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Exploring global barriers to optimal ovarian cancer care

Sfeir, Selina; Allen, Lucy; Algera, Marc Daniël; Morton, Rhett; Farrell, Rhonda; Brennan, Donal; Driel, Willemien J van; Rijken, Marcus J; Eiken, Mary; Sundar, Sudha S; Coleman, Robert L; Collaborators of the Global Equality in Ovarian Cancer Care project group

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4	Exploring global barriers to optimal ovarian cancer care: a thematic analysis
5	S. Sfeir S ¹ *, L. Allen ¹ *, M.D. Algera ^{2,3,4} *, R. Morton ⁵ , dr. R. Farrell ⁶ , prof. dr. D. Brennan ⁷ , dr. W.J. van
6	Driel ⁸ , dr. M.J. Rijken ⁸ , M. Eiken ⁹ , prof. dr. S. Sundar ¹ , dr. R.L. Coleman ^{9,10} , and the collaborators of
7	the Global Equality in Ovarian Cancer Care project group.
8	
9	*These authors contributed equally to the work.
10	¹ University of Birmingham, Birmingham, United Kingdom.
11	² Scientific Bureau, Dutch Institute for Clinical Auditing (DICA), Leiden, the Netherlands.
12 13	³ Department of Obstetrics and Gynecology, Maastricht University Medical Centre (MUMC+), Maastricht, the Netherlands.
14	⁴ GROW- School for Oncology and Reproduction, Maastricht, the Netherlands.
15	⁵ Queensland Centre for Gynaecological Cancer, Brisbane, Australia.
16 17	⁶ Gynaecological Oncology Department, Chris O'Brien Lifehouse, Camperdown, New South Wales, Australia
18 19	⁷ UCD Gynaecological Oncology Group, UCD School of Medicine, Mater Misericordiae, University Hospital, Dublin, Ireland.
20	⁸ Julius Global Health Department, University Medical Centre Utrecht, The Netherlands.
21	⁹ International Gynecologic Cancer Society
22	¹⁰ SCRI, Sarah Cannon Research Institute, Nashville, Tennessee, United States.
23	
24	Corresponding author:
25	M.D. Algera
26	Dutch Institute for Clinical Auditing
27	Rijnsburgerweg 10
28	2333 AA Leiden
29	The Netherlands

30 E-mail: <u>m.algera@nki.nl</u>

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56 ABSTRACT

57 Objective

58 This study aims to explore the barriers to ovarian cancer care, as reported in the open-ended 59 responses of a global expert-opinion survey. We expect to highlight areas for improvement in global 60 ovarian cancer care and propose potential solutions to overcome these barriers.

61 Methods

Data from the expert-opinion survey, designed to assess the organisation of ovarian cancer care worldwide, were analysed. The survey was distributed across a global network of physicians. We examined free-text open-ended responses concerning the barriers to ovarian cancer care. A qualitative thematic analysis was conducted to identify, analyse, and report meaningful patterns within the data.

67 Results

A total of 1,059 physicians from 115 countries completed the survey, with 438 physicians from 93 countries commenting on the barriers to ovarian cancer care. Thematic analysis yielded five major themes regardless of income-category or location: societal Factors, inadequate resources in hospital, economic barriers, organisation of the specialty, and need for early detection. Suggested solutions include accessible resource-stratified guidelines, multi-disciplinary teamwork, public education, and development of gynecological oncology training pathways internationally.

74 Conclusions

This analysis provides an international perspective on main barriers to optimal ovarian cancer care.
The themes derived from our analysis highlight key target areas to focus efforts to reduce global care
disparities. Future regional analysis involving local representatives will enable country-specific
recommendations to improve the quality of care and ultimately to work towards closing the care gap.

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83 KEY MESSAGES

84 What is already known on this topic

Research is lacking on the perspectives of clinicians involved in ovarian cancer care and their perceptions of the barriers faced. The structure paper of the Global Equality in Ovarian Cancer Care Survey has identified multiple global disparities in care organisation, but in-depth qualitative analyses of the main barriers that physicians face, have not yet been undertaken.

