

## BREAST CANCER

# Advancing Breast Cancer Advocacy in Eastern Europe and Central Asia: Findings From Women's Empowerment Cancer Advocacy Network (WE CAN) Summits

Nicoleta Antone, MD<sup>1</sup>; Darya Kizub, MD<sup>2</sup>; Julie Gralow, MD<sup>3,4</sup>; Jo Anne Zujewski, MD<sup>5</sup>; and Allison Dvaladze, MD<sup>3,4</sup>

**PURPOSE** Breast cancer civil society organizations have emerged in Eastern Europe and Central Asia to raise awareness about cancer as a survivable disease and provide patient support. We explored the experiences and priorities of these organizations with the goal of making recommendations to advance cancer advocacy and improve cancer care.

**METHODS** We conducted in-depth interviews and focus group discussions with representatives of civil society organizations attending the 7th Women's Empowerment Cancer Advocacy Network Summit in Romania in 2015. Interviews were audiorecorded, transcribed, coded, and analyzed for key themes. Findings were discussed at the 8th Women's Empowerment Cancer Advocacy Network Summit in Ukraine in 2017 to ensure accuracy.

**RESULTS** We conducted nine in-depth interviews and three focus group discussions with a total of 36 participants. Survivor- and oncologist-led organizations played an important role in filling existing gaps in public health care systems through awareness raising, patient support, and advocacy to improve early detection and access to treatment. Barriers to these efforts included persistent stigma, mistrust of patients toward the public health care system, limited access to evidence-based guidelines, difficulty adapting existing best practices to their setting, and insufficient involvement of policymakers. Key facilitators of advocacy efforts included effective local and international partnerships with physicians, like-minded organizations, and policymakers to facilitate access to educational resources, improve breast cancer early detection and care, and catalyze meaningful policy change.

**CONCLUSION** Our findings highlight the value of providing opportunities for advocates to connect and share experiences. To advance cancer advocacy and improve cancer care, the following needs were identified: dissemination of resource-adapted information for improving outcomes; needs assessments; improved program-monitoring practices; and fostering and promotion of collaboration between advocates, medical professionals, and local governments.

JCO Global Oncol 7:585-592. © 2021 by American Society of Clinical Oncology

Creative Commons Attribution Non-Commercial No Derivatives 4.0 License 

## BACKGROUND

Breast cancer is the most common cancer in the world, with 2,088,849 new cases and 626,679 deaths annually.<sup>1</sup> Barriers to improving early detection and quality of life have been understudied in Eastern Europe and Central Asia (EECA).<sup>2</sup>

EECA countries vary in income,<sup>3</sup> health care expenditure per capita,<sup>4</sup> and breast cancer incidence and mortality<sup>1</sup> (Fig 1) and have political and health care systems that diverged following the dissolution of the Soviet Union. However, they share a recent common history and have a young, vibrant civil society, including patient and cancer advocacy organizations.

Incidence-to-mortality ratios in EECA do not always track with country income or health care expenditure per capita (Fig 1). Needs assessments to inform evidence-based strategies for improving general cancer care are scarce<sup>5,6</sup> and do not exist for breast cancer. Higher breast cancer mortality in EECA countries is attributed to late-stage diagnosis as a result of patient-related and health care system-related factors<sup>7-12</sup> and insufficient access to treatment.<sup>13</sup> Quality of life for patients can be improved through greater access to psychosocial support<sup>13</sup> and palliative care.<sup>5,14</sup>

Advocacy by patients, survivors, and civil society organizations (CSOs) has been recognized by the

Author affiliations and support information (if applicable) appear at the end of this article.

Accepted on March 9, 2021 and published at [ascopubs.org/journal/go](https://ascopubs.org/journal/go) on April 23, 2021; DOI <https://doi.org/10.1200/GO.20.00532>

## CONTEXT

### Key Objective

To our knowledge, this is the first article to present the key facilitators and barriers to breast cancer advocacy in Eastern Europe and Central Asia from the point of view of patient advocates.

### Knowledge Generated

Barriers to these efforts included persistent stigma, mistrust of patients toward the public health care system, limited access to evidence-based guidelines, difficulty adapting existing best practices to their setting, and insufficient involvement of policymakers. Key facilitators of advocacy efforts included effective local and international partnerships with physicians, like-minded organizations, and policymakers to facilitate access to educational resources, improve breast cancer early detection and care, and catalyze meaningful policy change.

