

1 Endometriosis Policy and Delivery 2 Systems: A Comprehensive Global 3 Scoping Review

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106 **Summary**

107 Despite its prevalence and socioeconomic impact, endometriosis is underrepresented in
108 global health policy. This scoping review is the first to comprehensively map the availability
109 of global endometriosis policies. The 477 included documents demonstrated three
110 governance methods used globally to outline endometriosis policy: 1) Endometriosis National
111 Action Plans (NAPs); 2) Integration of endometriosis policy and initiatives into other health
112 NAPs; and 3) Endometriosis laws. Endometriosis initiatives also existed outside organised
113 policy frameworks. A thematic analysis enabled the aggregation of global endometriosis
114 policies and initiatives within the WHO Health System Building Blocks. Further analysis
115 revealed the maturity of countries' policy development. Unfortunately, no information could
116 be detected for 98 countries. However, 48 countries had identified endometriosis as a national
117 problem, 36 countries had set the agenda for a national endometriosis strategy, 8 countries
118 were adopting policies for a national endometriosis strategy, and 4 were implementing and
119 evaluating their strategies. Despite the global scarcity of endometriosis policy frameworks,
120 the review highlights promising examples, most notably Australia and France's
121 endometriosis NAP, that could be adapted by countries seeking to advance their
122 endometriosis policies.

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155 **Introduction**

156 Endometriosis is a condition that affects approximately 190 million people worldwide, and
157 for some, it can be a disabling disease with a significant impact on quality of life.¹ Despite its

158 prevalence, endometriosis has historically been underrepresented in public health discourse
159 and policy agendas. This oversight is reflective not only of the stigma often associated with
160 diseases considered as menstrual-related but also of the gender health gap in medical care
161 globally.²⁻⁴ Similarly to endometriosis, mental health conditions present significant
162 healthcare and socioeconomic burdens that require coordinated approaches spanning
163 healthcare, workplace, and social systems. Mental health conditions have also been
164 historically stigmatised and neglected in policy representation. In response, the World Health
165 Organisation (WHO) developed Project Atlas⁵ in 2000 to map, track and promote the
166 availability of mental health policies across the globe. A 2021 report⁶ demonstrated that 75%
167 of the 194 WHO member countries had a stand-alone policy or plan for mental health (an
168 increase from 68% in 2014) and 57% had a mental health law (an increase from 51% in
169 2014). To date, there is no programme to map or track global endometriosis policy reform.

170 Various stakeholders, including non-governmental organisations (NGOs) and governmental
171 organisations, have made attempts to improve the political prioritisation of endometriosis.
172 For example, in 2004, the European Parliament began calling upon governments to promote
173 an annual EU Endometriosis Day, to raise awareness of endometriosis and for the European
174 Commission to include prevention of endometriosis in future Community Action
175 Programmes.⁷ This progressed further in 2017, with the European Parliament urging EU
176 member states to increase funding for endometriosis research, draft clinical guidelines,
177 establish reference centres, promote awareness-raising campaigns on endometriosis, and
178 support the training of specialised health professionals. Moreover, member states were asked
179 to consider making endometriosis treatment free and providing sick leave during acute
180 periods of illness.⁸ The response of the EU governments to this call, along with those of other
181 countries to the broader challenges of endometriosis, has not yet been systematically assessed

182 A country demonstrates its response to national challenges and its degree of prioritisation by
183 the policies it implements.⁹ Policies as described by the WHO “provide a strategic vision for
184 the health sector...in a single document, a set of policies, laws...to which governments can
185 be held accountable”.¹⁰ Policies are often operationalised in National Action Plans (NAPs),
186 which describe carefully selected initiatives (specific actions) tailored to reach the objectives
187 of the policy. Policies can influence research priorities, resource allocation, and healthcare
188 provider practices, as well as promote collaborative initiatives among multiple stakeholder
189 levels.^{3,9} In 2023, the WHO emphasised the importance of advocacy for policies related to
190 endometriosis.⁹

191 NGOs such as advocacy groups and clinical professional bodies also generate initiatives in
192 response to identified gaps in support or guidance for those living with health conditions.¹¹
193 These examples of healthcare governance outline one of the six core WHO health system
194 building blocks¹² of a healthcare system (Service Delivery, Health Workforce, Health
195 Information Systems, Access to Essential Medicines, Health Financing, and Leadership &
196 Governance). They are interwoven and integral to the operationalising of the remaining
197 building blocks that make up healthcare delivery systems.

198 This scoping review aims to systematically explore and map the global landscape of
199 endometriosis policies within healthcare frameworks, shedding light on healthcare
200 inequalities and identifying initiatives that could be implemented globally. The review
201 presents the first step in mapping and tracking the global progress of endometriosis policy.

202 **Methods**

203

204 An iterative scoping review was conducted using an adapted Arksey and O'Malley Scoping
205 review framework.¹³ Reporting was performed according to the Preferred Reporting Items for
206 Systematic reviews and Meta-analysis extension for Scoping Reviews (PRISMA-ScR)
207 checklist¹⁴ in the appendix (p 1-2).

208

209 The PCC framework¹⁵ (population, concept, and context) was followed to determine the
210 scoping review objective: To descriptively map for people with endometriosis (population),
211 the a) availability and b) maturity of healthcare policies and delivery systems (concept) by
212 country/geographic region (context).

213

214 **Search strategy and selection criteria**

215 OVID platform, MEDLINE, Embase, Global Health, CINHALL (EBSCO), Web of Science
216 (core collection), and Global Index Medicus (all indexes) databases were searched from
217 inception in English most recently on the 16th of July 2024. Full details of the method, search
218 strategy, search terms and search results are outlined in the appendix (p 2, 3 and 16-108).

