

1 **Availability of region-specific endometriosis care guidance: a global scoping review**

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49 **Summary**

50 Guidance on standards of care, particularly incorporating region-specific needs, is foundational
51 to high-quality health care. The availability of region-specific guidance on endometriosis care,
52 particularly in low-income and middle-income countries, has not previously been documented.
53 We conducted a scoping review of endometriosis care guidance in each of the 194 WHO-defined
54 member states to identify the highest organizational level of guidance by region. Nine sources
55 were defined, ranging from national society and government documents to news and social
56 media postings. There is geographical heterogeneity in the existence and sources of guidance,
57 with the greatest availability in Europe. In regions where national societies or advocacy groups
58 exist, many do not maintain or reference care guidelines – even when they exist locally. To
59 ensure patients, providers, and policymakers have access to endometriosis care guidance, patient
60 advocacy groups, professional societies, and governments need to create, maintain, and publicize
61 their resources for patients and providers.

62

63 **Introduction**

64 Endometriosis is a chronic inflammatory condition defined by the presence of endometrial-like
65 tissue outside the uterus that can be associated with pain, infertility, and organ dysfunction
66 depending on the location, extent, and depth of invasion.¹ It is estimated to affect 190 million
67 people of female sex worldwide,^{2,3} although the true prevalence is unknown.^{4,5} The economic
68 burden of endometriosis, mostly attributable to productivity loss related to impact on quality of
69 life, is comparable to other chronic diseases of similar prevalence like diabetes.⁶ Yet, whereas
70 diseases like diabetes have accumulated a wealth of data and innovations in systemic care
71 delivery like screening programs, endometriosis is so poorly addressed globally that a recent
72 systematic review on diagnostic delays identified up to 12 years between onset of symptoms and
73 diagnosis.⁷ The World Economic Forum estimates a 75 million disability-adjusted life year
74 (DALY) gender health gap worldwide, with endometriosis as one of the main contributors. By
75 improving effectiveness, uptake, access, and delivery of care for endometriosis alone, the global
76 gross domestic product (GDP) could rise \$116 billion USD by 2040.³ These figures highlight the
77 global magnitude of both the unmet clinical need and economic burden of endometriosis.

78

79 While there is no known cure for endometriosis, the primary treatments are hormonal therapies
80 and surgery, used independently or combined, with other complementary and alternative
81 therapies added depending on individualized needs.^{2,8,9} Given that the clinical implications of
82 endometriosis can range from mild dysmenorrhea or otherwise asymptomatic infertility to
83 chronic debilitating pain and visceral obstruction, there is a spectrum of needs for those affected.
84 These needs may range from simple ovulatory/menstrual suppression with conventional
85 hormonal contraceptives to complex, individualized treatment plans involving chronic pain
86 management, aggressive hormonal therapies, and/or collaboration between multiple surgical
87 specialties.^{2,8,9} Consequently, many people who are affected by endometriosis may benefit from
88 centres of expertise with multidisciplinary specialist care.^{2,8,9} However, there are many potential
89 socioeconomic, geographical, and clinical barriers to reaching these specialist services, so the
90 majority of people affected by endometriosis access care through primary care providers and
91 general gynecologists. Healthcare infrastructures and guidelines that support patients and care-
92 providers are vital to optimize care both within and outside of specialist centres.

93

94 Guidelines comprise recommendations from clinical experts—put together following a rigorous
95 analysis of current evidence—to propose standards for healthcare systems. In some regions,
96 governments may produce clinical guidelines based on the recommendations of national or
97 international experts. In the absence of national or international guidelines, healthcare providers
98 may look to academic societies for guidance to inform clinical decision-making. Sometimes,
99 guidelines also need to be tailored to the region for successful integration within existing
100 infrastructure and resource allocation. For example, with respect to endometriosis guidelines,
101 some countries in Africa have called for region-specific and cultural-specific care guidance and
102 resources,^{10,11} to address the concern that endometriosis is “neglected or forgotten” in Africa.¹²
103 This concern is not limited to Africa, with various other global regions calling for improved
104 education, guidance, and infrastructures for endometriosis care within their healthcare systems.
105 For instance, the EU parliament in 2017 called for member states to increase funding to draft
106 clinical guidelines, create reference centres, and train specialised health professionals.¹³

107

108 To date, no comprehensive analysis has been conducted to map the availability of endometriosis
109 guidance across the globe, including in LMICs. In this scoping review, we aim to map how
110 endometriosis care is being guided globally and to identify where guidelines could be developed,
111 improved, or adopted with region-specific modification. This work may support advocacy efforts
112 that aim to improve awareness and care for people with endometriosis worldwide.

113

114 **Methods**

115 A scoping review was performed following the Preferred Reporting Items for Systematic and
116 Meta-Analysis extension for Scoping Reviews (PRISMA-ScR) checklist¹⁴ (**Appendix page 2**)
117 and Joanna Briggs Institute methodology¹⁵ guidelines. The scoping review methods protocol was
118 published following study completion with Open Science Framework (<https://osf.io/7m42e/>).

119

120 The Population, Context, Concept (PCC) framework¹⁶ was used to define our two research
121 objectives: first, to identify the highest organizational level of healthcare guidance (concept =
122 inclusive of diagnosis, treatment, or comprehensive care) for people with suspected or confirmed
123 endometriosis (population) associated with each of the 194 World Health Organization (WHO)–
124 defined member states (heretofore “countries” = context). Second, to compile a list of every
125 relevant professional and advocacy society (concept) available to patients, providers, and
126 policymakers (population) in each country (context) across the globe.

