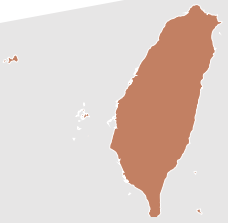
Endometrial Cancer – Improving Care and Driving Policy Change

A Case Study on Taiwan



BACKGROUND. Endometrial cancer is the most common gynecologic cancer in high-income countries. Unlike breast and cervical cancers, which benefit from global awareness and policy initiatives, endometrial cancer remains underrepresented in both international and national health agendas, including in Taiwan.

The Swedish Institute for Health Economics (IHE) published a comprehensive report titled ***Endometrial Cancer – Improving Care and Driving Policy Change*** in 2024 (1). Endorsed by the European Network of Gynaecological Cancer Advocacy Groups (ENGAGe) and the European Oncology Nursing Society (EONS), the report highlights unique challenges and opportunities for improving outcomes in this neglected cancer type.

Building on the findings of the main report, this case study focuses on the situation in Taiwan. It provides an overview of the burden of endometrial cancer and identifies key areas for improvement in care and policy response.

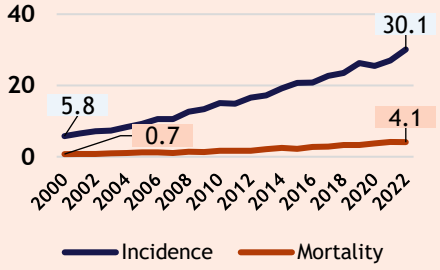
1 WHAT IS ENDOMETRIAL CANCER? Endometrial cancer originates in the inner lining of the uterus (womb), called the endometrium, and accounts for around 90% of all cancers in the body of the uterus (also referred to as uterine cancer or corpus uteri cancer)* (1). Overweight and obesity are the most common modifiable risk factors, linked to around 40% of cases (1). Abnormal vaginal bleeding (i.e., bleeding between menstrual periods or after menopause) is the most common symptom (1).

2 DISEASE BURDEN. Taiwan is witnessing a growing number of endometrial cancer cases, influenced by an aging population and rising obesity rates (2, 3).

Endometrial cancer trends

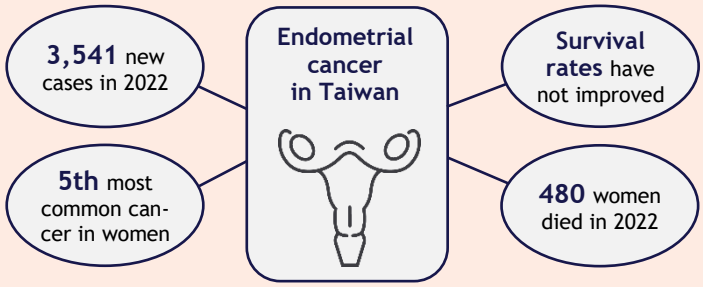
Notes: Incidence and mortality crude rates per 100,000 women in Taiwan.

Source: Taiwan Cancer Registry



Rising number of cancer cases and deaths. Between 2000 and 2022, endometrial cancer incidence rates increased about 5-fold, from 5.8 to 30.1 cases per 100,000 women (4). Over the same period, the mortality rates increased almost 6-fold, from 0.7 to 4.1 deaths per 100,000 women (5, 6).

Endometrial cancer is more common than cervical and ovarian cancer combined. In 2022, 3,541 new endometrial cancer cases were recorded in the Taiwan Cancer Registry – around 300 more cases than the combined cases of cervical and ovarian cancer (6). These numbers make endometrial cancer the 5th most commonly diagnosed cancer in women, and the 11th most common cancer related death among women in Taiwan in 2022 (6). In the global context, Taiwan had the largest increasing trend in age-standardized incidence rate (+6.08% per year), during the period 1990-2017, among 195 countries and territories (7).



There is little progress in improving survival rates. Although five-year survival rates of endometrial cancer are relatively high (>80%) compared to other gynecologic cancers, they remain lower than for breast cancer (1). In contrast to most other cancer types, survival rates have not improved in recent years. In Taiwan, the five-year relative survival rate of endometrial cancer was at 81.3% in the 2002-2006 diagnosis period and only slightly increased to 83.1% in the 2018-2022 diagnosis period (8). However, recent advancements in treatment options – especially new medicines for advanced disease – hold promise for improving future survival outcomes (1).