219

220 Grey literature refers to documents produced by various levels of government, academia, or
221 the media that are not subject to commercial publishing regulations.^{20 16} A systematic two-
222 step grey literature search was conducted on Google and Google Scholar, most recently
223 between February-April 2024. The first step involved searching for NAPs (for General
224 Health, Reproductive Health, Women's Health, and Endometriosis) in all 194 WHO member
225 countries¹⁷, in both English and the countries' majority language. The second phase involved
226 searching for the presence of endometriosis initiatives in prominent policy documents, such
227 as interparliamentary discussions, laws, and bills in each of the 194 WHO member countries
228 (full methods and search terms in the appendix p 3 and 109-110).

229

230 **Data selection criteria and hierarchy**

231 The review includes publications from policymakers or prominent NGOs (source) on those
232 with endometriosis (population), referring to policy and delivery systems (concept). The data
233 were grouped by country, defined as a WHO member state (context). All (inter)national and
234 regional documents were included, but priority was given to national documents. There was
235 no language or date restriction. Data not from government-commissioned working groups,
236 prominent expert groups, advocacy groups or NGOs were excluded, as priority was given to
237 high-level documents and policies. The full inclusion and exclusion criteria can be found in
238 the appendix (p 3-4).

239

240 **Synthesis of results**

241 An inductive and deductive Braun and Clarke's Thematic Analysis of results was conducted,
242 which involved the generation of codes to summarise the policy initiatives, for example, the
243 development of an awareness campaign. Unless specified, the 'n' represented the number of
244 countries where documents were identified, irrespective of the number of documents per
245 country identified, to reduce the inflation effect from countries with numerous documents.
246 Following the primarily inductive thematic analysis, a deductive framework was used to
247 aggregate themes into the WHO health system's six core building blocks¹²: Governance and
248 leadership (how endometriosis initiatives and policies are organised e.g. NAPs and laws),
249 Service delivery (initiatives develop a care system), Health workforce (initiatives to train and
250 inform the health workforce), Access to essential medicines (initiatives to provide timely
251 access to high-quality care), Health information systems (initiatives to raise awareness and to
252 promote patient education and research) and financing (initiatives to provide financial
253 protection).

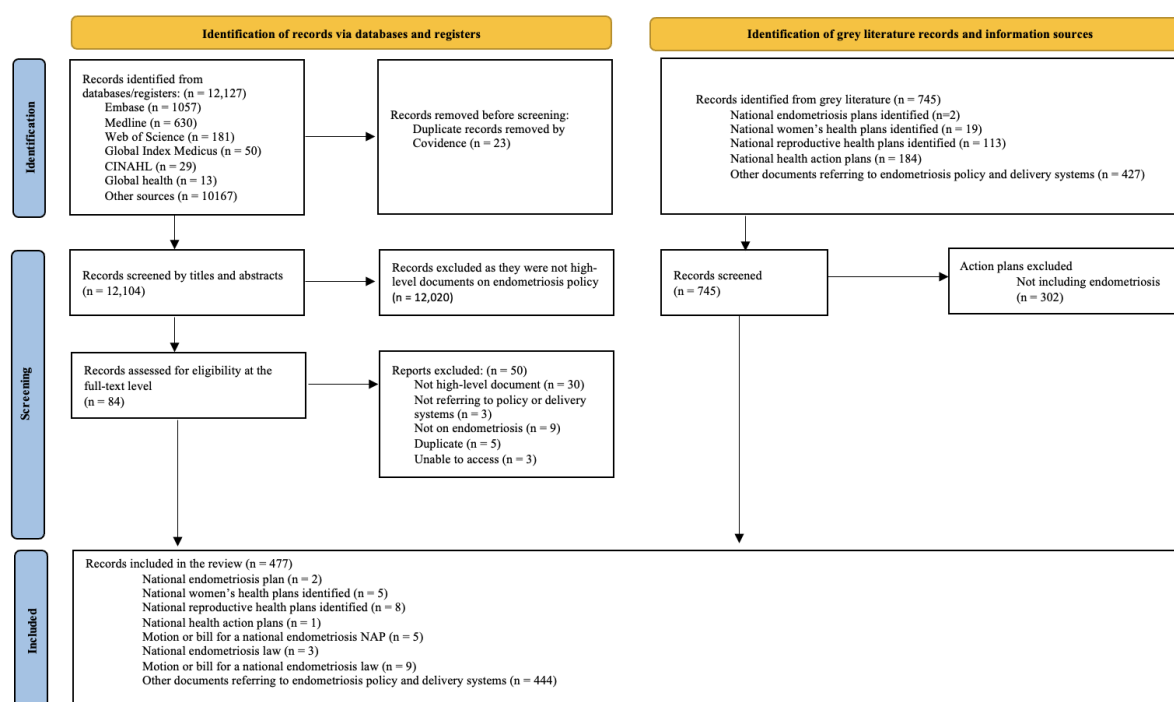
254 When reporting endometriosis NAPs and laws, key priorities and initiatives, and domains of
 255 the PANEL framework (Participation, Accountability, Non-discrimination, Empowerment,
 256 and Legality) were prioritised. Frameworks such as PANEL ensure that a human rights-based
 257 approach is taken when developing health policies (in the appendix p 4-5). When reporting
 258 endometriosis initiatives that exist outside of policy frameworks (e.g. NAPs and Laws),
 259 initiatives from countries without NAPs and Laws were prioritised to provide a broader scope
 260 of endometriosis activities. However, the full results are presented in the **Supplementary**
 261 **Excel file**.

262 Finally, the data were analysed for each country to determine where each country exists
 263 within its journey to develop a comprehensive endometriosis strategy (policy maturity) by
 264 comparing the findings to Heuristic Models of policy development, such as those presented
 265 by Howlett and Ramesh¹⁸ (full methods in the **appendix p 7-9**). Each country's stage of
 266 policy maturity was depicted on a map (**Figure 2**). The justification for each judgement can
 267 be found in the **Supplementary Excel file**. Judgments were based primarily on national data;
 268 however, in instances where there was convincing evidence, regional data were also used, for
 269 example, when there was evidence of evolving policy reform in countries with provincially
 270 led health policy systems.