127

128 We aimed to present this information as a descriptive summary of guidance by country and
129 WHO-defined region that highlights opportunities for improvements and might inform future
130 initiatives that work towards global awareness of endometriosis and contextually appropriate
131 care guidance.

132

133 Documents were selected for inclusion if they offered region-specific care guidance for
134 endometriosis. Documents were excluded for the following reasons: experimental or study
135 design description; cost-effectiveness analysis; regional validation of a tool; not endometriosis-
136 care focused; review that was not region-specific; commentary on an existing guideline. Region-
137 specific endometriosis care guidance documents that met these selection criteria and did not fall
138 within any of these exclusion criteria were nonetheless subsequently excluded if 1) a document

139 of higher organizational hierarchy was found for that specific country; or 2) a document of equal
 140 organizational hierarchy was found for that specific country that was more recently published.
 141 An organizational hierarchy of endometriosis care guidance was developed by the author group
 142 based on the level of organization required to generate the guidance as well as anticipated rigor
 143 and reach. The hierarchy was applied to the results to determine the inclusion of data (see panel).

- 144 Panel: Organizational Hierarchy of Endometriosis Care Guidance
- 145 1. Government plus professional society collaborative guidelines
 - 146 2. Government guidelines
 - 147 3. Professional society guidelines
 - 148 4. Government information on endometriosis (but absent of a care guideline)
 - 149 5. Professional society information on endometriosis (but absent of a care guideline)
 - 150 6. Region-specific published reviews
 - 151 7. Individual healthcare provider, clinic, or hospital information websites
 - 152 8. Patient advocacy websites and social media
 - 153 9. News media

154 The source providing the highest organizational level of guidance for each country was selected
 155 and recorded. If a country had both a professional society and a government guideline, both were
 156 selected and recorded.

157 Data were obtained through a bibliographic database search and a grey literature review. Grey
 158 literature, as defined by the Luxembourg Convention,^{17,18} is literature "...which is produced on
 159 all levels of government, academics, business and industry in print and electronic formats, but
 160 which is not controlled by commercial publishers." It was anticipated that the grey literature
 161 review would be necessary to identify the potential sources of guidance outside of peer-reviewed
 162 and indexed databases.¹⁹ Searches were conducted in both English and the primary language(s)
 163 of each country, with the inclusion pertinence of non-English language documents confirmed
 164 using Google Translate. There were no language, date or source location restrictions.

165
 166 A medical information specialist (BS) developed and tested search strategies through an iterative
 167 process in consultation with all named authors to ensure the terms aligned with the review's
 168 objectives. Strategies utilized a combination of controlled vocabulary (e.g., "Endometriosis",
 169 "Clinical Protocols", "Health Planning Guidelines") and keywords (e.g., "endometriosis",
 170 "consensus", "guideline"). Another information specialist peer-reviewed the MEDLINE
 171 strategies prior to execution using the Peer Review of Electronic Search Strategies (PRESS)
 172 checklist²⁰ (**Appendix page 4**). The complete search strategy is appended (**Appendix page 8**).

173
 174 Applying the multifile option and deduplication tool available on the OVID platform,
 175 MEDLINE, Embase, and Global Health were searched. CINAHL (EBSCO), Web of Science
 176 (core collection), and Global Index Medicus (all indexes) were also searched. All searches were
 177 performed on October 28, 2022, and updated July 16, 2024. Animal-only records and opinion
 178 pieces were removed from the results. Files were downloaded and deduplicated using EndNote
 179 version 9.3.3 (Clarivate) and uploaded to Covidence review software (Veritas Health Innovation
 180 Ltd).

181

182 Two authors (DE and TG) independently reviewed the results in the title and abstract and the
183 full-text phases for inclusion. Conflicts were discussed to reach a consensus, and the opinions of
184 the senior author (SM) were sought when necessary.

185 DE performed a grey literature review from March to April 2023, with frequent consultation
186 with the senior author (SM). This review included a manual search of all International Federation
187 of Gynaecology and Obstetrics (FIGO) member states' links to national obstetrics and
188 gynecology (OBGYN) societies, member lists from IFFS and ICMART, World Endometriosis
189 Society (WES) database-listed endometriosis societies, World Endometriosis Organizations
190 (WEO) member societies, and snowball searches from each society website. Each previously
191 known or newly discovered society website was reviewed for endometriosis care guidance of
192 any form, and the presence/absence and general characteristics of endometriosis care guidance
193 were included in a spreadsheet organized by country. It was recorded whether each country had a
194 national OBGYN society or reproductive health/fertility/endometriosis/minimally invasive
195 gynecologic surgery (MIGS) society, whether each country was a listed member of FIGO,
196 whether each country was a listed member of an overlapping multi-regional (global) society, and
197 whether there was any endometriosis care guidance located on any of those websites. If so, it was
198 recorded what language that guidance was in, the format, location, and authorship of that
199 guidance (e.g., a single Facebook post by an OBGYN, a local news article about endometriosis
200 awareness and options for management, a national comprehensive guideline for endometriosis),
201 and the date on which this information was accessed.

202
203 The same author (DE) then performed a broader search over three months from December 8,
204 2023, to March 8, 2024, using Google and Google Scholar to search for the highest
205 organizational level of guidance by country. Searches were conducted from Winnipeg, Manitoba,
206 Canada. Multiple search strategies were used for each individual country (**Appendix page 23**),
207 including searches in both English and the most common non-English languages used in each
208 country with the help of Google Translate. Documents, websites, social media pages, and peer-
209 reviewed publications were included if they offered region-specific endometriosis care guidance
210 in the form of a guideline, a consensus statement, a review, or even a single-author article or
211 social media posting if that was the highest organizational hierarchy document identified. Both
212 the existing document listing country-specific bibliographic returns and the list of known
213 endometriosis-related societies were expanded with discoveries from this search and finalized to
214 present the highest organizational hierarchical item identified per country.