### Relevance

To increase the ability of advocates to improve breast cancer care and outcomes, the following needs were identified: dissemination of resource-adapted information for improving outcomes; needs assessments; improved program-monitoring practices; and increased collaboration between advocates, medical professionals, and local governments.

international cancer community as vital to improving breast cancer care and outcomes.<sup>15,16</sup> Countries can provide a foundation for advocacy efforts by monitoring trends in breast cancer stage at diagnosis and factors resulting in delays in care and collaborate with advocates to collect and disseminate information about the effectiveness of breast cancer early detection and treatment programs and policies.<sup>15,16</sup> A conceptual framework for engagement of patient advocates that includes a focus on the patient voice; capacity-building; and technical assistance to patients, survivors, caregivers, and CSOs followed by fostering collaboration between key stakeholders to implement a Call to Action on Cancer and continued monitoring of efforts has been implemented in South Africa and Japan and has broad applicability.<sup>16</sup>

Cancer advocacy in EECA countries is young, with CSOs first emerging in the late 1980s. Political and economic instability, as well as corruption, in the region resulted in less resources available for health care and scientific research, whereas distrust toward the international community left over from the Soviet Union and language barriers initially limited collaborations in cancer-related research and medical care. Survivor- and oncologist-led cancer CSOs were established to fill gaps in public health care systems and worked to lift stigma of cancer as a death sentence, improve early detection, and increase access to cancer treatment and psychosocial support.<sup>17-19</sup> A deeper understanding of experiences and priorities of breast cancer CSOs in the region has the potential to help

Country	Income Level	Health Care Expenditure per Capita in USD	Incidence	Crude Incidence per 100,000	5-Year Prevalence	Mortality	Incidence/Mortality <sup>a</sup>
Lithuania	High	1,078.18	1,742	112.3	6,733	575	3
Poland	High	906.82	20,203	102.5	78,361	6,921	2.9
Russia	High middle	585.87	71,426	92.5	259,981	23,181	3.1
Romania	High middle	555.1	9,629	95.4	35,298	3,378	2.9
Armenia <sup>b</sup>	High middle	407.64	1,054	67.8	3,261	557	1.9
Belarus	High middle	342.5	4,496	89	14,807	1,261	3.6
Georgia <sup>b</sup>	High middle	293.05	1,141	55.9	3,632	597	1.9
Kazakhstan	High middle	279.65	4,211	44.4	13,765	1,727	2.4
Moldova	Low middle	191.19	1,646	78.2	4,780	723	2.3
Ukraine	Low middle	177.41	18,958	80.1	58,281	8,294	2.3
Uzbekistan	Low middle	98.82	3,508	21.6	9,927	1,830	1.9
Kyrgyzstan	Low middle	78.82	697	22.5	1,852	296	2.4
Tajikistan	Low	57.9	530	11.7	1,317	216	2.5

**FIG 1.** Characteristics of EECA countries with respect to income; health care expenditure; and breast cancer incidence, prevalence, and mortality, sorted by high to low health care expenditure per capita.<sup>1,3,4</sup> <sup>a</sup>Higher mortality or incidence is more favorable; for reference, ratios for countries in Western Europe and North America are approximately 4-5.5; higher ratios are in green, medium in blue, and lower in orange. <sup>b</sup>Countries were low middle-income at the time when study data were collected. USD, US dollars

patient advocates and oncologists to improve cancer care.<sup>20–24</sup>

The Women's Empowerment Cancer Advocacy Network (WE CAN), based at the University of Washington School of Medicine, provides evidence-based education and advocacy mentoring and fosters connections between patient advocates, clinicians, and policymakers to improve awareness and access to cancer care, reduce stigma, and promote changes in policy and social norms.<sup>25</sup> Since 2003, WE CAN has hosted biennial summits in EECA, contributing to increased cancer knowledge and engagement of survivors in cancer policy, as well as new initiatives and collaborations.

We identified themes in breast cancer advocacy from the perspective of participants of EECA WE CAN summits with the goal of developing recommendations for advancing cancer advocacy and improving cancer care.

## METHODS

We conducted semi-structured in-depth interviews and focus group discussions (FGDs) with participants of the 7th WE CAN EECA Summit held in Bucharest, Romania, in October 2015. All attendees were invited to and agreed to participate in FGDs. In-depth interview participants were purposefully selected to a maximum variety of viewpoints. Basic demographic data and information about their organizations' activities were collected.