271 **Results**

272 A total of 12,127 documents were retrieved from the database search. Once the exclusion
 273 criteria were applied (criteria in the appendix p 3-4), only 34 documents were included due to
 274 databases holding primarily academic literature. In addition, 443 grey literature results were
 275 included, totalling 477 documents (**Figure 1** and the **Supplementary Excel file**)

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280 **The Leadership and Governance Building Block**

281

282 This building block discusses the strategic planning and oversight of health systems to ensure
 283 that policies are implemented effectively and are accountable through monitoring practices.

284

285 The scoping review found four key strategic frameworks used by countries to operationalise
286 their endometriosis policies: 1) Stand-alone endometriosis NAPs, 2) Integrated endometriosis
287 policies within other health NAPs, such as Women’s Health NAPs, 3) Stand-alone
288 endometriosis law.

289
290 ‘Stand-alone’ refers to a dedicated national document exclusively on endometriosis. Stand-
291 alone laws and plans are key indicators used to monitor policy progression in the WHO
292 Mental Health Atlas.

293 **Leadership and Governance Building Block: Stand-alone Endometriosis NAPs**
294 Two of the 194 WHO member states/countries, Australia and France, had independent
295 endometriosis NAPs.

296
297 The 2018 Australian National Action Plan for Endometriosis (NAPE)¹⁹ was the first to be
298 developed. Its generation was inspired by “passionate patients and parliamentarians”, called
299 parliamentary friends of endometriosis awareness.²⁰ The NAPE’s three main priorities were
300 raising awareness, maximising access to clinical management and promoting research. A
301 flagship initiative was the development of the National Endometriosis Clinical and Scientific
302 Trials (NECST) Network,²¹ comprising of clinicians, scientists and patients committed to
303 filling gaps in endometriosis research. To reduce the risk of discrimination and barriers to
304 health of at-risk groups, the NAPE highlighted that care provided should be culturally and
305 linguistically tailored.¹⁹ The Endometriosis Advisory Group ensured accountability to drive
306 the implementation of the plan's actions. Progress updates were scheduled for review at 1, 3
307 and 5 years. A 2024 progress report²² highlighted various project-specific investments
308 totalling 87.2 million Australian Dollars. The efforts included endometriosis research grants,
309 support for EndoZone²³ (an educational digital platform for patients), and the Periods, Pain
310 and Endometriosis Programmes²⁴ (teaching students about unusual menstruation). The report
311 stated that all the planned projects have been initiated, with estimated completion dates
312 provided up to 2026. The next phase will be to complete and evaluate the initiative’s
313 effectiveness.

314
315 The French endometriosis NAP²⁵ followed in 2020. Similarly to the Australian NAPE, the
316 French NAP was developed in consultation with nearly “200 experts, patient associations,
317 health professionals and researchers”. Both NAPs shared the same three priorities: raising
318 endometriosis awareness, improving access to quality care and supporting research. Its
319 flagship initiative is to develop the world's largest endometriosis epidemiological database
320 using six French cohort studies to generate accurate epidemiological data on endometriosis.
321 The NAP recognised the presence of populations and regions with unequal access to care. It
322 stipulated that these should be targeted in future regional health projects (PRS) with the
323 assistance of patient associations and regional health observatories. Accountability was
324 ensured through the oversight of various ministries, which have developed roadmaps to
325 achieve the NAP targets. In 2023, the NAPs steering committee, made up of various
326 ministries including the Minister of Higher Education and Research, the Minister of Health
327 and Prevention, and the Minister for Equality between Women and Men, declared that 85%
328 of NAPs initiatives have been implemented or completed.²⁶ For example, to ensure patients
329 receive a timely diagnosis and quality care nationwide, the NAP planned the establishment of
330 dedicated endometriosis units in each geographic region. Supported by €4.5 million annually
331 from the Regional Intervention Fund, five regions have already completed setup, and the
332 Health Minister stated that the remaining units must be set up by the end of 2023.

333
334 In six countries, policymakers have raised motions for an endometriosis NAP, including
335 Sweden in 2019, Austria, Canada, Germany, Spain (regional) in 2022 and Portugal in 2023.

336
337 **Leadership and Governance Building Block: Endometriosis Policy Integrated Within**
338 **Women’s Health NAPs**

339 Nineteen of the 194 WHO member countries were found to have Women’s Health NAPs (the
340 **Supplementary Excel file**). Only four countries had government-led Women’s Health NAPs
341 with endometriosis initiatives integrated: Australia and France (in addition to their NAPs),
342 Ireland, and two in the UK.

343
344 Scotland's Women's Health NAP of 2021-2024²⁷ was guided by the Endometriosis All-Party
345 Parliamentary Group (APPG) Inquiry,^{28,29} which included the insights of 10,783 people with
346 endometriosis. The NAP aimed to reduce the diagnosis delay from 8 years to 12 months.
347 Similarly to the stand-alone endometriosis NAPs, initiatives to raise awareness, improve
348 access to quality care and support research were discussed. A fundamental goal was to
349 empower women with consistent information on their health throughout their life course. The
350 NAP addressed gender inequalities in healthcare by aligning its policies with the European
351 Convention on Human Rights and the Convention on the Elimination of Discrimination
352 Against Women. The Women's Health Plan Implementation Programme Board ensured
353 accountability and that the plans were implemented appropriately. A 2023 progress report³⁰
354 highlighted completed initiatives being implemented to achieve the NAPs aims. For example,
355 to support the NAPs aim of developing care pathways, NHS Scotland has approved a
356 standardised Integrated Endometriosis Referral Care Pathway as part of the Modernising
357 Patient Pathways Programme (MPPP) to outline how patients with suspected or confirmed
358 endometriosis should be referred and managed. Moreover, to support the NAPs intentions to
359 commission research, in December 2022, £250,000 was allocated to research projects
360 developing improvements in endometriosis treatment and management.