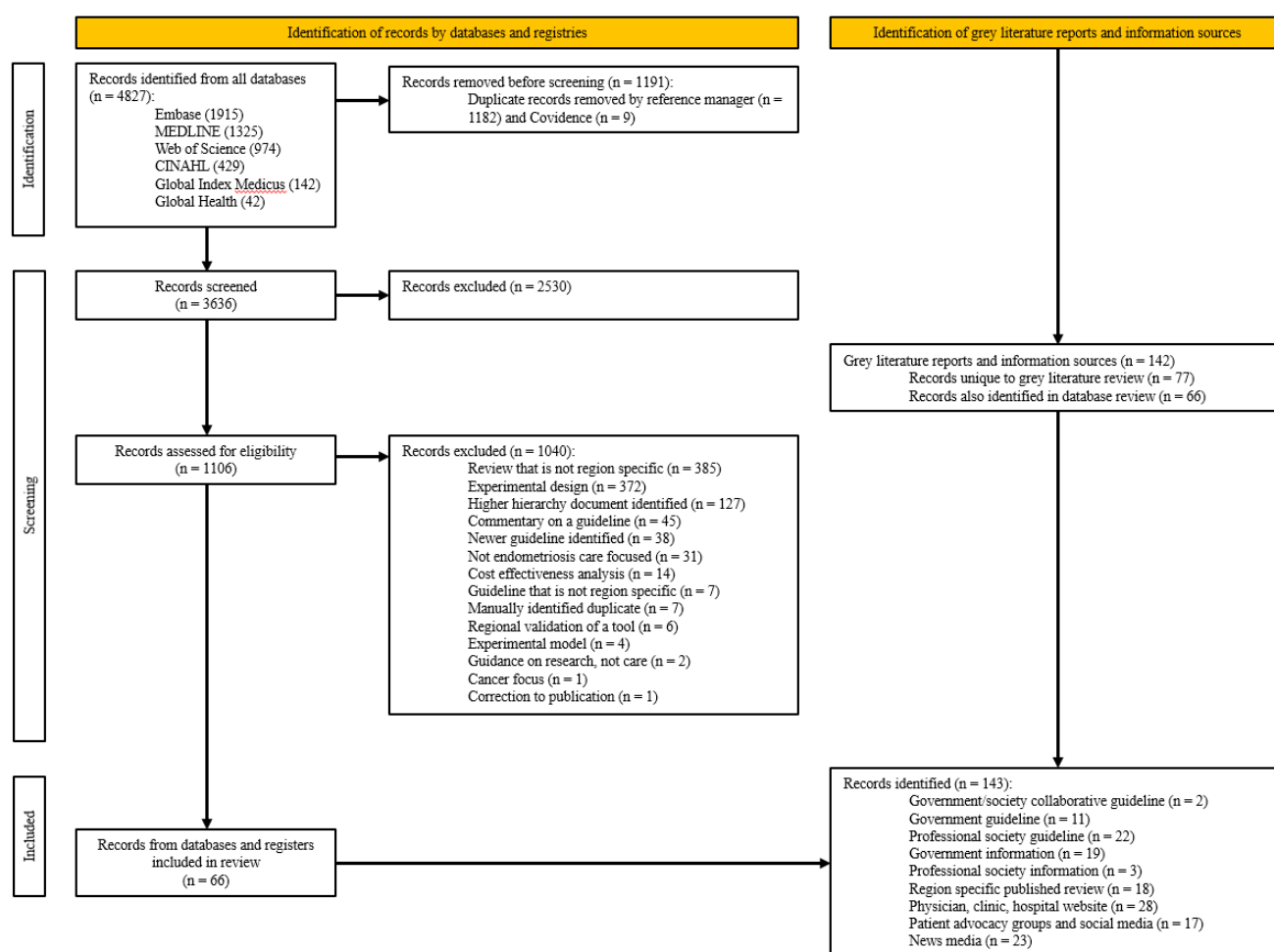
215 As indicated in the PRISMA-ScR checklist and methodologic recommendations,¹⁴ there was no
216 formal risk of bias or quality assessment. We anticipated marked heterogeneity of sources and
217 content, and the focus of this manuscript was identification of regional guidance, not assessment
218 of the quality of that guidance. A comprehensive spreadsheet **Supplementary Table S1** was
219 developed listing by every country the highest organizational hierarchy guidance identified, the
220 method of identification, the location and language of the guidance, the names and websites of
221 any national OBGYN societies and reproductive health, endometriosis, or MIGS societies
222 identified, FIGO membership, overlapping regional (global) care guidance, and overlapping
223 regional (global) societies. This information was then compared in table and map format to
224 highlight opportunities for improvement and characterize the level of guidance by country and
225 WHO-defined region (Africa, Eastern Europe, Western Europe, Americas, South-East Asia,

226 Western Pacific) with regional comparison of endometriosis care guidance and endometriosis-
 227 pertinent society coverage. Descriptive statistics are presented to summarize the findings.
 228

229 We engaged an international working group of endometriosis experts representing 16 different
 230 countries to help coordinate our interpretation and discussion of findings (Review of
 231 Endometriosis Global Care Guidance IFFS Working Group).
 232

233 **Results**

234 We searched six databases and identified 4827 records, of which 1040 were excluded and 66
 235 were included. All 66 documents identified in the database search were identified by the grey
 236 literature review, which also identified 77 additional sources of endometriosis care guidance
 237 (Figure 1).
 238