Most endometrial cancer cases are diagnosed early. The median age of endometrial cancer diagnosis is 56 years in Taiwan (6). The number of diagnosed cases is increasing with age and reaching a peak in the 55-59 age group, before starting to decline after that (6). Most endometrial cancer cases are identified in early stages, with more than 50% being in stage I, while fewer than 10% are diagnosed late in stage IV (6).

*This case study focuses on endometrial cancer; however, where specific data are unavailable, statistics for uterine cancer (corpus uteri cancer) are used instead. Hence, uterine cancer and endometrial cancer are used interchangeably in this case study.

3 ECONOMIC BURDEN.

The current health expenditure in Taiwan was 7.3% of GDP in 2023, while the public current health expenditure was 4.4% of GDP (9). The expenditure on pharmaceuticals was 1.2% of GDP and 16.1% of the current health expenditure (9). In 2019, the cancer medicine expenditure in Taiwan was 17% of the total pharmaceutical expenditure (10).

The economic burden of endometrial cancer in Taiwan is unknown. A few studies have assessed the economic burden of a variety of cancers in Taiwan (11-13). However, as of the time of writing this case study, no comprehensive studies or reports have been conducted to evaluate the economic burden of endometrial/uterine cancer in Taiwan, either at a national or regional level. In addition, there is no publicly available data on healthcare system investment in the care of this cancer type. In contrast, estimates from other high-income countries suggest that uterine cancer accounts for 1–3% of all cancer care expenditure (1). Apart from cancer care expenditure, indirect costs to society arise from the inability to work due to the disease (sick leave and early retirement) and lost earnings due to premature death before retirement age. Studies in other high-income countries have shown that the indirect costs of endometrial cancer are almost as high as the cancer care expenditure (1).

4 EARLY DETECTION.

Early detection of endometrial cancer increases the chances of successful treatment, improves survival rates, and reduces treatment costs (1). Unlike breast and cervical cancer, there is no established screening method for endometrial cancer. The condition is typically identified through symptoms — such as abnormal vaginal bleeding — noticed by the patient, making early detection heavily reliant on symptom awareness combined with easy access to healthcare services and prompt medical assessment by a gynecologist (1).

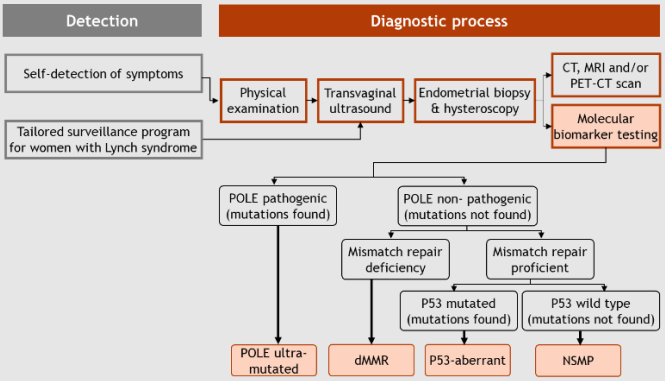
Access to healthcare providers and waiting times are generally at a good level. The National Health Insurance (NHI) in Taiwan achieves comprehensive coverage except for advanced medicines and procedures (14). People can visit any physician without referrals and waiting times are generally short (15). However, the quality of outpatient visits could be compromised by the large volume of patients that physicians see in a day, leaving a small amount of time to be allocated to each patient (15). Service utilization steadily increased from 1998 to 2019 in Taiwan (14), but the rate of bypassing primary care has decreased over time (16).

The role of health literacy and risk perception in early detection. Symptom awareness of cancer is vital for timely intervention. In Taiwan, some studies have shown that the health literacy level is lower among older individuals (17, 18). However, evidence is also available on lower health literacy levels among younger people (19). Furthermore, lower education and income level, living in less populated areas and language barriers for immigrants, were also associated with lower health literacy (17, 18, 20). Health literacy has been found to be a predictor of health-promoting behavior (19). A study on women's likelihood to use self-sampling tests for cervical cancer screening found that those with high HPV knowledge and higher perceived risk of cervical cancer were more likely to use the method (21). Among women in Taiwan, misinformation or misconceptions regarding breast cancer and screening were found (22). Perceived "no need to get screened" was one of the main reasons for not getting screened, and more than 60% of women considered that they had no or low risk of developing breast cancer (22). Nonetheless, endometrial cancer-specific evidence is not available, and, thus, findings related to other women's cancers or general health, should be interpreted with caution.