361
362 The second NAP in the UK that integrated endometriosis policy is England's 10-year
363 Women's Health Strategy 2022³¹, that responded to the gender inequality in healthcare and a
364 call for evidence from women and expert stakeholders. Similarly to the other NAPs
365 discussed, England's NAP initiatives aimed to raise endometriosis awareness, improve access
366 to clinical care and support research. A cross-government delivery system is overseeing the
367 implementation of the NAP, and an implementation framework has been provided to
368 demonstrate how the NAP will be implemented and refined, with a progress report expected
369 in 2025.

370
371 The Irish Women's Health NAP 2022 – 2023³² aimed to improve endometriosis clinical care.
372 The 2023 progress report highlighted the establishment of two supra-regional specialist
373 centres and additional funding to develop a regional network for endometriosis.

374
375 **Leadership and Governance Building Block: Endometriosis Policy Integrated Within**
376 **Reproductive Health NAPs**

377 113 out of 194 WHO member countries were found to have reproductive (including sexual or
378 fertility) health plans; only 31 were current as of 2024. NAPs of only 8 countries referred to
379 endometriosis, including 5 that outlined government initiatives (Finland, France, Italy, the
380 Maldives, and Mauritius). See the **Supplementary Excel file**, for the identified NAPs.

381
382 The Maldives' 2020-2025³³ National Reproductive Health Action Plan (RMNCAH), a
383 collaborative effort of various stakeholders, including the Ministry of Health, NGOs and UN
384 agencies, aimed to increase endometriosis awareness, access to care (including services for
385 complex cases), and endometriosis research. The NAP highlighted that the unknown national
386 prevalence of endometriosis, limited awareness, and insurance providers' disease
387 classifications were current barriers to care, which could be overcome through national
388 research. This would support the advocacy for endometriosis care to be included in national
389 health insurance packages. Accountability was ensured by assigning each intervention a
390 responsible group and developing annual targets, for example, the gradual increase in tertiary
391 hospitals offering endometriosis care from 75% in 2020 to 100% in 2025.

392

393 Three reproductive health NAPs included a single endometriosis initiative, most centring
394 around education and research. Italy’s 2014 fertility NAP³⁴ focused on teaching healthcare
395 professionals factors that affect fertility and strategies to assist with the early diagnosis of
396 endometriosis. Finland’s sexual and reproductive NAP 2014–2020³⁵ wished to investigate the
397 effects of environmental toxicants on diseases such as endometriosis. Whilst Mauritius’
398 2022-27 NAP³⁶ set research priorities of data gathering for an endometriosis “severity and
399 infertility” survey.

400
401 Cabo Verde’s 2008-2012 NAP highlighted endometriosis as a frequent cause of
402 consultations. Whilst Chile and Malawi referred to the use of oral contraceptives for
403 endometriosis.

404 405 **Leadership and Governance Building Block: Endometriosis Policy Integrated Within** 406 **General Health NAPs**

407 General Health NAPs typically outline the nation's health priorities and could indicate how
408 far endometriosis was considered a national priority. National health plans were identified in
409 184 countries, but only 106 were current in 2024 (found within the **Supplementary Excel**
410 **file**). Only Italy included endometriosis, to support endometriosis research, including the
411 study of national incidence.

412 413 **Leadership and Governance Building Block: Stand-alone Endometriosis ‘laws’**

414 Ten countries (Argentina, Brazil, Chile, Costa Rica, Dominican Republic, Italy, Mexico,
415 Portugal, Uruguay and the USA) have taken an alternative approach to developing an
416 endometriosis policy by raising bills for a national ‘endometriosis law.’

417
418 Endometriosis laws have been passed in 5 countries: Panama, Colombia and Peru nationally,
419 Italy and Argentina regionally. These bills and laws often provide a comprehensive
420 framework and legislative obligation for policymakers to develop and implement strategies
421 for endometriosis. Initiatives included in the Endometriosis NAPS and Laws share many
422 similarities, as explored in the policy comparison table in the appendix (p 10-12). All of the
423 laws promoted initiatives to improve access to care, train healthcare staff, promote research,
424 and develop patient registries.

425
426 In April 2021, Panama passed the endometriosis bill (440) into ‘Law 213’.³⁷ This law
427 assigned the Ministry of Health the responsibility of developing strategic initiatives to raise
428 awareness, provide training for groups such as healthcare workers, improve access to care,
429 and promote research. NGOs such as patient groups were encouraged to participate in the
430 development of initiatives that followed from the law. Furthermore, an interinstitutional
431 commission would be developed to empower endometriosis patients with information and
432 support. To promote labour rights, the law recognised endometriosis as a chronic disease
433 under Panama’s Labour Law 59 of 2005. Finally, in Law 213, budgetary and oversight
434 responsibilities were stipulated to ensure accountability. The search did not locate
435 information on the implemented initiatives.

436
437 Two endometriosis laws were passed in South America in 2023. Peru passed Law 31868³⁸
438 encouraged initiatives to improve health worker training, creating specialised service units, a
439 patient registry, and progressively implementing programs to assist with fertility preservation.
440 Two months later the president of Colombia sanctioned ‘Law 2338,’³⁹ which allocated the
441 Ministry of Health one year to implement a comprehensive endometriosis public policy. Both
442 Peru and Columbia’s law actively encouraged citizen and NGO participation in the

443 development of initiatives. Similarly to the Australia, France, Scotland, England and the
 444 Maldives NAPs and Panama’s law, Colombia’s Law proposed initiatives to raise awareness,
 445 improve clinical care services and pathways, health worker training and research programs. A
 446 key initiative was the promotion of flexible working arrangements for those with
 447 endometriosis. Accountability was encouraged with the requirement of an annual report to
 448 the Columbian Congress. However, the report was not identified in the search.