239
 240

241 The 143 unique sources identified corresponded to some level of endometriosis care guidance for
 242 141 of the 194 WHO-defined countries (73%); reciprocally, no endometriosis care-related item
 243 of any kind was found for 53 countries (27%). There were two countries (New Zealand and
 244 Peru) that have both a professional society guideline and a government guideline^{21,22} for
 245 endometriosis. The UK National Institute for Health and Care Excellence (NICE)²³ and French
 246 collaboration between Haute Autorité de Santé (HAS) and Collège National des Gynécologues et

247 Obstétriciens Français (CNGOF)²⁴ guidelines were considered collaborations between
248 government and society. The highest organizational level guidance by country (**Table 1**) was
249 government plus society collaborative guidelines (2/194, 1%), government guidelines (11/194,
250 6%), professional society guidelines (22/194, 11%), government information (19/194, 10%),
251 professional society information (3/194, 2%), region-specific published reviews (18/194, 9%),
252 physician/clinic/hospital information websites (28/194, 14%), advocacy websites and social
253 media (17/194, 9%), news media (23/194, 12%). All countries of the Western European region
254 had some level of endometriosis care guidance.

Region-specific OBGYN and endometriosis groups				
	National professional OBGYN society identified (regional proportion, %)	Patient advocacy group, reproductive health/endometriosis/MIGS society identified (regional proportion, %)		Professional Society and Government Collaboration
African region	28/47, 60% Algeria, Benin, Burkina Faso*, Cameroon, Congo, Cote d'Ivoire, Democratic Republic of the Congo*, Ethiopia*, Gabon, Ghana, Guinea, Kenya, Liberia*, Malawi*, Mali, Mauritania, Mozambique*, Niger*, Nigeria, Rwanda*, Senegal, Sierra Leone*, South Africa, South Sudan*, Uganda*, United Republic of Tanzania, Zambia, Zimbabwe	13/47, 28% Botswana, Congo, Gabon, Gambia*, Ghana, Kenya, Lesotho, Nigeria, South Africa, Togo*, Uganda*, United Republic of Tanzania, Zimbabwe		-
Eastern European region	15/21, 71% Egypt, Iran, Iraq, Jordan, Kuwait, Lebanon, Libya, Morocco, Oman, Pakistan, Saudi Arabia, Sudan*, Syrian Arab Republic*, Tunisia, United Arab Emirates,	3/21, 14% Egypt, Morocco, United Arab Emirates		-

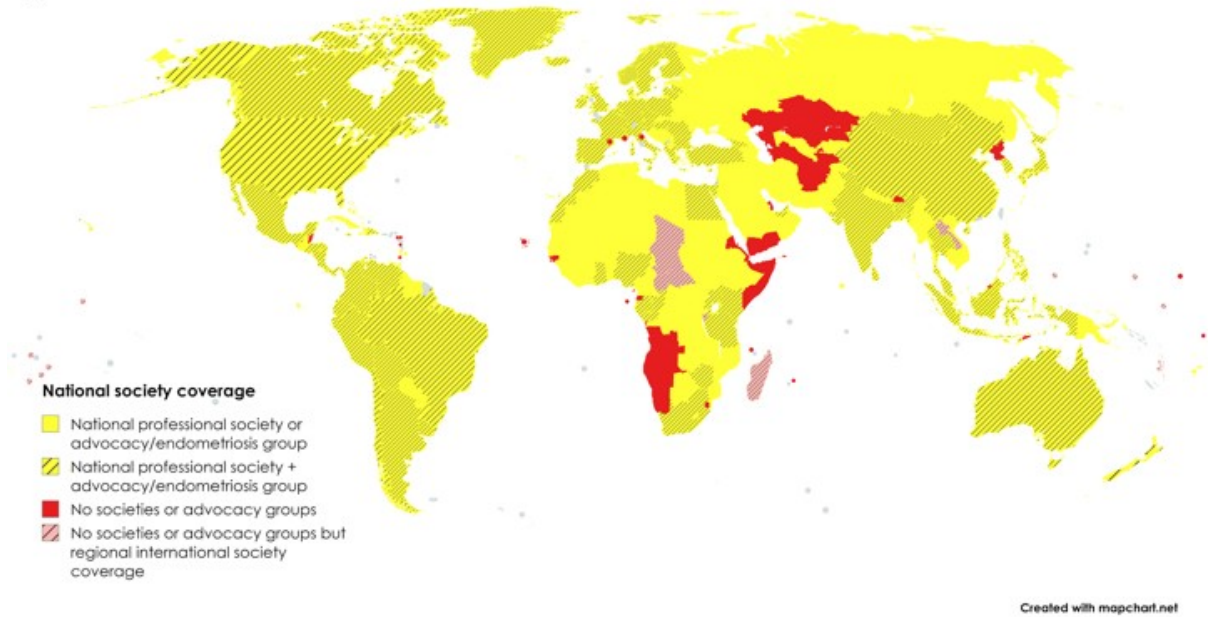
255
256

257 Of all 53 countries with no identifiable care guidance, 28 (53%) did have an endometriosis-
 258 specific national society and 11 (21%) had regional international society coverage; however, 15
 259 (28%) had no society coverage outside of overlapping regional (global) societies (**Table 2;**
 260 **Figure 2**). Of the 32 countries in the African region, for which no endometriosis care guidance
 261 item was found, 21 (66%) did have an endometriosis-specific national professional society or
 262 advocacy groups. Three (6%) were listed members of overlapping regional (global) societies, but
 263 none of these country-affiliated societies offered any endometriosis care guidance items.
 264

