

## The Evolution of Population-Based Cancer Registries in Iran: A 70-Year Journey

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### ABSTRACT

Cancer registration is a cornerstone of effective cancer control programs, providing essential data on cancer incidence, prevalence, and mortality. This paper reviews the development, current status, and challenges of the Population-Based Cancer Registry (PBCR) program in Iran. Since the 1950s, Iran has made significant efforts to establish systematic cancer registration, culminating in the expansion of PBCRs across multiple provinces. The Golestan Province Cancer Registry was the first Iranian registry included in the international Cancer Incidence in Five Continents (CI5) report in 2014, with Ardabil Province joining in 2023, reflecting growing international recognition.

The Iranian PBCR program has evolved through national legislation mandating cancer reporting, expansion from pathology-based to population-based registries, and continuous quality improvement initiatives. Despite progress, challenges remain, including underreporting, data completeness, and timeliness. The most recent national PBCR report (2018) documented approximately 141,000 new cancer cases with age-standardized incidence rates of 182.8 and 165.3 per 100,000 for men and women, respectively. Regional disparities were evident, with higher rates of oesophageal, stomach, and lung cancers in northern provinces and breast, colorectal, and prostate cancers more common centrally. Projections indicate a 42.6% increase in new cancer cases by 2025, underscoring the urgent need for enhanced cancer control strategies. Survival analyses reveal substantial variation by cancer type and region, with higher survival in provinces with better socioeconomic indicators. Furthermore, modifiable risk factors such as smoking, overweight, opium use, and *Helicobacter pylori* infection contribute significantly to cancer burden in Iran.

To strengthen the PBCR program, priorities include timely publication of reports, improving data quality and coverage, and expanding international certification and publication. Sustained political commitment and resource allocation are essential to optimize cancer surveillance and support evidence-based policy to reduce Iran's growing cancer burden.

**Keywords:** Population-Based Cancer Registry; Iran; History



## INTRODUCTION:

In 2022, approximately 20 million people were diagnosed with cancer, and 10 million died of it. Additionally, it is estimated that 54 million individuals are living with cancer worldwide (1). As a critical component of cancer control programs (CCPs), cancer registration systematically collects and reports annual cancer statistics to improve cancer management within these programs. The primary objective of a cancer registry is to gather and classify comprehensive information on all cancer cases, providing continuous and reliable incidence data within a defined population (2). Cancer registration systems are generally categorized into three types: hospital-based, pathology-based, and population-based cancer registries (PBCRs) (2). PBCRs collect data on all reportable cancer cases within a specific geographic area from multiple sources. The findings from PBCRs are typically published regularly and serve to deliver accurate and precise statistics on cancer incidence, prevalence, and mortality. These data play a pivotal role in supporting CCPs and conducting epidemiological research (2).

What defines a Population-Based Cancer Registry (PBCR) as a high-quality registry are key indicators such as completeness, validity, and timeliness. Valid PBCR data from around the world are published in the Cancer Incidence in Five Continents (CI5) report, which serves as a valuable resource for international cancer comparisons (3). From 1966 to 2023, twelve volumes of the CI5 series have been released, providing standardized, high-quality cancer incidence data from PBCRs globally. The first volume included data from 29 countries and 32 registries. Over the decades, the scope of CI5 has expanded significantly, encompassing 65 countries and 460 registries in its most recent volume (3).

In Iran, multiple efforts have been made to establish Population-Based Cancer Registries (PBCRs). Among these, the Golestan Province Cancer Registry has continued its operations successfully, while initiatives in other provinces were either unsuccessful or discontinued. The first Iranian data appeared in the Cancer Incidence in Five Continents (CI5) Volume X, published in 2014, featuring data from Golestan Province (4). In 2023, data from a second province were included in CI5 Volume XII, marking an important expansion of Iran's representation in this international cancer registry report.

## History of PBCR in Iran

Cancer registration activities in Iran date back to the 1950s, beginning with the establishment of the Iran Cancer Institute, which collected data from 1946 to 1956. The first formal cancer-related data were published in 1956 by Prof. Abdollah Habibi, who compiled cancer cases referred to pathology departments across the country, marking the earliest systematic cancer data reporting in Iran. His report indicated prevalence rates of cancer of approximately 28 per 100,000 in the southern regions and 42 per 100,000 in the northern parts of the country (5).