449
 450 In addition to the bills for a national endometriosis law, Italy (2012-2021) and Argentina
 451 (2019-2023), both with strong provincial healthcare regulations, passed numerous regional
 452 laws with similar objectives to the national laws (a table of global policy comparisons can be
 453 found in the appendix p 10-12). For instance, in 2016, the Italian Chamber of Deputies
 454 approved a motion⁴⁰ that called on the Italian government to adopt initiatives recognising
 455 endometriosis as a disability, reducing healthcare costs, improving workplace support, and
 456 enhancing research and awareness, including the establishment of a national register. In
 457 response, several Italian regional councils and governments have introduced regional laws⁴¹⁻⁵⁰
 458 that reflect many of these objectives.

459
 460 **Endometriosis Initiatives Not Integrated Within NAPs or Laws**
 461 Even in the absence of coordinated ‘Governance and Leadership’ policies in the form of
 462 NAPs and Laws, fragmented endometriosis initiatives exist which have been analysed and
 463 aggregated alongside the NAPs and Laws and described within the remaining 5 WHO
 464 Healthcare Building Blocks. The full list of initiatives for each country and the building
 465 blocks they serve can be found in the **Supplementary Excel file**.

466
 467 **Initiatives Within the ‘Service Delivery’, ‘Health Workforce’, and ‘Access to Essential**
 468 **Medicines’ Building Blocks**
 469 46 countries described initiatives within the clinical care building blocks. Governments often
 470 began by commissioning working groups to provide clinical recommendations. The most
 471 common initiatives within this theme included the development of accredited specialist
 472 services (n=25) usually to address specific needs of those with severe disease, refinement of
 473 training for healthcare staff (n=18), cohesive care networks (n=15) and the development of
 474 structured care pathways (Argentina, Australia, France, Ireland, Italy, Spain, USA, and the
 475 UK). Endometriosis clinical care guidelines were another common initiative.⁵¹ and were
 476 complemented by twelve documents on international clinical consensus statements from
 477 clinical experts such as the World Endometriosis Society (WES) and the EndoKey Group.^{52,53}
 478

479 **Initiatives Within the ‘Financing’ Building Block**
 480 Sixteen countries demonstrated initiatives to alleviate some of the financial burden associated
 481 with endometriosis (**Table 1** demonstrates key examples, the remaining initiatives can be
 482 found in the **Supplementary Excel file**).

483

Country	Year	Initiative
Slovakia	2004	Act No. 777/2004 Coll in 2004 was an early example of policy reform entitling those with endometriosis three cycles of assisted reproduction procedures up to the age of 39. ⁵⁴
Kenya	2019	In 2019, endometriosis medical treatments including Danazol, Dienogest, Goserelin and the Levonorgestrel-releasing Intrauterine systems were introduced within Kenya’s Essential Medicines List (KEML). ⁵⁵ Inclusion of endometriosis treatments in the KEML supports access to care by ensuring they are prioritised in public financing. As the KEML shapes

		Universal Health Coverage benefit packages, this step also contributes to reducing out-of-pocket costs.
Iceland	2020-2022	In 2020, the government announced ISK 20 million in subsidies for hormonal IUDs for women requiring them for clinical reasons, such as endometriosis. ⁵⁶ Subsequently, the Ministry of Health entered a formal agreement in 2022 with private clinics to fund endometriosis surgeries, aiming to reduce waiting times, improve access to care and provide financial protection. ⁵⁷
Spain	2023	Spain introduced several key measures to provide financial support individuals with endometriosis. The 2023 approved State Budget Law ⁵⁸ allocated €3 million for egg preservation for those with endometriosis. Moreover, the 2023 Law 1/2023 ⁵⁹ amended Law 2/2010 on sexual and reproductive health and provided sick leave (menstrual leave) entitlements by recognising endometriosis as a temporary disability to increase support in the workspace.

484 **Table 1:** Notable examples of initiatives raised to reduce the economic burden of endometriosis. As per the
485 protocol, countries without NAPs or national laws (which have already been discussed) were prioritised to
486 provide a wider scope of global initiatives. All the initiatives can be found in the **Supplementary Excel file**.

487 Progressive trajectories for financial protection exist, starting with reimbursing specific
488 medical treatments, progressing to providing universal coverage for care and advancing to
489 providing fertility services, such as cryopreservation.

491 **Initiatives Within the ‘Information Health Systems’ Building Block**

492
493 Three key types of information health systems are being implemented for endometriosis:
494 information systems to raise awareness, provide education and promote research.

495
496 Initiatives by multiple stakeholder levels have been implemented to raise awareness and
497 education of endometriosis (n=52). Initial efforts by policymakers include publishing
498 educational articles on their websites (n=13), with more advanced efforts including declaring
499 a national Endometriosis Awareness Day/Week/Month in March (n=12). Argentina
500 (regional), Italy, Canada (regional), Croatia, Brazil, and Portugal have in fact passed laws or
501 acts establishing an Endometriosis Awareness Day. Awareness efforts not only improve the
502 societal understanding and appreciation of endometriosis but can even stimulate policy
503 reform as seen in the EndoMarch Global Movement, which involved over 100 organisations,
504 and has contributed to political initiatives such as the bipartisan bill for endometriosis
505 research funding in the United States.⁶⁰

506 Education is another crucial information system, especially in adolescents, when
507 endometriosis symptoms often develop. Numerous countries have made efforts to develop
508 educational campaigns in schools to enhance understanding of what symptoms are abnormal
509 (n=14). Promotion of school educational campaigns establishment can be found in various
510 commissioned reports, drafted or actioned endometriosis bills, laws NAPs and even
511 guidelines (e.g. South Africa).