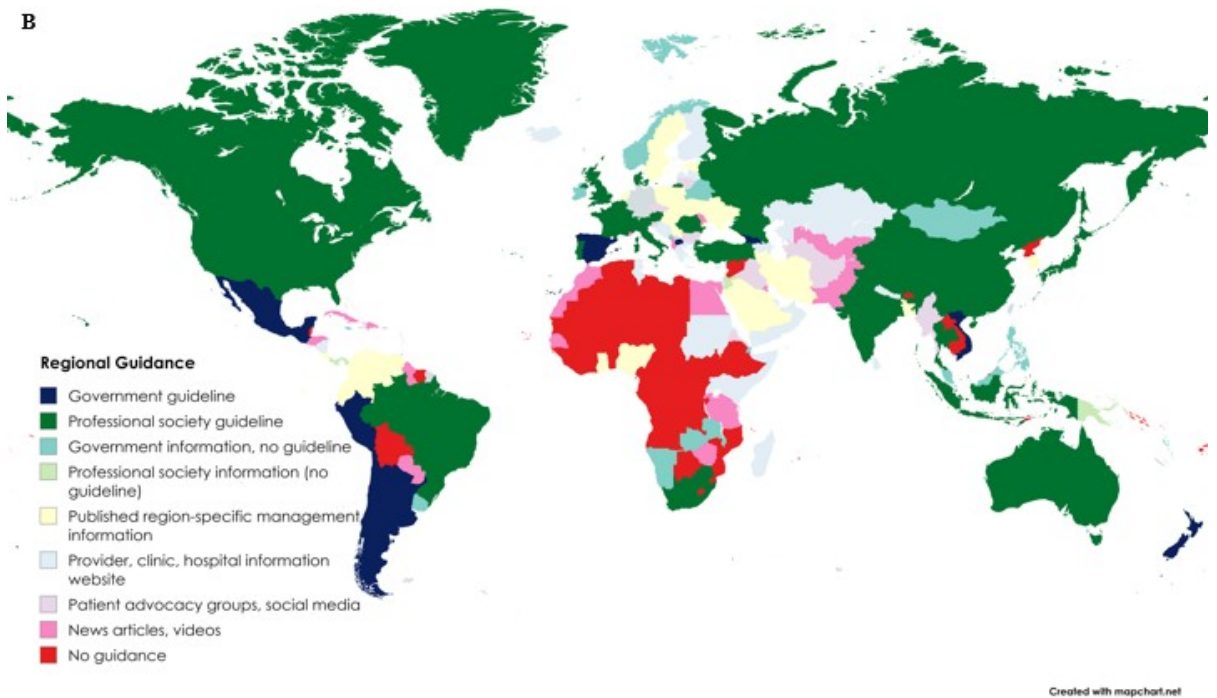
International OBGYN and endometriosis groups within each region				Society coverage	
Region	Regional international professional societies	Societies providing endometriosis guidance	No guidance (regional proportion, %)	Countries with no guidance, but national society coverage	Countries with no guidance, but national society coverage
African region	African Federation of Obstetricians and Gynecologists (AFOG), African Society for Sexual Medicine (ASSM), Societe Africaine de Gynecologie et d'Obstetrique (SAGO)	-	32/47, 68% Algeria, Angola, Benin, Botswana, Burkina Faso*, Burundi*, Cabo Verde, Cameroon, Central African Republic*, Chad*, Cameroon, Congo, Cote d'Ivoire, Democratic Republic of the Congo*, Equatorial Guinea, Eswatini, Ethiopia*, Gabon, Guinea, Guinea-Bissau*, Lesotho, Liberia*, Mali, Mauritania, Mauritius, Mozambique*, Niger*, Sao Tome and Principe, Seychelles, Sierra Leone*, South Sudan*, Togo*	21/47, 45% Algeria, Benin, Botswana, Burkina Faso*, Cameroon, Congo, Cote d'Ivoire, Democratic Republic of the Congo*, Ethiopia*, Gabon, Guinea, Lesotho, Liberia*, Mali, Mauritania, Mozambique*, Niger*, Sierra Leone*, South Sudan*, Togo*	
Eastern European region	Middle East Society for Sexual Medicine (MESSM)	-	2/21, 9% Libya, Syrian Arab Republic*	2/21, 9% Libya, Syrian Arab Republic*	
European region	European Society of Human Reproduction and Embryology (ESHRE), European Board and College of Obstetrics and Gynecology (EBCOG), European Endometriosis League (EEL), European Society for Gynaecological Endoscopy (ESGE), European Society for Sexual Medicine (ESSM), Nordic Federation of Societies of Obstetrics and Gynecology (NFIG)	European Society of Human Reproduction and Embryology (ESHRE), European Board and College of Obstetrics and Gynecology (EBCOG), European Endometriosis League (EEL), European Society for Gynaecological Endoscopy (ESGE)	0/53, 0% -	-	
Region of the Americas	American Association of Gynecologic Laparoscopists (AAGL), American Society for Reproductive Medicine (ASRM), Caribbean Society of Endoscopic Surgeons (CASES), formerly known as The Caribbean Association of Gynaecological Endoscopic Surgeons (CAGES), Federacion Latinoamericana de Sociidades de Obstetricia y Ginecologia (FLASOG), Federacion Centroamericana de Asociaciones de Obstetrician y Ginecologia (FECASOG), Sociedad Latinoamericana de Medicina Sexual (SLAMS), Sexual Medicine Society of North America (SMSNA)	American Society for Reproductive Medicine (ASRM), Federacion Latinoamericana de Sociidades de Obstetricia y Ginecologia (FLASOG), Federacion Centroamericana de Asociaciones de Obstetrician y Ginecologia (FECASOG)	4/35, 11% Belize, Bolivia, Saint Kitts and Nevis, Suriname	Bolivia, Suriname	
South-East Asia region	South Asian Society for Sexual Medicine (SASSM), Asian Society of Endometriosis & Adenomyosis (ASEA), Asia Pacific Association for Gynecologic Endoscopy and Minimally Invasive Therapy (APAGE), Asia-Pacific Endometriosis Expert Panel (APEX)	Asia Pacific Association for Gynecologic Endoscopy and Minimally Invasive Therapy (APAGE)	3/11, 27% Bhutan, Democratic People's Republic of Korea*, Timor-Leste	-	
Western Pacific region	Asia Pacific Initiative on Reproduction (APSIRE), Asia & Oceania Federation of Obstetrics & Gynaecology (AFOG), Pacific Society for Reproductive Health (PSRH), Asia Pacific Society for Sexual Medicine (APSM)	-	13/27, 48% Brunei Darussalam, Cambodia, Cook Islands, Fiji, Lao People's Democratic Republic, Marshall Islands, Micronesia (Federated States of), Niue, Palau, Samoa, Solomon Islands, Tonga, Tuvalu	Cambodia, Fiji	