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90 What this study adds

This study adds a unique qualitative dimension to the published data from the Global Equality in Ovarian Cancer Care structure paper. The thematic analysis conducted in this study identified societal factors, lack of hospital resources, economic factors, the organisation of the specialty, and the need for early detection as key barriers to optimal ovarian cancer care. Potential solutions include the development of accessible resource-stratified guidelines, promoting multi-disciplinary teamwork, public education initiatives, and the expansion of gynaecological oncology training programs on a global scale.

98

99 How this study might affect research, practice or policy

100 This study provides an international perspective on the obstacles faced by physicians in delivering 101 effective ovarian cancer treatment worldwide. The findings hold significance for policymakers, 102 clinicians and patient advocates, offering valuable insights to guide specific areas to enhance the 103 management of ovarian cancer globally. Future analyses of the survey data should consider a 104 regional approach, involving representatives from the different regions.

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110 INTRODUCTION

Ovarian cancer has the highest mortality among all gynecological cancers, with survival differences observed worldwide, both between and within countries [1–4]. However, it is often patients from resource-poor countries who face the worst prognoses. While significant research has investigated the treatment and diagnosis of ovarian cancer [1,2], little is known about the barriers to implementing these care plans in different countries, especially in resource-poor areas. This has key ramifications for women in terms of quality of life and life expectancy.

117 There are multiple reasons why international ovarian cancer survival disparities exist. Studies 118 have suggested that survival disparities could be explained by differences in stage at diagnosis [4]. 119 However, international survival disparities exist within each stage, suggesting poor or unequal access 120 to optimal treatment impacts survival rates [3,4]. Furthermore, within high-income countries, a two-fold 121 difference in survival from ovarian cancer can be observed, suggesting the presence of complex 122 structural challenges to care [5].

123 Current literature on global barriers to ovarian cancer care was scarce: only one study described barriers in high-income countries [6]. However, our project group recently published the 124 125 first results of the Global Equality in Ovarian Cancer Care expert-opinion survey [7]. In this structural 126 paper, we have described the global organisation of ovarian cancer care across low, middle, and 127 high-income countries, and we identified the main barriers to optimal ovarian cancer care, both 128 unrelated to income category and income related. While these results provide a unique global view on 129 barriers faced by physicians, the published results lack in-depth qualitative analyses of the open-130 ended responses [7].

The current study aims to build upon the results of the structural paper and identify and explore the barriers physicians encounter in treating patients with ovarian cancer across different hospitals, regions and countries. We will undertake a qualitative review of the perceptions of barriers to optimal ovarian cancer care worldwide. By examining the challenges faced by those on the front line of ovarian cancer care, we aim to elucidate the major areas for improvement in its management globally, address the observed disparities, and propose potential solutions to overcome these barriers.

139 METHODS

140 Study Design and Setting

We analysed data from the Global Equality in Ovarian Cancer Care expert-opinion survey study [7], which aimed to assess ovarian cancer care organisation worldwide and ultimately close the care gap. The survey was distributed by (the strategic partners of) the International Gynecologic Cancer Society, European Society of Gynaecological Oncology, and Society for Gynecologic Oncology. Therefore, the project reached a worldwide network of physicians treating ovarian cancer. The survey was distributed in five languages (English, Spanish, Portuguese, Mandarin, and Russian), and responses were translated into English and analysed.

148 The qualitative analysis focused on the free-text open-ended response question to "What are 149 the main barriers to optimal ovarian cancer care in your hospital, region, or country? Please provide 150 any further comments in the space below". Thematic analysis was used to identify, analyse, and 151 report meaningful patterns from the data. The approach to the thematic analysis was inductive and 152 data driven. There were no prior assumptions about what was to be revealed from the free-text responses, as the researchers were interested in understanding what the participants identified as 153 154 barriers to ovarian cancer care rather than using what previous literature had suggested was 155 meaningful.