Country	Year	Initiative
New Zealand	1998-2024	The What about me® programme ⁶¹ , developed by Endometriosis New Zealand, is one of the most successful and evidence-based school initiatives globally for menstrual and endometriosis education. Launched in 1998, it reached over 300,000 students and significantly improved early recognition of endometriosis, with the proportion of under-20s seeking help rising from 12% in 2001 to 62% in 2015. The programme combines WHO-endorsed health education practices with accessible,

		inclusive content and has received international recognition and awards. Now available as a free national e-learning platform, it serves as a global model for empowering adolescents to understand menstrual health and seek timely care.
Barbados	2014-2019	A progress report ⁶² by was published by the United Nations Economic Commission for Latin America and the Caribbean to track the progress Barbados had made between 2014-2019 in advancing gender equality and empowering women and girls, specifically in relation to the Beijing Platform for Action, an international agreement established at the Fourth World Conference on Women in 1995. The review highlighted the important work of the Barbados Association of Endometriosis and PCOS who had launched educational initiatives such as visiting schools and speaking to students and sharing a book they published a book, with UNFPA's to schools but also governmental agencies. Moreover, the association has created various culturally grounded toolkits to support Caribbean and Afro-Caribbean individuals affected by endometriosis.
Argentina (Tucumán region)	2019	Tucumán was the first Argentine province to pass an endometriosis law in 2019 which guaranteed comprehensive, free access to diagnosis, treatment, and follow-up for endometriosis patients. A key initiative was the "Aula Amarilla" (Yellow Classroom) ⁶³ within a hospital, that served as a space for community-based educational and psychosocial support. Workshops are held in this classroom led by nutritionists, psychologists, and physical activity specialists, along with recreational sessions and public education talks.

512 **Table 2:** Notable examples of implemented initiatives identified to raise awareness and education of
513 endometriosis, especially among the young. As per the protocol, countries without NAPs or national laws
514 (which have already been discussed) were prioritised to provide a wider scope of global initiatives. All the
515 initiatives can be found in the the **Supplementary Excel file**.

516 Finally, promotion of research is a vital information system implemented by many countries
517 (n=18), primarily through funding endometriosis research projects (n=9).
518

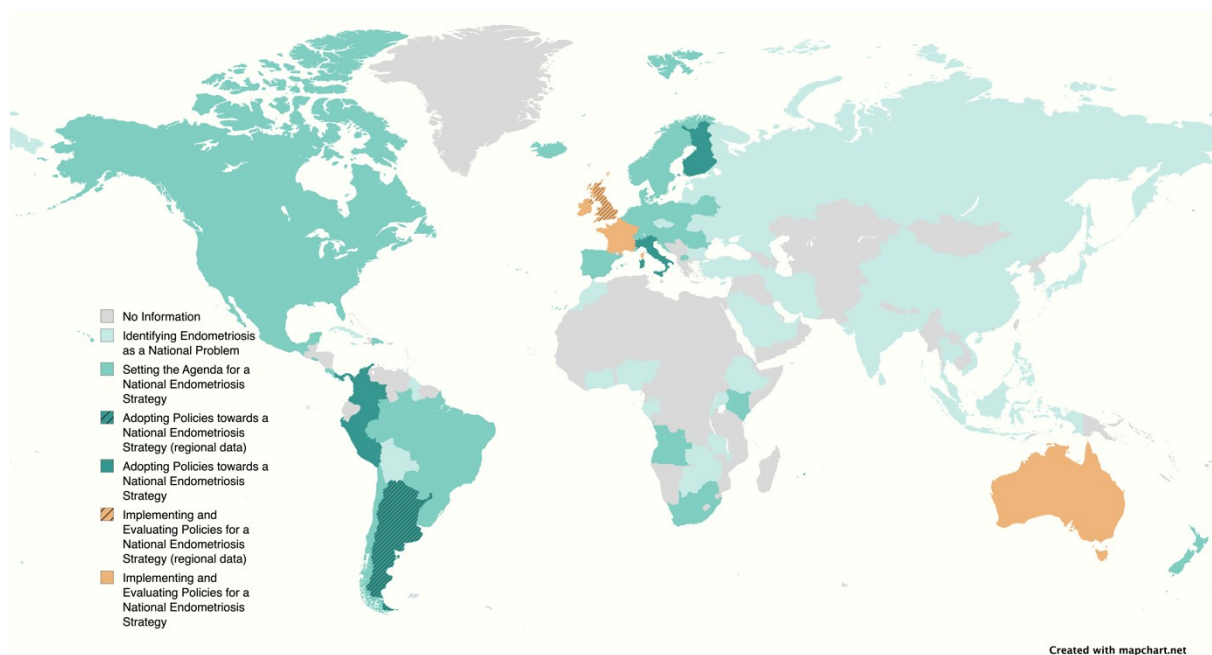
Country	Year	Initiative
Canada	2018-2020	The Canadian Institutes of Health Research (CIHR), a government federal funding agency for health research, has supported various notable endometriosis research initiatives. For example, The CIHR Early Career Investigators in Maternal, Reproductive, Child and Youth Health Grant, was awarded to an endometriosis project in 2018. ⁶⁴ Moreover, a Women's Health Clinical Mentorship Grant ⁶⁵ supported the "next generation of women's health clinician-researchers" in fields such as endometriosis. In 2020, the programme awarded a maximum of CAD 50,000 for one year to each of the selected 12 mentorships. Two grants were provided to endometriosis mentorships. Finally, the CIHR Canada Research Chairs Program which invests over CAD \$300 million to "achieve research excellence" included the appointment of a national chair for endometriosis research. ⁶⁶
US	2022 - 2023	In 2020, the US House of representatives approved an amendment to double the funds for endometriosis research from \$13 million in 2019 to \$26 million for the fiscal year beginning Oct. 1, 2020. ⁶⁷ Subsequently, the US congress introduced the HR 7974 Coverage, Awareness, Research, and Education (CARE) Act ⁶⁸ of 2022 which required the Department of Health and Human Services to address endometriosis through various initiatives such as those to increase awareness and research. No results were found on its enactment status. The 2022 HR 2617 bill however has been passed and enacted by US Congress. It aimed to provide funds for endometriosis research programmes to assess endometriosis causes, treatments and potential cures. Later, in 2023 the first White House initiative was launched to fund research in conditions such as endometriosis affecting women.