In 1967, cancer registration began in the city of Babol through collaboration with the International Agency for Research on Cancer (IARC) (6). The following year, Shiraz University of Medical Sciences established its own cancer registry. In 1969, prompted by a notably high incidence of oesophageal cancer in the Caspian Littoral region, the first population-based cancer registry (PBCR) was established jointly by the University of Tehran and IARC to study this phenomenon (7). This initiative reported an incidence rate of 109 per 100,000 in men and 174 per 100,000 in women living in the eastern part of the region, where the Turkman ethnic group was living. This represents the highest incidence rate of oesophageal cancer ever reported worldwide.

After the Islamic Revolution, a major legislative milestone was reached on October 5, 1984, when the Islamic Consultative Assembly passed a law mandating cancer registration and reporting. The law required all pathology and diagnostic laboratories, as well as treatment centres—governmental or private—to confidentially report confirmed or suspected cancer cases to designated centres under the Ministry of Health. The executive bylaw for implementing this law was prepared within two months, and the law was experimentally enforced for three years starting June 7, 1985 (8).

During the 1980s, the Ministry of Health and Medical Education (MOHME) initiated pathology-based cancer registration, with the first national report published in 1986. Annual cancer registration reports have been published regularly since then. However, studies indicated that pathology-based registries tend to underestimate cancer incidence, highlighting the need for PBCRs (9, 10, 11).

Parallel to national efforts, research centres launched PBCR programs in various provinces. In 1988, the Cancer Research Centre of the Cancer

Institute in Tehran started a PBCR (12). In 1992, the Gastroenterology and Liver Research Centre (DDRC) at Tehran University of Medical Sciences began registering gastrointestinal cancers, initiating registries in Ardabil and later expanding to Gilan, Mazandaran, and Golestan provinces, and published a national estimate for cancer from these registries and reported (6, 12, 13, 14, 15). In addition, cancer statistics were published from Kerman (1996-2000), Semnan (1998-2002), and Eastern Azarbayjan (2006-2007) provinces (16, 17). These provincial registries, however, were often cross-sectional and discontinued following the implementation of national programs. Table 1 summarizes the key milestones in the history of cancer registration in Iran.

From 2004 to 2009, the Ministry of Health and Medical Education (MOHME) implemented a National Pathology Cancer Registration Program, publishing annual reports based on pathology data. In 2008, population-based cancer registries (PBCRs) were established in five provinces, expanding to 20 provinces by 2009. Between 2015 and 2018, the population-based

approach was further extended to 31 provinces, marking a significant expansion of the National PBCR program. PBCR data from Golestan Province were first published in Cancer Incidence in Five Continents (CI5), Volume XI in 2013, and more recently, data from both Golestan and Ardabil provinces were included in CI5, Volume XII in 2023, reflecting the program's ongoing progress and growing international recognition.

### Expert Review of the Population-Based Cancer Registry (PBCR) in Iran

The PBCR program in Iran has undergone multiple evaluations by international cancer registration experts. Specialists from the International Agency for Research on Cancer (IARC) and the International Atomic Energy Agency (IAEA) have conducted site visits to assess the national PBCR program and provided valuable expert recommendations. Table 2 summarizes these expert visits and their key recommendations. Although the PBCR program in Iran is not yet fully optimized, these expert insights remain highly relevant and offer practical guidance for its ongoing enhancement.

**Table 1.** History of Cancer Registration in Iran

Year	Activities
1950	Implementation of a patient registration program at the Cancer Institute
1967	Launch of the Babol Cancer Registry Program in collaboration with the School of Health, Tehran University of Medical Sciences, and IARC
1968	Establishment of the Shiraz Cancer Registration Program in cooperation with Shiraz University of Medical Sciences
1984	Approval of the law on mandatory registration of cancer cases by the Islamic Consultative Assembly
1992-2007	Research-based initiatives to establish PBCRs in the provinces of Ardabil (1996-1999), Mazandaran, Golestan, and Kerman (1996-2000), .(Tehran (1998-2001), Semnan (2006), and Eastern Azarbayjan (2006-2007
2009-2004	.Implementation of the National Pathology Cancer Registration Program and publication of annual reports by MOHME
2008	Implementation of PBCRs in five provinces by the MOHME
2009	Expansion of PBCR implementation to 20 provinces by the MOHME
2013	Evaluation of the National PBCR by WHO and the PACT Program of the Atomic Energy Agency
2013	Publication of the official PBCR report from Iran (Golestan Province) in Cancer Incidence in Five Continents (CI5) for the first time
2018-2015	.Implementation of the population-based approach in 31 provinces of Iran and implementation of the National PBCR program in Iran
2023	Publication of the PBCR data from Golestan and Ardabil Provinces in CI5, Volume XII

