

# Ovarian Cancer Survivors Help Promote Ovarian Cancer Treatment by Gynecologic Oncologists in Iowa



**A**mong cancers of the female reproductive system, ovarian cancer is the deadliest. The most recent data available show Iowa was among the 20 states with the highest ovarian cancer age-adjusted death rate (6.4 per 100,000 women), despite having an average age-adjusted incidence rate (8.4 per 100,000 women).<sup>1</sup>

There are only six practicing board-certified gynecologic oncologists in Iowa—five in Iowa City and one in Des Moines.<sup>2</sup> Based on an analysis of data collected for CDC’s Patterns of Ovarian Cancer Care and Survival in the Midwest Region of the United States investigation, almost one in five Iowans diagnosed with ovarian cancer in 2011 and 2012 was not referred to a gynecologic oncologist.<sup>3</sup>

## **Ovarian Cancer Demonstration Project**

To increase survival from ovarian cancer,

CDC funded a demonstration project to build evidence for strategies to increase knowledge and awareness of gynecologic oncologists’ role in ovarian cancer treatment and to increase receipt of ovarian cancer care by a gynecologic oncologist. The Iowa Comprehensive Cancer Control Program at the Iowa Department of Public Health was one of three National Comprehensive Cancer Control Program awardees selected for this project. Programs in Rhode Island and Michigan were also selected.

Input from ovarian cancer survivors and health care providers was important in selecting and designing the strategies to achieve the project’s goals. The Iowa Cancer Registry, the Iowa Department of Public Health, and the Iowa Cancer Consortium first conducted formative studies to assess patient and provider barriers and attitudes in receiving surgical care from a gynecologic oncologist.<sup>4</sup>



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Findings were used to select a strategy to educate women about the importance of seeking care from a gynecologic oncologist even if one is not recommended to them. To meet the identified needs, a patient education handout was developed. Cognitive interviews with ovarian cancer survivors were conducted to assess the handout's overall appeal, clarity, and success in communicating steps to get guideline-recommended treatment.



## Recruiting Ovarian Cancer Survivors

For the **formative studies**, ovarian cancer survivors were recruited through the Iowa Cancer Registry. The registry served as an excellent sampling frame because it was possible to identify women using registry data who did not appear to receive their ovarian cancer surgery at a hospital with a gynecologic oncologist. Forty eligible ovarian cancer survivors were mailed a letter containing information about the study and about an upcoming recruitment call.

The women were called by telephone four to eight days after receiving the letter and asked to participate in the study; 16 agreed to participate in an interview.

For the **cognitive interviews**, ovarian cancer survivors were recruited by partnering with a local support and advocacy organization called the NormaLeah Ovarian Cancer Initiative. Survivors were reached through this partner by using a listserv for a monthly support group NormaLeah offers. This was a successful approach, since members of the support group are used to speaking about their experience living with cancer and therefore more willing to participate in interviews. During the COVID-19 pandemic, three listserv messages were needed to secure interviews with six ovarian cancer patients.

The final patient handout educates women diagnosed with, or suspected of having, ovarian cancer on the basics of treatment, on communicating with providers, and on the importance of asking to be referred to a gynecologic oncologist. Health care providers can also access the handout online to print and send home with patients following a diagnosis of ovarian cancer.

## Benefits of Engaging Cancer Survivors When Developing Patient Education Material

During the formative studies and interviews, ovarian cancer survivors provided several insights that informed the need for, and focus of, our patient education handout.

- Patients broadly denied facing any of the barriers to obtaining surgical care by a gynecologic oncologist (fear, expense, travel burden, and time) that health care providers perceived.

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- Ovarian cancer patients trust their providers to give them the best care possible and generally did not seek out gynecologic oncologists or second opinions because they were not aware of the benefits of receiving ovarian cancer care from a gynecologic oncologist.

Plain language was used in the handout so that women with a wide range of reading skills could understand it. Medical terms were used only when necessary.

During the cognitive testing interviews, the survivors complimented the handout and provided constructive feedback to help us refine it.

- *Positive feedback:* clear and straightforward, not alarming.
- *Areas for improvement:* explain a few medical terms or jargon that survivors are likely to hear their providers say, such as debulking, and use color and boldface font to draw attention to important information.

## Considerations for Programs Seeking to Engage Cancer Survivors

Programs wanting to address the needs of ovarian cancer survivors in their state or region should, to the extent possible, engage survivors at all stages of the process. Survivors can provide unique viewpoints about their experiences and needs, and many are eager to make the experience better for other women facing this disease. Programs

can use the following information to identify gaps in care that need to be addressed and to guide the design and implementation of interventions to help this population:

- Reach survivors through trusted partners (such as local groups and community stakeholders) that have existing ways to connect with cancer survivors (such as social media, listservs, and support groups).
- Plan for multiple rounds of recruitment to reach the desired number of participants.
- Accommodate survivors' schedules by offering times to engage during evening hours and on weekends.
- Ask questions in a way that does not make survivors feel they did something wrong. For example:

*Instead of asking, "Why didn't you seek care from a gynecologic oncologist?"*

*Ask, "Thinking back to when you first found out you had ovarian cancer, could you describe how you decided where to go for surgery for your cancer care?"*

Ovarian cancer survivors are often willing to share their experiences and feedback on materials being developed for other patients. During the interviews, many survivors expressed appreciation for being included in the project. They emphasized the value of the work being done and the important role the handout could play in the life of a woman newly diagnosed with ovarian cancer.

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## More from Iowa's Ovarian Cancer Demonstration Project



### **Understanding Your Ovarian Cancer Treatment**

[PDF-313KB] (<https://canceriowa.org/wp-content/uploads/2021/01/Handouts-for-patients-newly-diagnosed-with-ovarian-cancer.pdf>)



### **Patients with Ovarian Cancer: Improving Health Outcomes**

[PDF-310KB] (<https://canceriowa.org/wp-content/uploads/2021/02/Ovarian-Cancer-Handout-for-Providers.pdf>)



### **Ovarian Cancer in Iowa**

(<https://cme-learning.brown.edu/iowaOC>)



### **Patient and Provider Perspectives on Barriers to Accessing Gynecologic Oncologists for Ovarian Cancer Surgical Care**

([www.liebertpub.com/doi/full/10.1089/whr.2020.0090](http://www.liebertpub.com/doi/full/10.1089/whr.2020.0090))

**Disclaimer:** *The findings and conclusions in this brief are those of the author(s) and do not necessarily represent the official position of the Centers for Disease Control and Prevention.*

<sup>1</sup>US Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute, US Cancer Statistics Working Group. US Cancer Statistics Data Visualizations Tool, based on 2020 submission data (1999–2018). [www.cdc.gov/cancer/dataviz](http://www.cdc.gov/cancer/dataviz), released in June 2021.

<sup>2</sup>Iowa Health Professions Inventory, Iowa Health Professions Tracking Center, Office of Statewide Clinical Education, University of Iowa Carver College of Medicine. <https://medicine.uiowa.edu/oscep/iowa-health-professions-tracking-center>.

<sup>3</sup>Weeks K, Lynch CF, West M, et al. Rural disparities in surgical care from gynecologic oncologists among Midwestern ovarian cancer patients. *Gynecologic Oncology*. 2021 Feb;160 (2):477–484.

<sup>4</sup>Weeks K, West M, Lynch CF, et al. Patient and provider perspectives on barriers to accessing gynecologic oncologists for ovarian cancer surgical care. *Women's Health Reports*. 2020 Dec; 1 (1): 574-583.