Interview guides were open-ended and explored organizational activities, collaboration with local and international

organizations, and barriers to and facilitators of advocacy efforts. Interviews and FGDs were audiorecorded, transcribed, and translated into English. A codebook was developed on the basis of emergent themes.<sup>26,27</sup> D.K. and N.A. coded the transcripts; discrepancies were resolved through discussion. Results were presented to participants of the 2017 WE CAN Summit in Kiev, Ukraine, to ensure accuracy.

Study procedures were approved by the Institutional Review Board of the University of Washington School of Medicine. All study participants provided written informed consent. Travel and accommodations were covered by WE CAN for all participants.

## RESULTS

### Study Participants and Characteristics of Participating Organizations

All 36 representatives of cancer CSOs agreed to participate in FGDs; participant characteristics are described in [Table 1](#). Nine in-depth interviews were conducted, including with breast cancer survivors, CSO representatives, and oncologists from Armenia, Belarus, Kyrgyzstan, Lithuania, Moldova, Russia, and Ukraine.

Participants represented CSOs with experience in patient support and education, cancer early detection, and policy engagement ([Table 2](#)). Survivor-led CSOs emerged to respond to the psychosocial needs of women diagnosed with cancer and partnered with local oncologists to reach patients.

Sixteen years ago, people were afraid to speak about this problem. We started to talk about breast cancer, since we faced it. Now there are seventeen volunteer organizations in Ukraine that visit oncological centers weekly and provide information and psychological support to women after diagnosis or during treatment.—Ukraine

For us, Muslims, this is a very closed topic. Women are afraid their men will leave them. I am trying to tell women, they have to live for themselves, for their families. I am trying to help them to find wigs and silicone implants to ease their condition. I eliminated the idea that cancer is horrible. With my own example I lead them forward.—Kyrgyzstan

Oncologist-led organizations focused on improving early detection and access to treatment, including by providing legal support to patients and lobbying local governments and partnered with survivors to raise community awareness and lift cancer stigma. Collaborations with local governments and international cancer organizations resulted in access to funding, technical expertise related to early detection and treatment, and advocacy training. Survivor-led organizations tended to be volunteer-based, channeling limited resources to patient support.

### Themes in Breast Cancer Advocacy

Key themes included stigma, trust and relationships, and knowledge and institutional capacity. The main priorities

**TABLE 1.** FGD Participant Characteristics

Participant Characteristic (N = 36)	No. (%)
FGD language	
Romanian	15 (42)
Russian	12 (33)
English	9 (25)
Nationality	
Romanian	15 (42)
Other <sup>a</sup>	21 (58)
Role (> 1 could be selected)	
NGO representative	21(58)
Cancer survivor	19 (53)
Clinician	10 (28)
Government representative	3 (8)
Education	
College, university, or graduate school	26 (72)
Some college	8 (22)
High school	2 (6)

Abbreviations: FGD, focus group discussion; NGO, non-governmental organisation.

<sup>a</sup>Armenia, Belarus, Bosnia, Georgia, Kazakhstan, Kyrgyzstan, Moldova, Russia, Tajikistan, Ukraine, and Uzbekistan.

**TABLE 2.** Cancer CSOs in EECA and Their Advocacy Activities

Region	Country	Organization	Mission and Activities
Eastern Europe	Belarus	Cancer patient organization Vo lmya Zhizhni	Advocacy and advocacy training and training and education of patient leaders and advocates to provide information and psychosocial support
	Estonia	Union of Oncology Patients	Information, education, and patient support
	Georgia	CSO HERA	Raising awareness, breast cancer screening, and fundraising
	Lithuania	CSO Nedelsk	Raising awareness about breast cancer; lifting stigma; and breast cancer prevention, screening, and early detection, including in rural areas
	Moldova	Centre for Health Strategies and Policy	Providing support and improving access to quality health care services, implementation of health system reform, advocacy, and capacity-building, including related to breast and cervical cancer
	Poland	Fundacja OmeaLife	Support groups for patients with breast cancer, educate patients and their families, cooperate with doctors and politicians, improve the quality of treatment in Poland, and promote preventive activities
	Romania	Homecare Association	(1) Public education and awareness related to breast and cervical cancer prevention and early diagnosis, (2) support group and navigation for women with breast and gynecologic cancer, and (3) home care services
	Russia	Patient Association Zdravstvuy	Patient education; patient aid; raising public awareness about cancer, policy, and advocacy related to access to treatment; and resolving drug shortages and issues related to disability benefits
	Ukraine	CSO Amazonki and Together Against Cancer	Education, information, and psychosocial support for patients with breast cancer, including in the postoperative period and with obtaining access to prostheses after mastectomy, raising awareness in the general population, advocacy related to breast cancer prevention and early detection, and improving patient-physician communication
Central Asia	Kazakhstan	CSO Healthy Asia	Patient education and psychosocial support and breast cancer prevention, screening, and early detection, including in rural areas
	Kyrgyzstan	CSO Ergene	Patient education and psychosocial support, raising population awareness, promotion of screening and early detection, lobbying policymakers, and fundraising
	Turkmenistan	CSO Avesto	Psychosocial support for patients with breast cancer
	Uzbekistan	National Breast Cancer Association of Uzbekistan	Patient education and support, raising population awareness, fundraising, and breast cancer screening and early detection