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157 Thematic Analysis

158 The thematic analysis proceeded according to the process described by Braun and Clarke [8]. The 159 free-text responses from the survey were read, and any that were not pertinent to the study aims were 160 excluded from the data set. Two researchers independently read through the free-text responses to 161 generate initial codes. These codes were then collated into potential themes by grouping codes with 162 similar patterns or concepts. The resulting thematic map had a collection of candidate themes and 163 sub-themes, reflecting all meaningful data. The next data analysis stage involved reviewing and 164 refining candidate themes, which was done in two parts. The first used Patton's criteria [9] of internal and external homogeneity to ensure that data within a theme formed a distinct, coherent pattern and 165 166 that data across different themes did not overlap. The second part involved referring to the dataset and searching for any extracts that fit within the previously unidentified theme and ensuring that the thematic map represented the whole dataset. Free-text responses that best represented the final themes were selected and embedded within a narrative highlighting the main barriers to ovarian cancer care globally. Finally, the project group discussed the potential solutions to the main barriers.

171

172 RESULTS

173 Respondent Characteristics

Overall, 1,059 physicians from 115 countries completed the survey (83% gynecological cancer surgeons, 8% obstetricians/gynecologists, 9% other specialists). Further respondent characteristics are described in the structure paper [7]. All respondents completed the multiple-choice question about the barriers to optimal care [7]. A total of 438 participants from 93 countries commented in the free-text fields (high-income n=137, upper-middle income n=142, lower-middle/low-income n=159) (Figure 1). The number of open-ended responses per country are displayed in Supplementary Table 1.
Figure 2 displays a flow diagram summarising the participant responses.

181

182 Thematic Analysis

Five interrelated themes were identified across the dataset, these themes are reported along with
their respective sub-themes, examples of comments and the potential solutions to the barriers (**Table**Our project group derived these potential solutions from the responses. Data excerpts have been
included to illustrate the views and perspectives described by the participants within each sub-theme.

187 Societal Factors

The country's political climate was a recurring motif in many responses. This was the case for countries affected by war and conflict, such as Cameroon and Ukraine; however, this barrier extended to countries where there was inequity between the public and private healthcare system, such as Brazil (**Table 1**). In many countries, geography posed a barrier as patients found it physically and logistically difficult to travel to facilities for care (for example in South Africa); this issue was especially prominent in large countries with rural populations (**Table 1**). A somewhat ambiguous sub-theme identified was that quality of ovarian cancer care still has a long way to go, irrespective of any identifiable obstacle. There is the sense that although progress has been made, current care issuboptimal (Table 1).

197 Inadequate Resources in Hospitals

198 The lack of human resources was a prominent sub-theme, with many responses citing lack of 199 specially trained staff members and overall personnel and appropriate training (Table 1). Increasing 200 patient demand was identified as directly impacting the care that ovarian cancer patients receive; 201 also, in some countries, patient demand has been exacerbated by the COVID-19 pandemic (Table 1). 202 Lack of access to diagnostic testing such as pathology and radiology services was seen in countries 203 from all income categories. Genetic counselling and molecular testing facilities were needed in lower-204 middle-income countries and were particularly difficult to access on large-scale national levels (Table 205 1).

206 Economic Barriers to Treatment

207 The cost of treatment was a significant sub-theme identified regardless of countries' income status 208 (Table 1). The high costs meant that many patients could not afford their care, causing them to forego 209 their treatment. Besides, the high cost was mainly attributed to newer classes of targeted therapies, 210 such as PARP inhibitors. The cost of treatment was also problematic for countries with national health 211 insurance systems, for example in New Zealand (Table 1). Access to treatment was a particular issue 212 for lower/middle-income countries: new treatments for ovarian cancer were difficult to access, with 213 many describing an absence of availability in their country (**Table 1**). The funding of treatment was 214 the final sub-theme identified. For high-income countries, this funding was pertinent to therapies such 215 as hyperthermic intraperitoneal chemotherapy (HIPEC), other countries described more intricate 216 barriers to funding, complicated by different funding streams available from insurance companies or 217 the government (Table 1).