Lack of systematic genetic risk assessment for at-risk women. Women with Lynch syndrome (LS) have a lifetime risk of 60% to develop endometrial cancer (23). Testing for Lynch syndrome is recommended for individuals who have a personal or family history suggesting an increased risk of developing Lynch syndrome-associated cancers (colon, endometrial, stomach, etc.). Without proper genetic risk assessment, individuals at high risk of Lynch syndrome may remain unidentified, missing out on the opportunity for early detection and preventative measures. A Taiwanese prospective cohort study found that 11.2% of endometrial cancer patients had LS (24). Patients with LS were more likely to have more than one cancer and to have stage II or III cancer, while they also had significantly higher 10-year "relapse-free" and similar overall survival rates, compared to those without LS (24). This underlines the importance of testing in prognosis and patient care decisions. In another hospital-based study, endometrial cancer was found in 2.2% of MMR carriers, while under-diagnosis of LS was noted (25). Almost half of Taiwanese patients visiting a genetic counseling clinic were undecisive about receiving a genetic test; a positive attitude towards counseling was associated with uptake of the test (26). Important factors influencing one's willingness for genetic testing are the cost of testing and management after a positive result (26, 27).

Socioeconomic disparities exist in early detection. While disparities in early detection of endometrial cancer in Taiwan are not well documented, there is evidence from other cancer types or general healthcare seeking. For example, women with higher income and education level were more likely to attend breast and cervical cancer screening (28). Women with disabilities had lower rates of breast cancer screening, compared to women without disabilities (29), and these numbers decreased with the severity of disability, lower monthly income, and living in more rural areas. Language, comprehension, and cultural barriers can make navigation of the healthcare system harder for immigrants (20). A qualitative study among overseas Filipino workers in Taiwan, found that the mentality that healthcare is expensive, as experienced in their home-country, followed them in Taiwan, with possible implications for timely healthcare seeking (30). As out-of-pocket levels and mandatory copayments for healthcare services increased in the last few years in Taiwan (14), this could further burden those in underprivileged groups. However, due to the lack of evidence related to endometrial cancer, safe conclusions cannot be drawn, and findings that are not specific to endometrial cancer should be interpreted with caution.

5 **DIAGNOSTIC PROCESS.** Endometrial cancer diagnosis involves a multi-step process (visualized below), including physical exams, imaging, biopsies, and molecular biomarker testing, which collectively guide staging and treatment decisions (1). Historically, classification relied on histology, categorizing cases into Type I (estrogen-related, slower progression) and Type II (aggressive, poorer prognosis). Since 2021, a molecular classification has redefined endometrial cancer into four subtypes—(i) POLE-ultra mutated, (ii) mismatch repair deficiency (dMMR), (iii) p53-aberrant, and (iv) no specific molecular subtype (NSMP) (1). This new classification, combined with staging insights and the introduction of novel medicines, enables more personalized treatment strategies tailored to each patient. Comprehensive biomarker testing is required to facilitate this personalized approach. Specialized expertise is essential for integrating these advancements into clinical practice, especially as new medicines continue to emerge.