Abbreviations: CSO, civil society organization; EECA, Eastern Europe and Central Asia.

included expanding early detection and improving access to treatment and patient support.

### Stigma as a Barrier to Advocacy Efforts, Early Detection, and Patient Care

Although voices of survivors were essential to increasing awareness about breast cancer, stigma interfered with the ability of some patients to share their stories.

Cancer is almost always a taboo. Even cancer survivors are not prone to saying that they had this disease.—Armenia  
We found a woman, a university professor, and she was able to speak about [her diagnosis] openly. But after some time, her family told her, why are you doing this? Why are you continuing to talk about this? Stop. So, she closed up and we have lost contact with her.—Kyrgyzstan  
Stigma surrounding cancer persisted, interfering with early detection, timely treatment, and patient support. We would like to raise awareness among women so that they can overcome the vacuum of information. Women do not trust us as much as they would trust patients, survivors. But in the regions, these patients are hidden, because of stigma.—Belarus

### Trust-Based Relationships and Collaborations as the Cornerstone of Effective Advocacy

Although it took years to establish mutual trust and respect, effective partnerships with local oncologists were essential to supporting patients' needs and improving outcomes.

The chief oncologist helped us with information and by accepting our volunteers when in many clinics they would not let us visit. It took several years to show the doctors that we are not against them, that we are professional, that we work with volunteers to engage people, not to protest.—Ukraine

The mistrust toward the public health care system as a result of lack of transparency in patient-physician communication and corruption related to treatment availability was a key obstacle to early detection and treatment.

We have 3,000 women who have breast cancer with good one-year survival, because we used to have free chemotherapy, even Herceptin. Now [the government] is out of money. You can get treatment in the capitol if you have connections.—Belarus

There is absolute mistrust among the general population in the quality of care provided by the health system.—Moldova

Participants desired greater transparency in communication and collaboration with ministries of health and sought more involvement from policymakers.

As we implement population-wide CBE screening, we see the problems in communication from primary care providers, we see resistance from financing mechanisms, we see lack of understanding from politicians who are focused on quick dividends.—Moldova

Our target is the Ministry of Health, which decides what resources are allocated to our patients. If there was more productive and open dialogue with the Ministry of Health where we receive feedback and if we suggest something, we are able to understand why our suggestion was not accepted.—Russia

### Knowledge and Institutional Capacity as Facilitators of Impact

Collaboration with local ministries of health, familiarity with evidence-based strategies for improving cancer early detection and care, and needs assessments and program evaluations were crucial to successful programming.

In 2005, we started a population-wide mammography screening. We reached many people. We can see that 30% are tested every two years, 30% about every four years, though we have tied a pink ribbon around every tree. I have been in the Ministry of Health, I know how to work with patients, politicians, physicians, everyone.—Lithuania

We invite our regional partners, local NGOs that have been in existence for a long time, our program coordinators, our most active volunteers, breast cancer survivors, and the medical community. Together we hold different events, for example education events for patients, oncological surveillance. We are thinking where we are now, to get us on the same page and identify our goals and priorities, work plans.—Russia

Moldova has a Strategy of Healthcare Development until 2017, and cervical cancer and colorectal cancer screening programs are included. This is a classic example of successful advocacy at the Ministry of Health and Parliament.—Moldova

Some participants lacked access to evidence-based guidelines, but those who did saw great benefit.

A very important document for us was the Breast Health Global Initiative, where we saw what was possible for our level of resources. We have a country document that was helpful. We saw that the first step was teaching women self-breast exam, so we worked with family physicians to raise awareness. Second, for family physicians and nurses to be able to do clinical breast exams to detect breast cancer in symptomatic women.—Kyrgyzstan

Participants wondered how to best tailor successful programs from other countries to their setting.

