) (Fig. 4). A specific webpage was created to house these materials on the CDC webpage titled Increasing Receipt of Ovarian Cancer Care from a Gynecologic Oncologist (https://www.cdc.gov/cancer/ovarian/gynecologic-oncologist). Further summary information of implementation activities and successes of Iowa, Michigan, and Rhode Island, including links to a five-part podcast series developed from this demonstration project is available on the webpage. The podcast series contains short discussions with Iowa and Rhode Island about why they participated in this demonstration project and the collaborations, partnerships, notable successes, and sustainability of this work moving forward.

Discussion

Through this demonstration project, NCCCP awardees in Iowa, Michigan, and Rhode Island created a suite of materials. The website where they appear (https://www.cdc.gov/cancer/ovarian/gynecologic-oncologist) is a valuable repository for other community-based or public health programs interested in implementing strategies to increase receipt of care by a gynecologic oncologist among women with ovarian cancer. Programs wishing to adapt this work can consider the following six steps when adapting these interventions^{17–19}:

- 1. Conduct an assessment to understand the local or state-specific ovarian cancer concerns, proportion of women receiving treatment from a gynecologic oncologist in the area, barriers to treatment, and what is needed to address the issues.
- 2. When selecting strategic approaches, consider: (a) engaging key partners, subject matter experts, and members of the target audience to help identify strategies and address barriers; (b) using multipronged, comprehensive, and complementary approaches; (c) working with partners to assess feasibility of the strategies.
- **3.** Develop and share a workplan with partners.
- 4. Implement, monitor, and document the process.
- 5. Develop and implement an evaluation plan that includes both short- and long-term outcomes.
- 6. Use evaluation findings to improve delivery, maintain partner engagement, mitigate challenges, develop plans for sustainability, and identify next steps.

Ovarian cancer remains a significant public health challenge due to the tens of thousands of women who die from it each year in the United States.¹ Ovarian cancer survival is significantly lower than breast cancer and has not increased appreciably in recent years.²⁰ In the absence of available screening protocols for the general population, improvements in ovarian cancer survival may result from greater adherence to standard treatment protocols and recommendations. In 2016 the National Academies of Sciences, Engineering, and Medicine (formerly the Institute of Medicine) identified receipt of care from a gynecologic oncologist as "a key message" ready for dissemination and recommended evaluating pathways of dissemination and implementation of this recommendation.²¹ This article

presents several methods for dissemination and evaluation of this message in communities of patients and providers.

This work has some limitations. All work was performed within the NCCCP grantee infrastructure, which is managed through state health departments. The methods and materials presented in this study may not be useful for clinical or academic institutions doing similar work in their patient or study populations. Also, this work represents the ovarian cancer patient and provider landscape of Iowa, Michigan, and Rhode Island; other NCCCP grantees may have different ovarian cancer patient needs or drivers of low ovarian cancer survival in their areas. Finally, disparities in survival are known to exist among women with ovarian cancer by race, with Black women having lower survival than White women.²⁰ Therefore, community-based work in ovarian cancer may not be "one size fits all," and specific materials for individual racial populations may be needed to achieve equitable increases in survival among all populations.

Given these limitations, it is important that the specific ovarian cancer patient and provider populations be thoroughly assessed before adapting the resources developed as part of this demonstration project. This may help maximize the effectiveness and efficacy of interventions to increase ovarian cancer survival through gynecologic oncologist treatment.

In summary, this demonstration project yielded several resources for comprehensive cancer control planners and other public health programs to help women with ovarian cancer in their population. These methods, materials, and lessons learned may provide valuable information for those interested in implementing changes that increase receipt of ovarian cancer treatment by gynecologic oncologists. These resources can be adapted by other NCCCP awardees who are interested in conducting community-based activities to increase access and referrals to gynecologic oncologists for ovarian cancer treatment.

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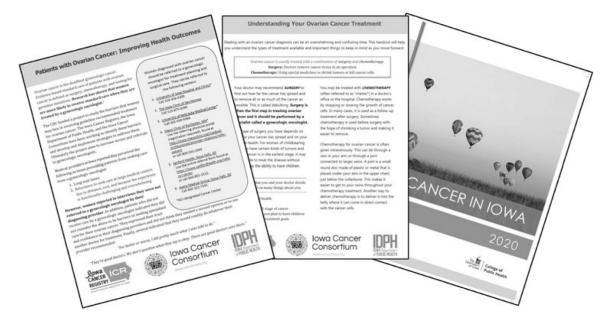
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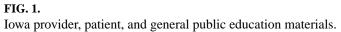
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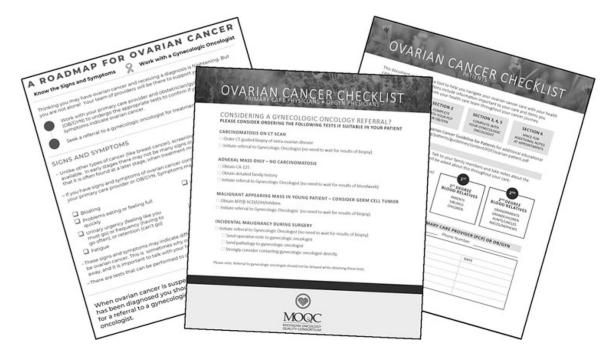
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Michigan provider, patient, and general public education materials.

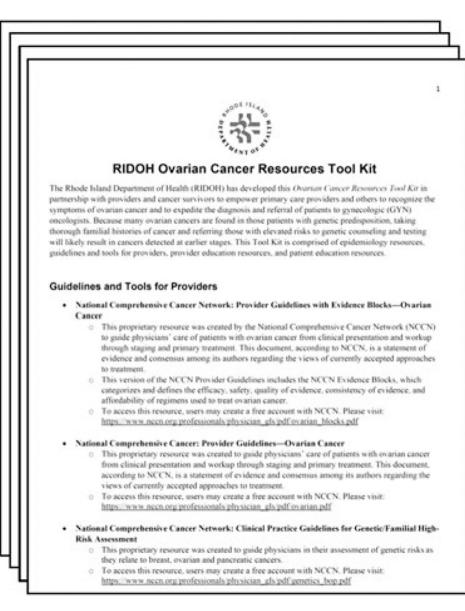


FIG. 3. Rhode Island provider and general public education materials.





CDC's action plan and toolkit to increase receipt of ovarian cancer care from a gynecologic oncologist.

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Table 1.

Strategic Approaches Implemented by Demonstration Sites

	Iowa	Michigan	Rhode Island
Strategy 1: Increasing knowledge and awareness	of the role and	l importance of gyr	necologic oncologists
Provider education	Yes	Yes	Yes
Patient education	Yes	Yes	No
General public education	Yes	Yes	Yes
Partnership development and enrichment	No	No	Yes
Strategy 2: Improving models of care			
Referral systems	Yes	No	No
Patient navigation	No	Yes	No
Strategy 5: Expanding or enhancing the gynecolo	ogic oncologist	workforce	
Use of survivors to teach students	No	No	Yes