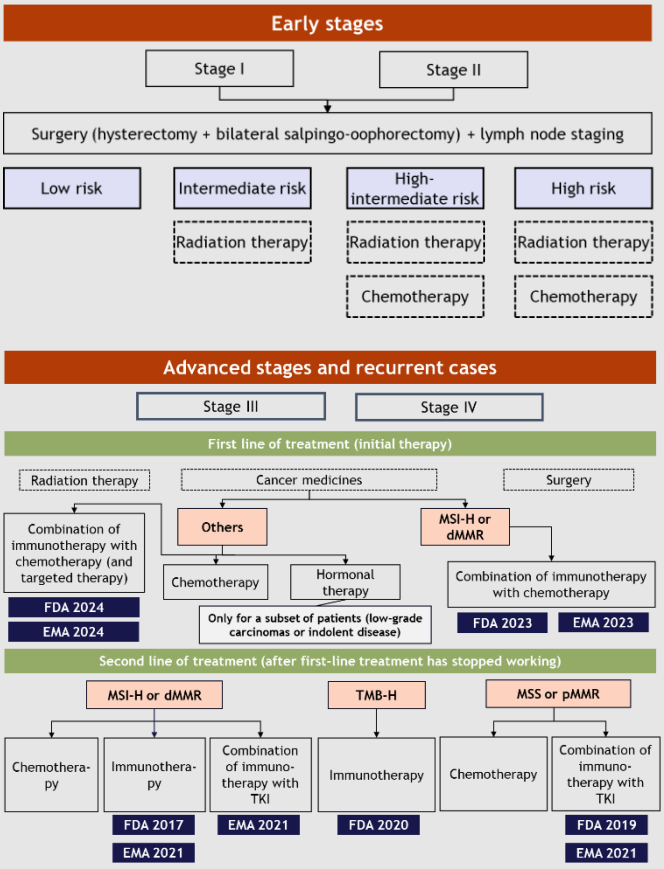
Workforce pressure and shortage of gynecologists. The examination of women with symptoms of endometrial cancer should ideally be performed by a gynecologist or another medical professional familiar with the disease (31). Consequently, limited access to gynecologists might result in delays in the diagnostic process (1). A nationwide Taiwanese study reported that nearly 40% of towns lacked gynecologists (32). Women living in these towns were less likely to seek care for gynecologic conditions and visited gynecologists less frequently compared to women in towns with available specialists. Most women (79%) had to travel outside their town to see a gynecologist, yet despite these barriers, no significant difference was observed in the overall likelihood of being diagnosed with gynecologic malignancies between the two groups. However, lower care-seeking rates and the need to travel could possibly lead to delays in evaluation, increased patient burden, and potential inequities in timely access to care. Another study showed that even though rural areas had the minority of OB/GYN clinics, these catered to the highest number of people per clinic; almost 4 times higher than the number catered to in urban areas and 2 times higher than in suburban areas (33). Based on 2012 data from Taiwan, the majority of ambulatory visits to OB/GYNs were made to physicians in the 50-59 age group (34). News outlets have highlighted the issue of aging gynecologists, which is the specialty with the highest average age in Taiwan (56.7 years) (35). If unaddressed, this could potentially heighten unmet gynecologic care needs in the future. In contrast, radiation oncology specialists constitute the youngest physician specialty (average age of 46.9 years).

Potential delays in time to diagnosis. As of the time of writing the present case study, no public data on the time to diagnosis of endometrial cancer in Taiwan were available. However, a study among breast cancer patients found that the average delay in diagnosis was approximately 28 days (36). Sociodemographic factors were not significantly associated with delay in diagnosis. Nonetheless, for women of younger age and divorced/separated women, it took longer to diagnose. Patients at medical centers, as well as those who received an MRI examination on their first visit, got a diagnosis within a shorter time. Women who needed to visit three or more hospitals to receive their diagnosis waited 10 times longer until getting diagnosed (147 vs 14 days). Since available evidence is specific to breast cancer, interpretation of the findings in the context of endometrial cancer should be exercised with caution.

Increased burden for radiologists. From 2000 to 2017, Taiwan saw an increase in CT and MRI examinations by 246% (37). As the number of images needing interpretation by a radiologist increased, the time spent on each image decreased from 16.0 to 2.9 seconds (38). Less time per interpretation – without additional aids such as AI technology – could possibly affect the quality of results and subsequent care of patients. Although the number of radiologists in Taiwan increased from 2000 to 2020, so did the needs for imaging services, meaning that around 1,168-1,552 radiologists will be needed in 2040 (18% more than in 2020), in order to cover these needs (39).