265
 266
 267 The relationship between professional society coverage and highest organizational hierarchy
 268 endometriosis care guidance is depicted graphically in **Figure 2**.

A



B



269
270

271 A table summarizing sources of endometriosis care guidance and endometriosis-specific
272 professional society coverage by country is available in **Supplementary Table S1**. This
273 document links to all sources of identified guidance, including news media, social media
274 postings, advocacy groups, professional societies, and governments, and lists how each source of
275 guidance was identified, when it was accessed, and a basic summary of the content and nature of
276 the guidance.

277
278

279 **Discussion**

280 Understanding the availability of endometriosis care guidance is crucial for addressing global
281 disparities and focusing advocacy efforts. The most recent review assessing national and
282 international endometriosis guidelines was conducted in 2016.²⁵ However, the search was limited
283 by the English-language restriction, review of only three indexed databases, and exclusion of
284 grey literature. The review identified two international and five national guidelines for review
285 and comparison, all of which represented high-income countries. Thus, the true global landscape
286 of endometriosis guidance was not captured. This scoping review aimed to comprehensively
287 assess the existence, availability, and sources of guidance for endometriosis care, both diagnosis
288 and treatment, by country - with no restrictions on language, location, or quality of guidance.
289

290 **Global availability of endometriosis guidance**

291 We identified dedicated endometriosis care guidelines published by, or in collaboration with, 13
292 governments in Western Europe,^{23,24,26-29} the Americas^{22,30-33}, and the Western Pacific^{21,34}.
293 Additionally, 20 dedicated endometriosis care guidelines were identified produced by
294 professional societies that support care in Europe,^{23,24,26,35-41} the Americas,⁴²⁻⁴⁵ South-East Asia⁴⁶⁻⁴⁸
295 and the Western Pacific.⁴⁹⁻⁵¹ One national professional society guideline for endometriosis care
296 was identified for the entire region of Africa⁵² and no government or professional society
297 guideline for any country in the Eastern Europe region.
298

299 In 22 of the countries with dedicated care guidelines, government sources of endometriosis
300 information were also located spanning regions in Africa,⁵³⁻⁵⁵ Eastern Europe,⁵⁶ Western
301 Europe,⁵⁷⁻⁶² the Americas,^{63,64} South East Asia,⁶⁵ and the Western Pacific.⁶⁶⁻⁷¹ However, the level
302 of care guidance provided by these sources varied in their comprehensiveness and applicability.
303 For example, a 2014 national Malawi reproductive health service document⁵⁵ lists endometriosis
304 among many conditions potentially treated by oral contraceptives; the Uruguay Ministry of
305 Health published a 2023 World Endometriosis Day awareness post online with basic guidance
306 information.⁶³ Some nations have provided guidelines for dysmenorrhea management and raised
307 endometriosis as a potential cause (e.g., Zambia Ministry of Health National Treatment
308 Guidelines document⁵³).
309

310 In the 68/194 (35%) remaining countries of the world, our extensive multilayered scoping review
311 found no regional endometriosis care guidance beyond physician/clinic/hospital websites, news
312 articles, interviews, patient advocacy websites, and social media postings. Patients and providers
313 in countries with no local endometriosis-specific professional societies or government
314 information may only be guided by unregulated social media postings and private
315 provider/clinic/hospital websites. These unofficial postings may carry significant influence in
316 regions – for example, in Somalia a single post in 2009 on a health information forum had been
317 read 25,950 times as of January 25, 2024 (26,186 by March 15, 2024⁷²). Although individual
318 posts like this may reference robust guidelines from other regions, the recommendations may not
319 be appropriate for the local health system or cultural context. Further, this type of lower
320 organizational hierarchy endometriosis care guidance has a higher risk of including erroneous,
321 outdated, or biased care guidance. Although no guidance was identified, in Antigua and Barbuda,
322 the sole endometriosis-related item found in our multilayered search was a website that hosts a
323 single patient’s review of the services available in the country.⁷³ Saint Kitts and Nevis appears to
324 have a local NGO medical advocacy group that has arranged a local showing of the US-produced

325 endometriosis documentary, *Below the Belt*, to improve awareness, but the review failed to
326 identify any endometriosis care guidance item or endometriosis-specific professional society
327 engaged with the country.