**Table 2.** Key Recommendations from International Experts on Iran's PBCR Program

Expert (Year)	Donald Max Parkin (2003)	Kiumars Nasserri (2001)	International Experts of the Atomic Energy Agency (IAEA) (2011)
Position / Country	Head of Cancer Registration, IARC, France	Cancer Registration Expert, USA	Experts and Specialists in Cancer Management
<b>Important Recommendations</b>	<ol style="list-style-type: none"> <li>1. Cancer registration should be conducted regionally (provincially), with strong cooperation and support from MOHME for provincial registries.</li> <li>2. Improve pathology-based cancer registration and expand data collection from additional sources.</li> <li>3. Ensure accuracy of data collected from pathology reports, particularly regarding patients' place of residence.</li> <li>4. Conduct program evaluations 12–18 months after implementation and prepare annual reports.</li> </ol>	<ol style="list-style-type: none"> <li>5. Establish a national committee to directly oversee the cancer registration program's activities, vision, and methodology.</li> <li>6. Align cancer registration activities under the supervision of a dedicated leader responsible for the cancer control program within the Ministry of Health.</li> <li>7. Develop and train a specialized workforce in cancer registration.</li> <li>8. Issue certification for trained cancer registration personnel, as qualified staff are essential for effective population-based cancer registration.</li> </ol>	<ol style="list-style-type: none"> <li>9. To achieve a high-quality cancer registration program, a population-based cancer registry or a high-coverage cancer registry is essential. Complete national coverage is not mandatory, but the population covered must be representative, and data quality must be sufficient to provide accurate incidence estimates for Iran.</li> <li>10. Improve the quality of death registration systems, as they form a critical foundation for the PBCR program.</li> </ol>

### National PBCR Reports

National cancer registry reports were published regularly from 2004 to 2009. The first report, released in 2003, included data on 38,469 cancer patients nationwide, estimating an age-standardized rate (ASR) of 15.74 per 100,000 population. With enhanced data collection efforts, the number of reported cancer cases increased to 74,067 by 2009, with an ASR of 34.13 per 100,000. These reports were primarily based on pathology-derived data, as patient information from medical records and clinical departments was not collected during this period. Several studies have indicated that these pathology-based registries underestimated the true cancer incidence in Iran (9, 10, 11). Following a four-year hiatus from 2010 to 2013, publication of national reports resumed in 2015, based on a memorandum of agreement between the Ministry of Health's Deputies for Health, Treatment, and Research and Technology. From 2015 to 2018, four additional regular reports were published. To date, a total of 12 national PBCR reports have been released. Table 3 and Figure 1 present a comprehensive list of these reports and their timelines (18, 19).

The most recent national PBCR report, covering data from 2018, provides a detailed map of cancer incidence across the country for both men and women. According to this report, there were approximately 72,000 male cancer patients, corresponding to an incidence rate of 182.8 per 100,000 population (19). For females, the

number of cancer cases was about 69,000, with an incidence rate of 165.3 per 100,000 population. Figures 2 and 3 illustrate the growth trends in incidence rates of the most common cancers among men and women, respectively, as documented in the series of published cancer registration reports.