Utilization and access to biomarker testing varies. In July 2022, a panel of Asian experts, including representation from Taiwan, adapted the most recent Clinical Practice Guidelines for the diagnosis, treatment, and follow-up of patients with endometrial cancer, published in 2022 by the European Society for Medical Oncology (ESMO) (40). The panel accepted the recommendations on diagnosis, pathology, and molecular biology, which call for universal molecular classification of all endometrial cancer specimens using immunohistochemical (IHC) staining for p53 and MMR proteins, combined with targeted tumor sequencing for POLE hotspot mutations. However, the panel raised the issue that POLE hotspot mutation testing is not widely available as part of routine molecular evaluation in many Asian centers (40). In Taiwan, IHC staining is reimbursed by the National Health Insurance Administration (NHIA) for up to five antibodies per case, which could include MMR testing (41). Physicians' criteria for biomarker status testing in other gynecologic cancers in Taiwan include younger age, financial stability, and having a history of failing first line of therapy (42); characteristics which could either enable or hinder access to biomarker testing. Since May 1, 2024, next-generation sequencing (NGS) is included in the National Health Insurance payment program for several solid and hematological cancer types (43). Although endometrial cancer is not included there, this is an important step for the adaptation of precision medicine in Taiwan. Even if access to biomarker testing in Taiwan looks reasonable on paper (e.g., IHC reimbursement and a broader NGS program), real-world data from metastatic cervical cancer show limited uptake, e.g., PD-L1 testing occurred in only 26.4% of cases and was often reserved for younger, fitter, self-funding patients (42). These testing constraints were tied to reimbursement gaps for innovative therapies.

6 **TREATMENT.** The treatment of endometrial cancer depends on the stage at diagnosis, but typically comprises surgery, radiation therapy, and medicines. Surgery involves the removal of the uterus (hysterectomy) and often also the removal of the fallopian tubes and ovaries. Radiation therapy is commonly used to target residual cancer cells after surgery or as a standalone option for non-surgical candidates (1). Chemotherapy has been the cornerstone therapy for decades, usually administered after surgery or as a standalone option for non-surgical candidates. Recent advancements, however, have introduced a wave of innovative therapies, particularly immunotherapies and targeted therapies, designed to leverage the cancer's molecular profile (1). These therapies transform the management of advanced and recurrent endometrial cancer cases. Treatment algorithms for early-stage and advanced/recurrent-stage endometrial cancer (based on ESMO and NCCN guidelines) are presented below (1). Comprehensive, timely, and equitable access to innovative medicines, specialized expertise, and multidisciplinary care is essential for integrating these advancements into clinical practice.



Delayed time from diagnosis to treatment. As of the time of writing the present case study, there were no publicly available data regarding the time from diagnosis to treatment of endometrial cancer in Taiwan. Evidence from other gynecologic cancers suggests that treatment delays might be a concern. In cervical cancer, most patients between 2004 and 2010 received treatment within 1.5 months of diagnosis; however, those with longer delays, particularly in advanced stages, had a higher mortality risk (44). Similar findings were observed in breast cancer where older patients with stage II and IV disease who experienced delays also faced a higher risk of mortality (45). Several factors have been linked to patients delaying or refusing treatment, including older age, comorbidities, cancer stage, and the level of the diagnosing hospital (46, 47). Socioeconomic status has not been shown to influence treatment delay or refusal in breast cancer (46). However, conclusions pertinent to endometrial cancer cannot be safely drawn, due to the lack of endometrial cancer-specific evidence.

Limited availability of internationally recommended novel treatment options. Despite the launch of several immunotherapy agents over the last years for the treatment of endometrial cancer and their inclusion in clinical guidelines of ESMO and NCCN in Europe and the United States (see treatment algorithm figure in the beginning of the section), none of these medicines are reimbursed for endometrial cancer in Taiwan in any setting (reimbursement status checked in November 2025) (50). This means that Taiwanese patients can only receive conventional chemotherapy, and even that comes with out-of-pocket payments (see challenge further below). In general, physicians across the Asia-Pacific region have identified limited treatment options as an important unmet need in gynecologic cancer care (42). In a study on metastatic cervical cancer, nearly 20% of physicians reported that the availability of effective treatment options was a key challenge (42). In Taiwan specifically, 22.2% of respondents considered this among the most impactful barriers to improving patient outcomes. This concern was reported alongside poor prognosis with current treatments (27.8%) and challenges with treatment affordability (21.3%), underlining the combined effect of limited therapeutic innovation and financial access barriers on patient care. However, findings related to metastatic cervical cancer cannot support conclusions about the availability of treatment options in advanced endometrial cancer.