218 Organisation of the Specialty

A recurring theme was the overall organisation of gyne-oncology as a specialty; a need for standardised care was highlighted (**Table 1**). While clear standards and guidelines have enhanced the quality of care in some countries, other respondents highlighted that there are still disparities in compliance and access to guidelines (**Table 1**). Further comments suggested that multi-disciplinary teams were the key to managing their patients effectively (**Table 1**). The final sub-theme described

gyne-oncology not being recognised as a distinct specialty; several comments recalled the challenges of multi-disciplinary teamworking and standardising care when the specialty does not exist within their healthcare system. As a result, this led to difficulties in managing care and impacted professional development (**Table 1**).

228 Need for Early Detection

229 The respondents frequently addressed delays in patients presenting to healthcare professionals as a 230 barrier to optimal care, creating complexity in managing cases; several factors were suggested to 231 explain women presenting at such advanced stages, like the lack of public knowledge on ovarian 232 cancer (Table 1). Public health awareness was a sub-theme related to the delayed presentation of 233 disease observed. Many responses expressed a desire to campaign for public health awareness and 234 education programs within communities, some suggested that governments should do more to 235 highlight the importance of this disease, while others suggested that it is the responsibility of primary 236 care physicians to educate patients about ovarian cancer (**Table 1**). Finally, the need for a national 237 screening program recurred amongst the free-text comments. A national screening program was 238 identified as something that would improve the early diagnosis of ovarian cancer, however none of the 239 responses suggested how this could be executed, nor acknowledged current literature of the 240 inadequacy of available screening tests (Table 1).

241

242 DISCUSSION

243 Summary of Main Results

244 This study identified and explored the barriers to optimal ovarian cancer care globally through 245 analysing questions from the Global Equality in Ovarian Cancer Care expert-opinion survey. This 246 qualitative, thematic analysis revealed the following themes as main barriers: societal factors, 247 inadequate resources in hospital, economic barriers to treatment, organisation of the specialty, and 248 the need for early detection. These themes were common across countries regardless of income category or geographical location. Suggested solutions include accessible resource-stratified 249 250 guidelines, multi-disciplinary teamwork, public education, and development of gynecological-oncology 251 training pathways internationally.

253 Results in Context of Published Literature

Limited literature exists on international barriers to ovarian cancer care, with most studies focusing on country-specific challenges rather than international comparisons. Nonetheless, several themes generated by our study have been referenced within the current literature [7]. Similar barriers to optimal cancer care have been recognised in the treatment of other cancers such as cervical cancer [10].

259 We observed an overlap between the previously reported multiple-choice results regarding 260 the main barriers to ovarian cancer care question and the current qualitative findings [7]. The multiple-261 choice results revealed main barriers regardless of income category, including patient, disease, and 262 social factors. Additionally, income-specific barriers to ovarian cancer care were identified, such as 263 the lack of surgical time and staff; patient preferences in high-income settings; treatment costs as well 264 as lack of access to radiology, pathology, and genetic services in middle and low-income contexts. 265 Furthermore, one-third of lower-middle and low-income respondents reported a lack of access to 266 systemic agents.

267 Geographical constraints continue to provide a barrier to optimal care, disproportionately 268 affecting the uninsured and the elderly, leading to delayed diagnoses [10]. Issues such as dispersion 269 of populations and distance from specialist centres were highlighted in our analysis. Lack of access to 270 specialised centres hinders effective management of ovarian cancer, particularly for patients from 271 lower socioeconomic backgrounds, while specialised centres are associated with improved outcomes 272 [10,11]. Strategies to overcome these barriers could include implementing telemedicine/telesurgery, 273 travel assistance, improving psychosocial support and increased social care involvement though their 274 implementation is often challenged by economic and healthcare constraints (discrepancy public vs. 275 private healthcare) or political instability (war and conflicts) [11,12].