519 **Table 3:** Notable initiatives identified in the search to fund endometriosis research. As per the protocol,
520 countries without NAPs or national laws (which have already been discussed) were prioritised to provide a
521 wider scope of global initiatives. All the initiatives can be found in the **Supplementary Excel file**.

522 Information systems, including awareness, education, and research efforts, are crucial to
523 ensuring patients are empowered with the information they need for clinical autonomy and
524 for ensuring policies receive societal acceptance.

525
526 **Analysing the Policy Development Narrative**

527 Analysing the results, a policy development narrative emerged that fit with the recognised 5-
528 stage policy development cycle (methods within the appendix p 7-10 and the stage and
529 justification for each country can be found in the **Supplementary Excel file**). The ultimate
530 goal is to develop a comprehensive, stand-alone policy that encompasses various elements of
531 the healthcare building blocks, with measurable outcomes, to evaluate and refine the
532 infrastructure based on the evolving requirements of its population. Not only would this be
533 beneficial for individual countries to track their progress, but it would also enable the
534 establishment of global programs, such as the WHO Mental Health Atlas, for endometriosis.
535



536

537 **Figure 2: Policy development cycle map**, representing how far countries are within the policy development
538 cycle. The boundaries and designations used on this map do not imply the author's opinion concerning the legal
539 status of any country or territory. Created using MapChart.net.

540
541 **Policy Development Narrative: No Information Detected (98 countries)**

542 Recognising endometriosis advocacy groups as a fundamental driver in developing
543 endometriosis policy, countries without detectable endometriosis policy documents,
544 initiatives or an endometriosis society were classified as 'no information detected'. This term
545 reflects the plausibility of missing data due to the challenges of obtaining international policy
546 documents. This classification was given to 98/194 countries (classifications for each country
547 are within the **Supplementary Excel file**). 80 countries were classified as low to middle-
548 income countries.⁶⁹ These regions may represent the countries in greatest need of
549 endometriosis advocacy.

550
551 **Identifying Endometriosis as a National Problem (48 countries)**

552 This initial stage of policy development involves stakeholders recognising endometriosis as a
553 national problem. The classification was often given due to the crucial representation of

554 prominent advocacy groups and NGOs. It also included cases such as in Botswana, where the
555 Minister of Health identified endometriosis as a public health concern, but among available
556 resources, life-threatening diseases were prioritised over endometriosis.

557

558 **Setting the Agenda for a National Endometriosis Strategy (36 countries)**

559 Agenda setting ranged from policymakers declaring their intent to develop reforms to
560 introducing bills for an endometriosis strategy. Moreover, it included countries such as
561 Croatia, Denmark, Romania, Luxembourg, Slovenia, and South Africa, where NGOs had
562 developed draft strategies for endometriosis, which had been presented to political leaders.
563 Although notable initiatives were identified, they lacked a strategic policy framework.

564

565 **Adopting Policies Towards a National Endometriosis Strategy (8 countries)**

566 8 countries had adopted endometriosis policies within a strategic framework, e.g.
567 comprehensive laws or NAPs, allowing for the development of a structured and accountable
568 response to the nation's endometriosis challenges. However, this group is limited by evidence
569 of the implementation of the described policies.

570

571 **Implementing and Evaluating a National Endometriosis Strategy (4 countries)**

572 Australia, France, the UK (Scotland) and Ireland demonstrated the development of
573 endometriosis strategies and provided evidence of their implementation in progress reports.
574 The stand-alone NAPs were the most comprehensive, but all had initiatives for clinical care,
575 awareness and research, except for Ireland, which had clinical care initiatives. Progress
576 reports are the initial stages of the evaluation process. The later stages are assessed by
577 evaluating the impact of the NAP on its population, which no country has yet conducted.
578 Australia is the furthest along, with the 2024 progress report demonstrating that the initiatives
579 are in the final stages, with the evaluation and refinement of the NAPE to commence.²²

580

581 **Discussion**

582 **Availability and maturity of endometriosis policies and delivery systems**

583 This scoping review has highlighted a notable worldwide inadequate representation of
584 endometriosis policies, especially if compared to the results of the WHO Mental Health Atlas
585 previously discussed. Only 1% of countries have a stand-alone plan for endometriosis
586 (compared with 75% for mental health), and only 4% have an endometriosis law (57% for
587 mental health)⁶. Endometriosis policy can also be found integrated within other health NAPs
588 or as stand-alone initiatives, but these often lack the comprehensive approach, goals and
589 accountability of a stand-alone plan. However, various stand-alone initiatives do exist and
590 often fall within the WHO health system building blocks. In terms of maturity, policies on
591 endometriosis are globally in the early stages of development, with a concerning number of
592 countries not having identified endometriosis as a problem, and no country having reached
593 the crucial evaluation and refinement process.

594

595 **Drivers of endometriosis policy**

596 Countries in the later stages of policy development have all attributed success to the
597 collaborative engagement of stakeholders, including with patients, advocacy groups—often
598 founded by patients—clinicians, researchers, and political leaders. NGOs ensure the voices of
599 endometriosis patients are heard and that reforms are tailored to their population's needs.
600 However, policymakers can allocate resources based on their country's resource availability
601 and ensure accountability through the implementation of steering groups and progress
602 analytics.

603

604 Collaborative NGO networks such as South America’s UNIENDO share advances in their
605 legal frameworks to build on each other’s successes.^{70,71} The World Endometriosis
606 Organisations is another example of international collaborative efforts aimed at improving
607 awareness.⁷² Further, the World Endometriosis Research Foundation Endometriosis Phenome
608 and Biobanking Harmonisation Project (EPHect) developed tools for global research
609 collaboration.^{73–77}

610

611 **Barriers and Challenges to Endometriosis Policy**

612 A lack of societal awareness of endometriosis, particularly among policymakers, is a
613 significant initial barrier to effective endometriosis policy. In addition, policies often require
614 significant funding, which is especially limited in low to middle-income countries, which
615 often must prioritise life-threatening conditions. However, even after endometriosis has been
616 prioritised, operational barriers exist. For example, in the province of Jujuy (Argentina), a
617 2023 endometriosis law that was expected to improve endometriosis research, clinical care
618 and awareness, was vetoed three months after passing due to insufficient funds. Moreover, in
619 Sardinia (Italy), it took eight years after the regional endometriosis law was passed for a
620 commission to be developed to act on the law.