Reimbursement of new cancer medicines is lagging. In 2019, Taiwan's spending on cancer medicines accounted for 17% of total pharmaceutical expenditure — a higher share than in other high-income areas in the region, such as Japan (11%) and South Korea (9%) (10). Per capita and per cancer case spending also placed Taiwan second behind Japan but ahead of South Korea (10). Despite this relatively high level of spending, important challenges remain for patient access to innovative cancer treatments. As of September 2020, only about 50% of cancer medicine-indications with local regulatory approval and 60% of innovative indications were reimbursed, leaving Taiwan behind Japan, which reimburses all locally approved indications, and on par with South Korea (10). Moreover, the time from regulatory approval to reimbursement is the longest among the three countries, averaging about two years (10). After the 2013 transition from the first-generation to the second-generation NHI system, the median reimbursement lag of new medicines increased from 378 to 458 days (data for new medicines reimbursed from 2007-2014; six years pre- and two years post-transition) (48). For cancer and immune-related medicines, the average wait for reimbursement more than doubled from 385 to 853 days. Although Taiwan has a well-established health technology assessment (HTA) system and updates its reimbursement list monthly, these findings underscore that the timeliness of reimbursement decisions is a persistent challenge (10, 49). Measures to enhance patient involvement in reimbursement decisions have been introduced since 2015, but their impact

remains unclear, and experts continue to rate policies on accessibility and rational use of medicines as ineffective and in urgent need of improvement (51, 52).

Uneven adoption of novel medicines in clinical practice. Recent advancements have significantly expanded treatment options for advanced and recurrent endometrial cancer, particularly through the introduction of immunotherapies and targeted therapies tailored to specific molecular characteristics (1). These therapies include options for patients with distinct tumor profiles, such as those exhibiting dMMR/MSI-H mutations or TMB-H. Importantly, some medicines now extend treatment options to patients regardless of their dMMR/MSI-H status, offering broader applicability. They have also moved from second-line to first-line treatment options (1). However, integrating these novel treatments in Taiwan may require additional system readiness. Experiences from other gynecologic cancers in Taiwan suggest that even when new medicines are available and reimbursed, gaps in system capacity and implementation can possibly limit patient access (42).

Socioeconomic disparities can affect health outcomes and access to treatment. A Taiwanese study found that the total out-of-pocket (OOP) payments constituted around one-third of the total national health expenditure in 2021 (53). Curative care accounted for half of the OOPs, while medical goods and pharmaceuticals accounted for 39%. People with poor health are disproportionally affected by OOP expenditure (54), as frequent and high-level care negatively affects the progressivity of OOP (53). Thus, those who are mostly in need of healthcare, e.g., less healthy individuals or individuals with more complex diseases, could potentially be unevenly burdened, heightening health and socioeconomic disparities. Intensive treatments and advanced cancer stage have further been associated with severe financial hardship (SFH) among working-age cancer patients in Taiwan (55). In turn, patients facing SFH encountered a higher risk of death, showcasing the possible effects of financial disparities on health outcomes. Geographic disparities may also play a role in access to cancer treatment. Although radiation therapy facilities are distributed across Taiwan aligned with population size, towns with lower socioeconomic status are likely to have poorer access to them, that may hinder equitable access to radiation therapy (56). Among nine Taiwanese regions with uneven public transport coverage, Yunlin county (where medical resources to treat major diseases are located in two inland towns) faces a stronger correlation between cancer mortality and transportation coverage than other regions (57). In 2012, the use and expenditure of cancer medicines were highest in southern Taiwan and lowest in the outer islands (58).

7 POLICY INITIATIVES.

Endometrial/uterine cancer has traditionally received limited attention in global and national health policies compared to other women's cancers like breast and cervical cancer (1). While global initiatives such as the WHO's Global Breast Cancer Initiative and the Cervical Cancer Elimination Initiative demonstrate the potential for ambitious, coordinated action (59, 60), no similar large-scale strategies exist for endometrial cancer. International efforts, such as the Uterine Cancer Awareness Month (June) and World Gynecologic Oncology Day (September 20), have recently begun to address this gap, focusing on raising awareness and improving care. However, significant disparities remain in prioritization, funding, and research. This underscores the need for dedicated initiatives to reduce incidence, improve survival, and enhance the quality of care for endometrial cancer patients.