A study examining barriers to accessing ovarian cancer treatments in seven high-income countries identified challenges such as limited access to clinical trials, hospital understaffing, and restrictions in prescribing expensive medications [6]. These challenges align with our themes of inadequate hospital resources and the economic barriers facing both medical professionals and patients. Notably, resource constraints affect all countries investigated, highlighting global disparities in access to care. Moreover, discrepancies in the adoption of treatments like bevacizumab, underscore differences in investment priorities globally [6]. In the current study, these observed

challenges are exacerbated in middle and low-income countries, necessitating further research to understand the extent of the economic barriers in managing ovarian cancer. Furthermore, global access to clinical trials should be improved and international societies like the International Gynecological Cancer Society and the Gynecologic Cancer Intergroup should support capacity building for clinical trials in middle and low-income countries.

A significant challenge is the lack of surgical staff and specialty-trained gynecological oncologists [13]. Limited training opportunities and funding for fellowships hinder efforts to address this gap, especially in low and middle-income countries [14]. Moreover, the migration of skilled individuals from low and middle-income countries to high-income countries, the so-called 'brain drain', further strains these healthcare systems [13]. Initiatives such as the Global Curriculum Mentorship and Training Program (International Gynecologic Cancer Society) aim to bridge the gaps in training, but additional efforts are needed to ensure adequate staffing levels worldwide [15].

Mirroring our findings, studies have supported centralised approaches to ovarian cancer care, though challenges in initial costs and incentivizing referrals must be addressed, particularly in politically unstable and lower-income countries [11, 12]. Locally applicable models of care like the hub and spoke model in the United Kingdom, aim to reduce regional disparities in survival [5]. However, the treatment of ovarian cancer by gyne-oncologists is limited by models of care, payment structures and the awareness of the need to refer to gyne-oncologists [16].

Our findings have shown that a major limitation facing many countries is the overall development of gyne-oncology as a specialty. Similarly, there is a recognised lack of clinical data comparing clinical practices in ovarian cancer care between countries [6,17]. Comparison of the clinical practices of seven high-income countries by Norell et al. determined that international guideline adherence was inconsistent [6]. However, it must be acknowledged that the implementation of international guidelines is not achievable in certain low-income regions, highlighting the need for guidelines tailored to local contexts [18].

Empowering patients with ovarian cancer to seek referrals and increasing public awareness of symptoms and treatments are crucial for early detection [12,17]. While many of our free-text responses stressed a need for a screening program, a recent large trial investigating screening in general populations found a stage shift but no evidence of reduced mortality [2,19]. Adopting

approaches like symptom-triggered testing could improve resource allocation, but long-term outcomesrequire further investigation [20].

314

315 Strengths and Weaknesses

316 Strengths of the study include the global representation of the respondents (115 countries in total, 93 317 countries in the qualitative analysis) and the proportions of upper-middle and lower-middle/low-318 income countries represented in the study (115 countries were represented in the study, including 47 319 out of 83 (57%) high-income, 36 out of 54 (67%) upper-middle income, and 54 out of 80 (67%) lower-320 middle and low-income countries). In addition, the data were collected anonymously and therefore the 321 likelihood of social-desirability bias was reduced. The data was collected to allow participants to 322 provide feedback as much as they wanted, without time constraints or external pressures. Last, the survey was distributed in five languages, ensuring there was no language bias. 323

324 The current study has certain weaknesses. First, the study was not initially designed to be a 325 qualitative study, and thus the free-text element of the survey was optional, introducing potential 326 participant bias. In addition, the respondents were predominantly contacted through the International Gynecologic Cancer Society, Society of Gynecologic Oncology and European Society of 327 328 Gynaecological Oncology, therefore physicians who are not part of this were underreported. Several 329 countries had many respondents and therefore may be overrepresented in the analysis, whereas 330 other countries had few respondents and thus may be underrepresented. However, data analysis 331 ensured that countries from all income status levels were equally represented in the final themes. 332 Nonetheless, the results cannot be said to apply to any individual country or region, and further 333 country-specific analysis is required to tailor local interventions. This regional approach would ideally 334 be holistic including stakeholders and triangulating data from other sources including the Every 335 woman study [21].