328
329 Although there are many patient- and provider- facing reproductive health-focused professional
330 societies that address issues relevant to obstetrics and gynecology across the globe, their websites
331 range from essentially cover pages with no information provided to websites with extensive
332 networks of posted resources and links to further care guidance information. Even in countries
333 with reproductive health societies, the highest organizational level of region-specific guidance
334 identified was often of limited scope.⁷⁴ Moreover many national and international OBGYN
335 societies with digitally accessible presence fail to mention endometriosis, infertility, or pelvic
336 pain on their platforms.⁷⁵

337
338 In the absence of identifiable professional OBGYN, endometriosis, or other relevant societies,
339 the dissemination of government sources of endometriosis information is particularly important.
340 For example, as seen in countries such as Kiribati, Namibia, or Vanuatu, their respective
341 ministries of health have published national guidelines on family planning and OBGYN care that
342 include some basic information about treating endometriosis.^{54,69,70} Djibouti and Nauru, also with
343 no identifiable relevant professional societies, have posted limited and basic information about
344 endometriosis management on their ministry of health website⁵⁶ and in national medical
345 treatment guidelines,⁷¹ respectively. This important work outside of professional gynecologic
346 societies is commendable, especially given the established problematic lack of endometriosis
347 care guidance directed towards primary care providers versus endometriosis-focused specialists
348 in most parts of the world.⁷⁶ This is an active area of research focused on improving
349 endometriosis care in the primary care setting and, in turn, reducing delays to diagnosis.^{77,78}

350
351 The examples discussed, in addition to the comprehensive list of the highest organizational
352 hierarchy endometriosis care guidance (**Supplementary Table S1**), highlight the fact that efforts
353 are being made to advance endometriosis awareness and guidance in most parts of the world.
354 Individual patients, providers, news agencies, clinics, hospitals, advocacy groups, professional
355 societies, and governments are all contributing in different ways. This reinforces a strong,
356 immediate, opportunity to provide the minimal financial and experiential resources needed to
357 update or create country-specific resources and improve regional access to best care practices for
358 endometriosis.

359 360 **Opportunities for improved access to guidance**

361 Dissemination and implementation of practice guidance is not a simple task. There is extensive,
362 active debate on how best to bridge the gap between research and practice through quality
363 improvement and implementation science.^{79,80} We propose that there are several ways to improve
364 regional guidance that may be high-impact but not require *de novo* generation of practice
365 guidance. Adaptation of existing guidance documents is one such strategy. For example, even in
366 countries where endometriosis care may be considered a low priority for public health needs,
367 existing comprehensive culturally contextual endometriosis care guidelines could be referenced
368 through the addition of links on government and health-related professional society and
369 advocacy group websites. Additionally, these could be translated to local languages as was done
370 by the Georgian Obstetricians and Gynecologists Association (GOGA).²⁸

371
372 Another example is the Netherlands, where there has been an effort to survey regional
373 gynecologists and summarize their level of agreement with each of the ESHRE guideline
374 statements rather than produce an entirely new guideline in order to save health care
375 professionals' time, and reduce costs for society.⁸¹ Linkage to existing guidelines may be a
376 particularly beneficial initial strategy for those international OBGYN societies in Africa (African
377 Federation of Obstetricians and Gynecologists (AFOG), African Society for Sexual Medicine
378 (ASSM), and Societ e Africaine de Gyn cologie et d'Obst trique (SAGO)) that span many
379 countries but perhaps have not yet produced an endometriosis care-focused item due to
380 competing public health concerns that have required prioritization of finite resources away from
381 endometriosis.

382
383 Improved access to regional guidance may also be achieved by linking an existing national
384 guideline to an existing national society or government website. Despite the presence of
385 dedicated guidelines, this review found that often, key sources of guidance (governments and
386 societies) had not provided links to one another, representing a missed opportunity to improve
387 the promotion of standardised care. For example, in Argentina, the Sociedad Argentina de
388 Endometriosis (SAE) links to external societies and provides information about endometriosis,
389 but could also provide a link to the Argentinian ministry of health national endometriosis
390 guideline.³¹ In New Zealand, the patient advocacy group Endometriosis New Zealand could add
391 a link to the New Zealand's national government guideline²¹ or the RANZOG guideline.⁴⁹ In
392 Mexico, patient advocacy group Endometriosis Mexico, Federaci n Mexicana de Colegios de
393 Obstetricia y Ginecologia (FEMECOG), and Instituto de Endometriosis y Dolor P lvico (IN-
394 ENDO) could each link to the national Mexican endometriosis guideline.³⁰

395
396 In geographical regions where the predominant publicly available information on endometriosis
397 is maintained by patient advocacy groups, the posted information may reach and connect with
398 the affected population effectively, but the factual accuracy of medical content might be
399 optimized by collaboration and engagement with healthcare providers. Historically, perhaps in
400 large part due to inadequate provider knowledge connected to dismissive care, there has been a
401 high degree of patient mistrust in their providers around the world.⁸² However, given the intuitive
402 suggestion that there is an inverse relationship between provider competence and patient
403 mistrust,⁸³ collaboration between providers and patient-led advocacy groups on improving local
404 practice guidance could have bi-directional, mutual benefits. Collaboration between gynecologic
405 specialty societies and primary care societies may also help to improve the relevance and
406 practicality of guidance recommendations for regions where primary care providers serve as
407 gatekeepers to specialty care. Ideally, everyone affected by endometriosis would have access to
408 consistent and contemporary evidence-based care regardless of geography.