Europe and the United States are ahead of CIS countries, so we are trying to replicate best practices and figure out how to apply these. You have to take into account financial resources, but also for each region we have different cancer incidence, its own financial resources, its own way the health care system is organized in terms of medical supplies and personnel.—Russia

Two oncologist-led organizations conducted program evaluations on the basis of indicators for breast cancer screening, and one conducted a needs assessment with the help of foreign cancer experts.

At the primary health center level, we have introduced two quality indicators for breast cancer and two for cervical cancer that we analyze every trimester. The information enables us to indicate to the medical facility if there is a need to build capacity.—Moldova

Survivors were more attuned to logistics of patient support, including volunteer burnout. Oncologists were more aware of early detection and treatment guidelines. International meetings and partnerships with international cancer organizations were invaluable to advancing advocacy efforts.

We found many friends at these summits. I have visited Poland, Lithuania, Georgia. We collaborate closely with Poland. This is not financial support but sharing experience. When you visit, you talk to people, listen to presentations, and inevitably take something for yourself, and see how this experience can be implemented into your work.—Ukraine

We were able to become part of Europa Donna, to learn about advocacy, to think about how Ministry of Health officials and politicians can be together with us. We sent them to an advocacy training and now we all speak the same language. We understood that we needed to do a detailed needs assessment; we met with European experts in breast cancer screening and treatment who helped.—Kyrgyzstan

### Validation of Results and Feedback

Study results were presented to participants of the 8th WE CAN Summit in Kiev, Ukraine, in October 2017. Summit participants agreed that these were an accurate reflection of their experiences. The subsequent discussion centered on shifting from cancer screening to early detection of symptomatic disease and accessible treatment.

### DISCUSSION

To our knowledge, our study is the first to describe the key themes in breast cancer advocacy in EECA. Persistent cancer stigma and lack of trust toward the public health system continue to hinder early detection efforts. Although greater involvement from country ministries of health and policymakers is needed to scale up early detection and access to novel treatments, many of the patient advocates in the region were more focused on patient support and still finding their footing in policy and health care advocacy. Trust “underpins the co-operation within health systems that is necessary to health production.”<sup>28</sup> To build partnerships, advocacy organizations need to demonstrate knowledge of evidence-based practices, reliability, and the ability to deliver as well as an honest and generous motive. The same expectations stand for clinicians, public health care systems, and policymakers, where trust can be built through demonstrating transparency, competence, and benevolence.

Local needs assessments that include breast cancer stage at diagnosis, factors affecting delays in and access to

treatment, ability to evaluate existing early detection and treatment programs,<sup>15,16</sup> and access to existing early detection and treatment guidelines are essential to achieving the patient advocates' priorities of expanding early detection, access to treatment, and patient support. Some participants sought additional technical support and education in these areas, and many wanted to know how to adapt successful programs from other countries to their setting. Breast cancer early detection and care resource-stratified guidelines are available,<sup>29-34</sup> as are descriptions of barriers to early cancer detection in some EECA countries<sup>7-13</sup> and cancer advocacy resources,<sup>35</sup> but much of this literature was not accessible to many study participants as it published in English and in journals that require a paid subscription. In the setting of limited information, advocates valued opportunities to share experiences among like-minded organizations in the region and partner with international cancer organizations that provided relevant technical training and support.

Compared with EECA, where each country has one recently established breast cancer CSO (Table 2), each country in Western Europe has multiple long-standing breast cancer CSOs. Regional patient-advocacy-focused Europa Donna promoted dissemination of accurate information about breast cancer early detection and screening, multidisciplinary care including supportive care, access to clinical trials and second opinions, and advancing cancer research. It provided some study participants with advocacy training and technical support.<sup>36</sup> The European Society of Breast Cancer Specialists advocates for research into novel breast cancer treatments, fosters collaboration between scientists and clinicians, advocates for more breast cancer specialty training programs, and defines standards of high-

quality breast cancer care.<sup>37</sup> Creation of similar infrastructure in EECA will require time; greater incentives for creation of a formal network of breast cancer CSOs that could work toward unified standards for breast cancer care and lobby for policy change; and more collaborative breast cancer data collection, early detection, and care projects between breast cancer CSOs, ministries of health, and policymakers leading to greater recognition and support of breast cancer CSO priorities.

A summary of recommended interventions to support breast cancer advocacy and improve cancer care in the region on the basis of our results is provided in Table 3.