336

337 Implications for Practice and Future Research

These analyses give insight into the main barriers to ovarian cancer care. Additional analyses should be performed on the current survey data to enable regional recommendations to improve care, especially in resource-poor countries. These future analyses should consider a regional approach,involving representatives from the different regions.

We will need consensus building on what the best solutions are to improve equality in care and outcomes. Potential solutions identified from our themes include accessible resource-stratified guidelines, promoting multi-disciplinary teamwork, public education initiatives, and the expansion of gynecological oncology training programs on a global scale. However, many of these potential solutions will require significant societal changes and governmental financial support.

347

348 CONCLUSIONS

349 This analysis provides an international perspective on the main barriers to optimal ovarian cancer care. The thematic analysis identified that Societal Factors, Inadequate Resources in Hospitals, 350 351 Economic Barriers to Treatment, Organisation of the Subspecialty of Gynecologic Oncology, and the 352 Need for Early Detection are the main barriers to optimal ovarian cancer care. Suggested solutions 353 include accessible resource-stratified guidelines, promoting multi-disciplinary teamworking, public 354 education, and the further development of gyne-oncology training pathways internationally. The Global Equality in Ovarian Cancer Care project group aims to overcome these barriers through a 355 356 regional approach and, ultimately, to work towards closing the care gap.

357

358 Author contribution

SSf, LA, and MDA were shared first authors who contributed equally to the manuscript. SSf and LA performed the qualitative analysis. SSf, LA, and MDA wrote the manuscript. MDA was guarantor. RM revised the manuscript and performed analysis. RF, DB, WJvD, MJR, ME, SSu, and RLC performed interpretation of the data and revision of the manuscript. The collaborators all approved the manuscript.

364

365 Competing interests

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Singapore), A. Nogueira Rodrigues (Brazilian Group op Gynecologic Oncology, Brazil), L. Randall
(VCU Medical Center, Richmond, United States), B. Rau (University Hospital Berlin, Berlin,
Germany), M. Seoud (Sheikh Shakhbout Medical City, Abu Dhabi, United Arab Emirates), I. Vergote
(University Hospital Leuven, Leuven, Belgium).

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Table 1: Themes and potential solutions from the qualitative thematic analysis

Major themes	Sub-themes	Examples of comments	Potential solutions*
1. Societal Factors	Political climate	<u>Cameroon</u> : "This region is a conflict zone which impacts access to care"	- Resource stratified guidelines
		<u>Ukraine</u> : "The difficulties of patients treatment due to the war in my country"	- Regional approach involving representatives
		<u>Brazil</u> : "There are great discrepancies between public and private care in our country".	from the different regions
	Geographical constrains	South Africa: "Patients reside far from Chemofacility, leading to hesitancy to treat"	 Investment in patient transport to centralized cancer
		<u>Spain:</u> "One problem is the distance and dispersion of populations"	care centres - Promotion of
		Hawaii: "We are separated by the ocean"	grass roots community led
	General improvement needed	India: "We are improving in India with respect to oncological services yet not there yet".	initiatives and groups to lobby government
		Zambia: "There has been some improvement in the care of patients in the last decade, but a lot more needs to be done"	- Telemedicine and
		<u>Colombia</u> : "We have the resources, but we recognize that much remains to be known".	telesurgery implementation
2. Inadequate Resources in Hospital	Lack of human resources	<u>Peru:</u> "In my hospital. We are only 2 surgeons for five cities (1-2 million people)"	- Resource stratified guidelines
ricopital		<u>Cameroon</u> : "Substandard nursing with inadequate nursing training in oncology especially for ward nursing"	- Regional approach involving representatives
		<u>Russia</u> : "Debulking surgeries are often limited by the personnel's availability (coloproctologist, abdominal surgeon)"	from the different regions
	Increasing patient demand	India: "Patient load is far more than the operating theatre availability leading to delay in starting treatment"	 Training and incentivized retention of staff
		Bangladesh: "Ovarian Cancer Patients are increasing day by day in our country"	- Enhanced recovery after
		<u>Greece</u> : "The problems with surgical time and ICU beds have deteriorated during pandemic and surgical lists are growing fast"	surgery programs
	Access to diagnostic testing	<u>United States</u> : "It has taken longer to get radiologist procedures (biopsies) and diagnostic procedures (CT scans) performed because of lack of staff and access after COVID"	
		<u>Indonesia</u> : "No accredited laboratory for genetic testing, no genetic counsellor available, hence certain treatments are out of the international guidelines".	
		Nigeria: "genetic studies are required"	
		<u>Argentina</u> : "the genetic test for BRCA and HDR mutation is still not requested from all patients"	