409
410

411 **Limitations and strengths**

412 Despite the bibliographic database search being peer-reviewed and conducted rigorously, it was
413 limited by the fact that the majority of endometriosis care guidance is published in sources not
414 accessible by peer-reviewed databases. Consequently, we designed the subsequent grey literature
415 review in consideration of the most globally accessible methods and sources of evidence. Of
416 note, had we excluded grey literature from social media, news media, advocacy websites, and

417 blog content, we would have devalued the contributions these individuals and groups have made
418 to provision of local endometriosis care guidance in 68 countries around the world (35% of all
419 WHO-recognized member-states). Such an approach would apply a geopolitically biased lens,
420 similar to previous attempts at assessing regional guidance, which have missed and devalued the
421 important work that has been done outside of the peer-reviewed, indexed literature dominated by
422 high-resource countries.

423

424 Simple Google and Google Scholar searches (i.e., country name + endometriosis) are much more
425 accessible than indexed database searches due to the ability of these tools to search full text. Our
426 findings offer pragmatic information for patients, providers, and policymakers with respect to
427 what is available to them readily through simple internet searches and review of their local
428 professional society, patient advocacy, and government websites. However, the output of our
429 searches may have been limited by ‘black box’ search filters in the Google search algorithms
430 incorporating search location and history (searches were performed from Winnipeg, Manitoba,
431 Canada). Additionally, our attempts at non-English language searches relied heavily on Google
432 Translate, which may not have accurately translated search terms for all languages.⁸⁴ Similarly,
433 although engagement with country-level stakeholders for regional validation of findings would
434 be ideal, this would have been impossible to achieve for all 194 countries assessed during this
435 study protocol.

436

437 Another limitation of this study is that we did not formally assess the quality of guidance beyond
438 the ‘organizational hierarchical levels’ that we defined based on location and context of the
439 guidance. However, the goal of this study was not to assess the quality of endometriosis care
440 guidance, but rather to explore whether endometriosis care guidance exists by region. Future
441 work should explore the relative quality of guidance as well as the cultural competence of the
442 country in which it would be implemented. This type of quality assessment will be a significant
443 undertaking, requiring in-depth analysis of regional guidance and ideally with multi-level
444 stakeholder engagement to create meaningful, contextually appropriate comparisons. However,
445 we propose that evaluating care guidance must occur in parallel with improving access to it
446 given the worldwide dearth in endometriosis awareness and barriers to diagnosis and any
447 treatment. This is a natural and anticipated future direction from our work in this scoping review.

448

449 **Conclusion**

450 We present what to our knowledge is the only comprehensive assessment that has been
451 performed to date for region-specific endometriosis care guidance worldwide. There is marked
452 geographical heterogeneity in the existence, number, quality, and published location of
453 endometriosis care guidance items. In regions where national professional societies or advocacy
454 groups exist, many do not reference published endometriosis care guidelines even when they
455 exist locally. Particularly, in many African and Eastern Mediterranean regions, it appears that
456 clinicians and patients have no context-appropriate endometriosis care guidance to reference.
457 There are reproductive health societies affiliated with most countries in the African region that
458 could provide this. In Eastern Mediterranean regions, there is an absence of both reproductive
459 health societies and endometriosis care guidance.

460

461 This review identified significant efforts put forth in high-, middle-, and low-income countries to
462 provide some level of local guidance for endometriosis. There is probably a ‘hierarchy of needs,’

463 but even where there are public health concerns prioritized above those burdened by
464 endometriosis, reproductive health advocacy groups and professional societies could reference
465 (including translation where needed) existing high-quality, regionally culturally competent,
466 guidelines for endometriosis care. To ensure that patients and providers have access to high-
467 quality endometriosis care guidance documents, region-specific or not, reproductive health-
468 focused groups and societies need to review and maintain their patient- and provider-facing
469 digital resources.

470

471 We present this scoping review as a descriptive summary of regional availability of practice
472 guidance and hope that it can inform future initiatives that work towards global awareness of
473 endometriosis and contextually appropriate care guidance. This review also offers opportunities
474 for collaboration in the future: We welcome letters to the authors, ICMART, IFFS, WHO, and
475 WES.

476

477 **Contributors statement**

478 SM, KZ, LG, GDA contributed to conceptualization and supervision of the project. DE, TG, SM,
479 and KZ developed the methodology of the project, with administrative tasks performed by DE
480 and TG. BS contributed to data curation by assisting with and coordinating the development,
481 peer review, and execution of the indexed database search protocols. Funding for the
482 contributions by BS was acquired by GDA and LG. DE and TG contributed to data curation,
483 investigation, validation, and analysis by performing independent review of the indexed database
484 returns and selection of included works. DE independently performed the grey literature review.
485 Writing of the original draft was by DE, TG, SM, and KZ, with visualization and review and
486 editing by all listed authors equally. The Review of Endometriosis Global Care Guidance IFFS
487 Working Group reviewed the original draft and provided feedback equally to inform the final
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489

490 **Declaration of interests**

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743

744 **Figure Legends**

745 **Figure 1.** PRISMA-ScR flow diagram summarizing the process of record identification and selection

746

747 **Table 1.** Professional society and advocacy group coverage and highest organizational level of endometriosis care
748 guidance by World Health Organization–defined member states (“countries”) and region. *Low-income economies
749 (World Bank, 2024). **New Zealand and Peru have separate dedicated government and society guidelines.

750

751 **Table 2.** Relationship between professional society coverage and absence of endometriosis care guidance by WHO-
752 defined region. *Low-income economies (World Bank, 2024).

753

754 **Figure 2.** WHO–defined country-specific relationship between (a) endometriosis-pertinent professional society
755 coverage and (b) highest organizational hierarchy item of endometriosis care guidance available.