Our studies in East and Southern Africa and the Andean region similarly found that lingering cancer-related stigma, lack of access to evidence-based information, and lack of trust hindered advocacy efforts, whereas sharing experiences among advocates generated ideas to overcome common obstacles.<sup>35,38</sup> Cancer CSOs in South America faced similar challenges, including limited availability of information about early detection, treatment, and program evaluation and a focus on patient support at the expense of policy change because of gaps in the health care system.<sup>24</sup> Compared with EECA, participants from East and Southern Africa focused more on how to make diagnosis and treatment more affordable, in part because of lower resources in the region, and proposed specific early detection interventions and initiatives to lower cancer care cost, in part because of having access to country-specific needs assessments that outlined these challenges and possible solutions.<sup>35</sup>

This study has some limitations. Our findings may not represent views of all patient advocates in the region or

**TABLE 3.** Recommendations to Improve Breast Cancer Advocacy and Cancer Care in EECA

Area Where Participants Requested Technical Assistance	Recommendations
Knowledge and/or competency	Access to and understanding of evidence-based and resource-adapted strategies for cancer diagnosis and treatment, including by translating existing literature into local languages; technical training about how to conduct local needs assessments and translate results into interventions appropriate to the local context; encouraging ministries of health to collect and make available data on breast cancer outcomes to guide advocacy efforts
Networking	Support of formal collaborations, formation of networks, and sharing of experiences among advocacy organizations in the region
Strategic collaboration	Promotion of engagement and collaboration between survivors, advocates, civil society partners, medical societies and associations, media, policymakers, academic researchers, and other stakeholders to build trust and exchange information, including by connecting stakeholders for specific bilateral or multilateral collaboration and providing funding for innovative joint projects
Advocacy training	Training in gap analysis, stakeholder mapping, policy process, country-specific barriers to accessing cancer care, and engaging policymakers
Organizational development	Support for strategic planning; networking; and elevating the patient voice in policymaking, targeted messaging for policymakers and physicians, grant writing, and donor cultivation
Monitoring and evaluation	Methods to measure program effectiveness through data collection, analysis, and publishing of reports to demonstrate professionalism and transparency

Abbreviation: EECA, Eastern Europe and Central Asia.

those of policymakers since there were only three in attendance. A plurality of conference participants was from Romania at the original conference, whereas a plurality at the second conference was from Ukraine. Because there was code saturation<sup>39</sup> and sufficient cross-validation, the results are appropriately valid providing valuable insights into breast cancer advocacy in EECA.

In conclusion, survivors, patient advocates, and oncologists in EECA, through their respective expertise in patient needs and gaps in the health care system, are uniquely positioned to work together to lifting lingering cancer stigma, increase trust in public health systems to facilitate early detection, and work to achieve greater engagement from

policymakers and scale up access to treatment. International cancer organizations can help empower advocates through encouraging formation of formal networks and collaborations to leverage limited resources and increase impact, raising awareness among policymakers and ministries of health about the centrality of the patient voice and advocacy in improving cancer outcomes and encouraging them to collect data related to breast cancer outcomes to focus advocacy efforts, making available evidence-based breast cancer care guidelines, and providing training and technical assistance to facilitate needs assessments and program evaluation to translate existing guidelines and successful programs to the local setting and resources.

## AFFILIATIONS

<sup>1</sup>Institute of Oncology “Ion Chiricuta,” Cluj-Napoca, Romania

<sup>2</sup>The Everett Clinic, Everett, WA

<sup>3</sup>University of Washington, Seattle, WA

<sup>4</sup>Seattle Cancer Care Alliance, Seattle, WA

<sup>5</sup>Leidos Biomedical Research, Inc, Frederick, MA

## CORRESPONDING AUTHOR

Julie Gralow, MD, Seattle Cancer Care Alliance, 825 Eastlake Ave E, LG-540, Seattle, WA 98109; e-mail: julie.gralow@asco.org.

## DISCLAIMER

The content of this publication does not necessarily reflect the views or policies of the Department of Health and Human Services, nor does mention of trade names, commercial products, or organizations imply endorsement by the US Government.

## PRIOR PRESENTATION

Presented at the 8th Annual Eastern Europe and Central Asia Women's Empowerment Cancer Advocacy Network (WE CAN) Breast and Cervical Cancer Education, Outreach and Advocacy Summit, Kiev, Ukraine, October 14, 2017.

## SUPPORT

Supported by Susan G. Komen Leadership Grant and National Cancer Institute, National Institutes of Health, Contract No. HHSN261200800001E. Additional travel and summit funding was provided by Susan G. Komen, Pfizer Oncology, and Health Policy Journal (Romania).