3. Economic Barriers to Treatment	Cost of treatment	India: "cost of treatment causes limitation of systemic therapy and increase in drop-out rate". Peru: "few women can be treated with some treatments like iPARP because it is very expensive" United States: "financial toxicity is the biggest burden for patients currently the drugs costs are unsustainable" New Zealand: "some drugs are unfunded". Thailand: "there are still some limitations for ovarian cancer	 Regional approach involving representatives from the different regions Involving pharmaceutical companies
	treatment	patients [] to access to anti-VEGF, PARP inhibitor and/or some second-line chemotherapy" <u>Tunisia</u> : "targeted therapy and immunotherapy are not accessible in our country"	
	Funding of treatment	United Kingdom: "lack of funding for HIPEC for Ovarian Cancer" India: "Poor renumeration to hospital and doctors through insurance and government programs limits offering proper care to ovarian cancer patients"	
4. Organisation of the Specialty	Standardisation of care	Venezuela: "it is necessary to standardize the approach of these patients and generate a more targeted training" <u>Colombia</u> : "Multiple cancer centers in the city lack care protocols" <u>Greece</u> : "North American guidelines are being applied and the treatment has a very high standards similar to the major	Further development of gynae-oncology training pathways internationally Resource stratified guidelines
	Effective multi- disciplinary team working	referral centres of Europe and North America" Brazil: "The union of the multidisciplinary team with the patient diagnosed with ovarian cancer has brought very positive results in the patient's outcome" India: "It needs multidisciplinary dedicated team to manage the cases"	- Promotion of multi-disciplinary team care
	Not a recognised specialty	<u>China</u> : "In China, there is no certification of Gynecologic Oncology" <u>Brazil</u> : "Gyn-oncologist is not considered an official sub- specialty. This political issues impede the development of certification and training standardization"	
5. Need for Early Detection	Delayed presentation of disease	Indonesia: "Ovarian cancer is complicated case in my hospital because the patient came almost in advanced-stage" <u>Mexico</u> : "the service offered is for low-income people, our population is not educated, they arrive in very advanced clinical stages"	 Public education and awareness Creating diagnostic referral pathways
	Public health awareness	Uganda: "There is a serious lack of knowledge among patients regarding ovarian cancer symptoms hence they usually present late" India: "More awareness amongst the primary physicians to diagnose the disease early as still majority present in advanced-stage"	- Improving testing capabilities
	Lack of screening	Bangladesh: "Standard screening procedure is necessary for diagnosis of early-stage ovarian cancer" <u>Russia</u> : "Screening program developing is needed"	

484 *The potential solutions were derived from the (sub-)themes by the Global Equality in Ovarian Cancer

485 Care project group.

486 Figure Legend

487 **Figure 1:** Global Equality in Ovarian Cancer Care Survey: number of open-ended responses per

488 country to the barriers to optimal ovarian cancer care question.

Figure 2: Flow diagram of the participant responses.