621

622 A crucial challenge in developing endometriosis policy is addressing the varying disease
623 impact. Whilst some people are severely affected, others have mild to no symptoms. Thus,
624 policy development must be nuanced to recognise these differences so resources can be
625 allocated appropriately.

626

627 Future outlook – Progressive realisation

628 Societal consciousness of the importance of endometriosis policies has increased in recent
629 years, instilling a promising outlook for the future. The presence of stand-alone mental health
630 NAPs in 75% of countries demonstrates it is achievable and that the NAP must be country
631 and resource-specific. Australia and France have demonstrated that the NAPs enable the
632 country’s strategic vision to be publicly visualised, hold governments accountable and allow
633 for progress to be tracked and refined. Until a stand-alone NAP is achieved, integrating
634 endometriosis within existing NAPs (e.g. reproductive health NAPs, which exist in 58% of
635 countries) still ensures accountability. The Maldives’ reproductive health NAP, for example,
636 assigned quantitative yearly targets and responsible groups for each of its endometriosis
637 initiatives. As highlighted by Australia’s 2024 progress report, after implementing a NAP, a
638 structured evaluation of the effects of the initiatives on affected individuals’ lives, with
639 dynamic adaptations, is crucial.

640

641 Strengths and weaknesses of the review

642 A strength of this scoping review is that it presents, for the first time, a comprehensive search
643 of all WHO-recognised countries to encompass a global understanding of the availability and
644 maturity of endometriosis policy. This resource may be used to support the establishment and
645 development of national endometriosis policy by demonstrating positive examples (most
646 often to improve access to clinical care, raising awareness and promoting research) and the
647 various forms that policy can take (plans, laws or stand-alone initiatives). It crucially
648 demonstrated critical factors that must be considered whilst designing endometriosis national
649 policy, including healthcare frameworks such as the WHO Building Blocks and human rights
650 frameworks such as the PANEL approach. Finally, using the healthcare policy development
651 cycle, the importance of country-specific objectives, action timeframes, adequate funding
652 allocation and accountability measures such as steering groups and progress reports were
653 demonstrated.

654

655 A crucial strength of the paper is the success of a comprehensive systematic grey literature
656 search strategy that identified pivotal policies and initiatives, overcoming the limitation of the
657 database search, which identified only 34 documents due to the nature of policy document
658 archiving and databases that typically publish academic works. The reliance on grey literature
659 does increase the risk of bias from individual agendas. This was minimised by limiting
660 inclusion to documents from leading NGOs and policymakers and by presenting all the
661 included results in the **Supplementary Excel file**. Despite the comprehensive language-
662 tailored search strategy, there is a risk of missing eligible documents due to the nature of
663 policy searching. Parliamentary discussions, for example, are not always published publicly.
664 Additionally, country-tailored search methods may have limited effectiveness in policy
665 identification. Google search algorithms limit results based on location, and despite efforts to
666 overcome language barriers by using translated terms, Google Translate has known
667 limitations, especially for medical terms.⁷⁸ Searching was limited to WHO member states.
668 Thus, territories and regions within states were not specifically searched, which may be a
669 limitation in countries with strong provincial regulation. To assess the impact of this, a
670 regional search was conducted in Italy, given its largely regionally governed healthcare
671 system. The search without region-specific terms had already identified 10 regional
672 endometriosis laws. The remaining 10 regions were searched, revealing 2 missing regional
673 laws that did not affect the overall conclusions of the review.

674

675 **Conclusion**

676 Most countries, regardless of economic status, are only beginning to shape their response to
677 endometriosis. However, the future holds promise, demonstrated by a marked surge in recent
678 policy initiatives and an enhanced societal and state consciousness regarding endometriosis,
679 often driven by patients and their advocacy groups. Policy makers hold the potential to
680 formulate and implement refinable, tailored policies within the nation's resource capacity.
681 Encouraging progress is being made through the development of comprehensive frameworks
682 that serve as reference points for other countries seeking to expand their infrastructure. We
683 present this as an opportunity for collaboration and welcome letters to the authors, ICMART,
684 IFFS, WHO, and WES.

685

686 **Contributors statement**

687 KZ, SM, DA, LG and CB contributed to conceptualisation and supervision of the project.
688 TG, DE, and KZ developed the project methodology, with administrative tasks performed by
689 TG and DE. BS contributed to data curation by assisting with and coordinating the
690 development, peer review, and execution of the indexed database search protocols. DA and
691 LG acquired funding for the contributions by BS. TG and DE contributed to data curation,
692 investigation, validation, and analysis by performing an independent review of the indexed
693 database returns and selection of included works. TG independently performed the grey
694 literature review. The original draft was written by TG, DE, SM, and KZ, with visualisation,
695 review, and editing contributions from all listed authors. The International Committee for
696 Monitoring Assisted Reproductive Technologies Working Group reviewed the original draft
697 and provided feedback to inform the final manuscript for publication.

698

699 **Declaration of interests**

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719 Conference 2025 and EndoFound Conference 2025. SAM reports paid Field Chief Editor
720 work with Frontiers in Reproductive Health, paid advisory board work with LIDEA Registry,
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1003 **Figure legends**

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1005 **Figure 1:** PRISMA-ScR flow diagram summarising the process of record identification and selection

1006

1007 **Figure 2: Policy development cycle map**, representing how far countries are within the policy development
1008 cycle. The boundaries and designations used on this map do not imply the author’s opinion concerning the legal
1009 status of any country or territory. Created using MapChart.net.

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