## AUTHOR CONTRIBUTIONS

**Conception and design:** Nicoleta Antone, Julie Gralow, Jo Anne Zujewski  
**Collection and assembly of data:** Nicoleta Antone, Julie Gralow, Jo Anne Zujewski, Allison Dvaladze

**Data analysis and interpretation:** All authors

**Manuscript writing:** All authors

**Final approval of manuscript:** All authors

**Accountable for all aspects of the work:** All authors

## AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The following represents disclosure information provided by authors of this manuscript. All relationships are considered compensated unless otherwise noted. Relationships are self-held unless noted. I = Immediate Family Member, Inst = My Institution. Relationships may not relate to the subject matter of this manuscript. For more information about ASCO's conflict of interest policy, please refer to [www.asco.org/rwc](http://www.asco.org/rwc) or [ascopubs.org/go/authors/author-center](http://ascopubs.org/go/authors/author-center).

Open Payments is a public database containing information reported by companies about payments made to US-licensed physicians ([Open Payments](http://Open Payments)).

**Nicoleta Antone**

**Travel, Accommodations, Expenses:** Pfizer Romania, Roche/Genentech

**Julie Gralow**

**Consulting or Advisory Role:** Genentech, Sandoz, AstraZeneca, Immunomedics

**Jo Anne Zujewski**

**Stock and Other Ownership Interests:** Olema Pharmaceuticals  
**Consulting or Advisory Role:** Leidos Biomedical Research, PMK Bioresearch, BeyondSpring Pharmaceuticals, Olema Pharmaceuticals

No other potential conflicts of interest were reported.

## ACKNOWLEDGMENT

The authors would like to thank the patient advocates and survivors; the Palace of Parliament, Senate of Romania; the local authorities and international speakers who attended the meeting; Susan G. Komen; the US National Cancer Institute Center for Global Health; and local partners HomeCare Association and Amazonki.

## REFERENCES

1. Bray F, Ferlay J, Soerjomataram I, et al: Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin* 68:394-424, 2018
2. Begum M, Lewison G, Jassem J, et al: Mapping cancer research across Central and Eastern Europe, the Russian Federation and Central Asia: Implications for future national cancer control planning. *Eur J Cancer* 104:127-136, 2018
3. World Bank Country and Lending Groups. World Bank. <https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups>