There are no specific targets related to endometrial cancer in the national cancer plan. In 2003, Taiwan adopted the Cancer Control Act, based on which several phases of the National Cancer Prevention and Control Plan have been implemented since 2005 (61). The fifth phase of the national cancer plan started in 2024 and spans until 2030 (61, 62). The plan sets five main objectives to prevent and control cancer: (i) to strengthen the cancer prevention and control system and improve intersectoral partnerships, (ii) to reduce and control cancer risk factors, (iii) to expand and improve screening, diagnosis, and treatment services, (iv) to improve quality of life of cancer patients and their families, and (v) to promote the use of monitoring data and research to enhance prevention and treatment strategies. In the national cancer plan, uterine/endometrial cancer is mentioned in relation to certain risk factors, e.g., overweight and obesity and endocrine disruptors. Although the plan aims to reduce cancer risk factors and improve cancer services, which are relevant to endometrial cancer, it sets no specific goals for this cancer type.

Lack of policy initiatives targeting endometrial cancer. Specific policy initiatives targeting endometrial cancer are not available in Taiwan. The Health Promotion Administration (HPA) occasionally publishes educational materials on its website to raise awareness about endometrial cancer, its risk factors, and the importance of early detection (63-65). For example, in October 2024 the HPA issued a public advisory titled *"Watch Out for Abnormal Bleeding, Be Aware of Endometrial Cancer"*, encouraging women to seek medical attention for symptoms such as post-menopausal bleeding, irregular cycles, or persistent abnormal discharge. Although this communication is not part of a sustained campaign, it reflects growing governmental recognition of endometrial cancer as a public health concern.

Positive policy developments in health care and cancer care. At a broader health system level, the Healthy Taiwan Cultivation Plan 2025–2029 is a major NT$48.9 billion (US$1.5 billion) initiative aimed at strengthening Taiwan's health system through workforce support, talent cultivation, digital health integration, and promotion of sustainable medicine (66). However, the plan does not set cancer-type-specific goals, including for endometrial cancer. Without targeted measures, such as symptom-awareness programs, improved diagnostic pathways, and equitable access to novel therapies, these system-wide reforms may not be sufficient to address the rapidly rising incidence and mortality of endometrial cancer. In addition, the establishment of a new cancer medicines fund worth NT$10 billion (US$ 306.9 million) was suggested in 2024 (67), which is part of a wider initiative to build a healthier Taiwan and combat cancer through improving early-stage cancer screening, focusing on genetic-testing and precision medicine, and establishing the fund.

Patient advocacy gap for endometrial cancer. Although uterine cancer is the most common gynecologic cancer in Taiwan, no dedicated, national endometrial-cancer advocacy

group was identified (6). Existing organizations focus on gynecologic cancers more broadly, e.g., the Formosa Cancer Foundation and the ROC Female Cancer Foundation, and provide education, psychosocial support, and prevention programs (68-71). Advocacy groups are critical for raising awareness, supporting patients, influencing research priorities, and shaping reimbursement and access policies (1, 72). Taiwan has mechanisms for patient input into HTA and Pharmaceutical Benefits and Reimbursement Scheme (PBRS) deliberations, and Taiwanese patient group members seem to be more frequently involved in these processes compared to other countries (51, 72). An endometrial-focused group could leverage these mechanisms to improve timely access and tailored services; however, public awareness efforts for endometrial cancer remain episodic rather than sustained for now (51, 72, 73).

Recommendations for Taiwan

Integrate endometrial cancer into national health strategies. Develop specific goals, initiatives, and funding mechanisms to address its growing disease burden.

Enhance early detection and diagnostics. Raise awareness of symptoms and risk factors, and ensure equitable access to specialists and diagnostic tools across the population, including novel biomarker testing, to improve timely and accurate diagnosis.

Ensure access to innovations and optimal care delivery. Increase the availability and uptake of internationally recommended treatment options and address workforce shortages to meet the growing care needs and close socioeconomic disparities across the population.

Improve data collection and availability. Routinely collect and analyze data on endometrial cancer care, such as waiting times along the care pathway and use of biomarker testing and medicines, that can inform further investment and targeted actions.

Support advocacy and patient voices. Establish a national advocacy group for endometrial cancer to raise awareness, influence research priorities, and ensure patient involvement in shaping care policies.

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