4. Current Healthcare Expenditure per Capita. World Bank. <https://data.worldbank.org/indicator/SH.XPD.CHEX.PC.CD>
5. Goss PE, Strasser-Weippl K, Lee-Bychkovsky BL, et al: Challenges to effective cancer control in China, India, and Russia. *Lancet Oncol* 15:489-538, 2014
6. Vrdoljak E, Bodoky G, Jassem J, et al: Cancer Control in Central and Eastern Europe: Current situation and recommendations for improvement. *Oncologist* 21:1183-1190, 2016
7. Badoeva ZA, Eshtrikova AM, Alikova ZR, et al: The characteristics of morbidity of breast cancer in the Kabarda-Balkar Republic [in Russian]. *Probl Sotsialnoi Gig Zdravookhranennii Istor Med* 28:39-43, 2020
8. Kołacińska A, Herman K, Morawiec J, et al: Improvement in outcomes of breast cancer patient treatment in Poland in the 21st century. *Breast J* 25:474-478, 2019
9. Cipora E, Konieczny M, Czerw A, et al: Causes of delays in breast cancer diagnosis in Poland. *Pol Merkur Lekarski* 47:85-90, 2019
10. Zejda JE, Kaleta A: Modes of early detection of breast cancer in Katowice Region, Poland. *Int J Environ Res Public Health* 17:2642, 2020
11. Chukmaitov AS, Kaidarova DR, Talaeyva ST, et al: Analysis of delays in breast cancer treatment and late-stage diagnosis in Kazakhstan. *Asian Pac J Cancer Prev* 19:2519-2525, 2018
12. Jakab Z, Galea G, Mauer-Stender K, et al: Cancer in Russia: Reflections from WHO in Europe. *Lancet Oncol* 15:487-488, 2014
13. Cherny N, Sullivan R, Torode J, et al: ESMO European Consortium Study on the availability, out-of-pocket costs and accessibility of antineoplastic medicines in Europe. *Ann Oncol* 27:1423-1443, 2016
14. Grassi L, Fujisawa D, Odyio P, et al: Disparities in psychosocial cancer care: A report from the International Federation of Psycho-oncology Societies. *Psychooncology* 25:1127-1136, 2016
15. World Health Organisation: Global Action Plan for the Prevention and Control of Non-Communicable Diseases 2013-2020. Geneva, Switzerland, WHO, 2013
16. Schear RM, Manasco L, McGoldrick D, et al: International framework for cancer patient advocacy: Empowering organizations and patients to create a national call to action on cancer. *J Glob Oncol* 1:83-91, 2015
17. Bishop A, Kovtun A, McGoldrick D, et al: Lives renewed: The emergence of a breast cancer survivor movement in Ukraine. *Reprod Health Matter* 9:126-134, 2001
18. Eniu A, Antone N: Access to affordable breast cancer care in Eastern Europe. *Curr Breast Cancer Rep* 10:170-178, 2018
19. Vrdoljak E, Gligorov J, Wierinck L, et al: Addressing disparities and challenges in underserved patient populations with metastatic breast cancer in Europe. *Breast* 55:79-90, 2020
20. Koon KP, Soldak T, Graolw JR: Breast cancer advocacy: Changing perceptions. *Salud Publica Mex* 51:s323-s328, 2009 (suppl 2)
21. Azenha G, Bass LP, Caleffi M et al: The role of breast cancer civil society in different settings. *Breast* 20:S81-S87, 2011 (suppl 2)
22. Perez C, de Castilla R, Yabar E, et al: Session 2: Mobilizing "all of society" for effective cancer control. ICC-5:24-36, 2015 (suppl 1)
23. Sloan FA, Gelband H (eds): Cancer control opportunities in low- and middle-income countries, in Committee on Cancer Control in Low- and Middle-Income Countries. Washington, DC, National Academies Press, 2007
24. Durstine A, Leitman E: Building a Latin American cancer patient advocacy movement: Latin American cancer NGO regional overview. *Salud Publica Mex* 51:s316-s322, 2009 (suppl 2)
25. WE CAN: What We Do. <http://www.womenscanceradvocacy.net/en.html>
26. Patton MQ: *Qualitative Research and Evaluation Methods* (ed 3). Thousand Oaks, CA, Sage Publications, 2002
27. MacQueen KM, McLellan E, Kay K, et al: Codebook development for team-based qualitative analysis. *Cult Anthropol Methods* 10:31-36, 1998
28. Gilson L: Trust and the development of health care as a social institution. *Soc Sci Med* 56:1453-1468, 2003
29. Anderson BO, Shyyan R, Eniu A, et al: Breast cancer in limited-resource countries: An overview of the Breast Health Global Initiative 2005 Guidelines. *Breast J* 12:S3-S15, 2006 (suppl 1)
30. Anderson BO, Yip CH, Smith RA, et al: Guideline implementation for breast healthcare in low-income and middle-income countries: Overview of the Breast Health Global Initiative Global Summit 2007. *Cancer* 113:2221-2243, 2008 (suppl 8)
31. National Comprehensive Cancer Network: NCCN Framework for Resource Stratification of NCCN Guidelines (NCCN Framework). <https://www.nccn.org/framework/>
32. Carlson RW, Scavone J, Koh WJ, et al: NCCN framework for resource stratification: A framework for providing and improving global quality oncology care. *J Natl Compr Canc Netw* 14:961-969, 2016
33. Duggan C, Dvaladze A, Rositch AF, et al: The Breast Health Global Initiative 2018 Global Summit on improving breast healthcare through resource-stratified phased implementation: Methods and overview. *Cancer* 126:2339-2352, 2020 (suppl 10)
34. Koh WJ, Anderson BO, Carlson RW: NCCN resource-stratified and harmonized guidelines: A paradigm for optimizing global cancer care. *Cancer* 126:2416-2423, 2020 (suppl 10)
35. Kizub DA, Zujewski J, Gralow JR, et al: Patient advocacy approaches to improving care for breast and cervical cancer in East and Southern Africa. *JCO Glob Oncol* 6:49-55, 2020
36. Europa Donna: [www.europadonna.org](http://www.europadonna.org)
37. EUSOMA: [www.eusoma.org](http://www.eusoma.org)
38. Dvaladze A, Kizub DA, Cabanes A, et al: Breast cancer patient advocacy: A qualitative study of the challenges and opportunities for civil society organizations in low-income and middle-income countries. *Cancer* 126:2439-2447, 2020 (suppl 10)
39. Hennink MM, Kaiser BN, Marconi VC: Code saturation versus meaning saturation: How many interviews are enough? *Qual Health Res* 27:591-608, 2017