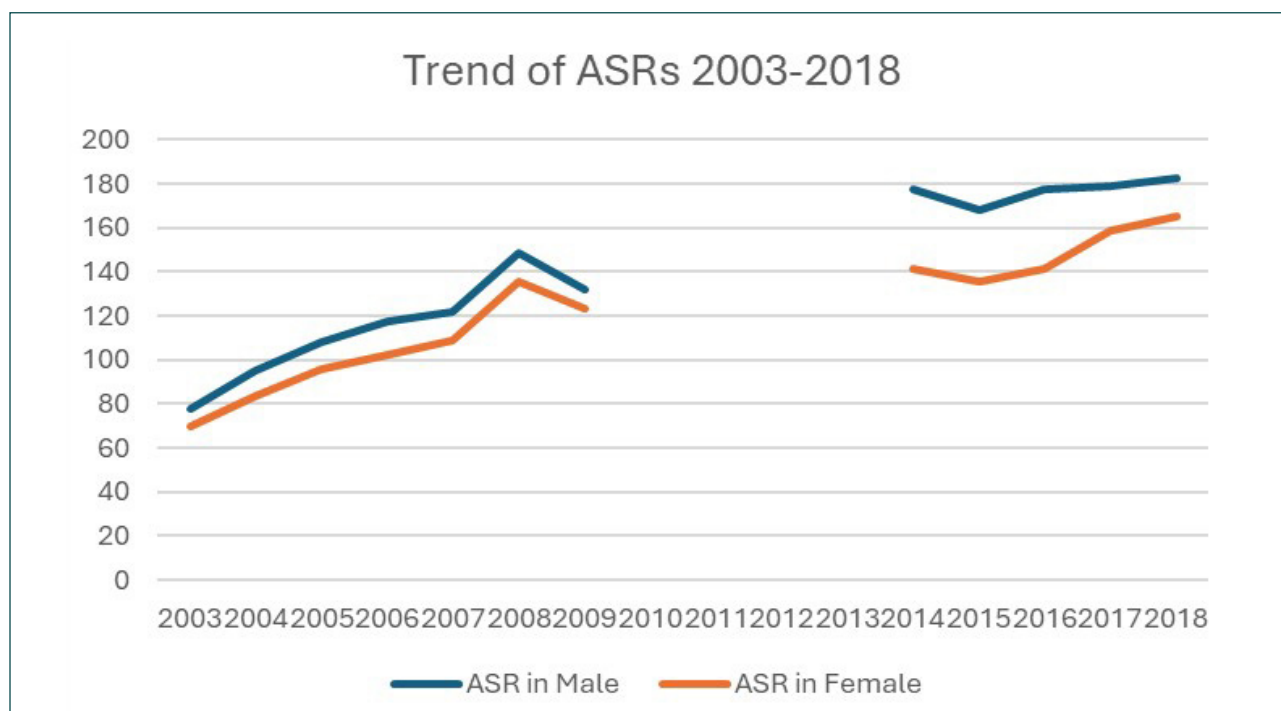
### Scientific Peer-Reviewed Publications

Since its establishment in 1967, the Iranian Population-Based Cancer Registry (PBCR) program has expanded significantly, producing a substantial and growing body of scientific literature. To date, several peer-reviewed publications have emerged, spanning from pioneering studies in the early 1970s to the latest research published as recently as 2025. These studies collectively capture the dynamic cancer landscape in Iran, offering valuable insights into cancer incidence trends, risk factors, survival outcomes, and regional disparities across the country.

The research generated by the PBCR program covers a broad spectrum of topics. Key areas of focus include national and regional cancer incidence and projections, with particular attention to rising trends in thyroid, breast, stomach, oesophagus, colorectum, prostate, liver, kidney, and bladder cancers. Geographic variations are well documented, highlighting higher incidences of oesophageal, stomach cancers in northern provinces. (20, 21, 22, 23, 24, 25, 26, 27).

**Table 3.** ASR of all cancer sites overall reported between 2003 and 2018 in Iran.

Report year	Male		Female		Both	
	Number	ASR*	Number	ASR	Number	ASR
2003	21620	77.7	16849	69.6	38469	74.15
2004	26743	95.4	20474	83.4	47217	90.22
2005	31355	108.1	24498	96.2	55853	102.39
2006	33770	117.3	26016	102.4	59786	110.82
2007	34636	121.6	27404	109.2	62040	116.12
2008	42279	148.8	33880	135.8	76159	142.99
2009	41169	132.2	39898	123.6	74067	128.34
2010	Not reported		Not reported		Not reported	
2011	Not reported		Not reported		Not reported	
2012	Not reported		Not reported		Not reported	
2013	Not reported		Not reported		Not reported	
2014	60432	177.4	51628	141.2	112060	158.41
2015	58511	168.3	51162	135.5	109673	150.9
2016	65678	177.4	58450	141.2	124128	159.45
2017	69916	179.1	64788	158.9	134704	168.56
2018	72575	182.8	69066	165.3	141641	173.48



**Figure 1:** Cancer incidence in Iran over the years

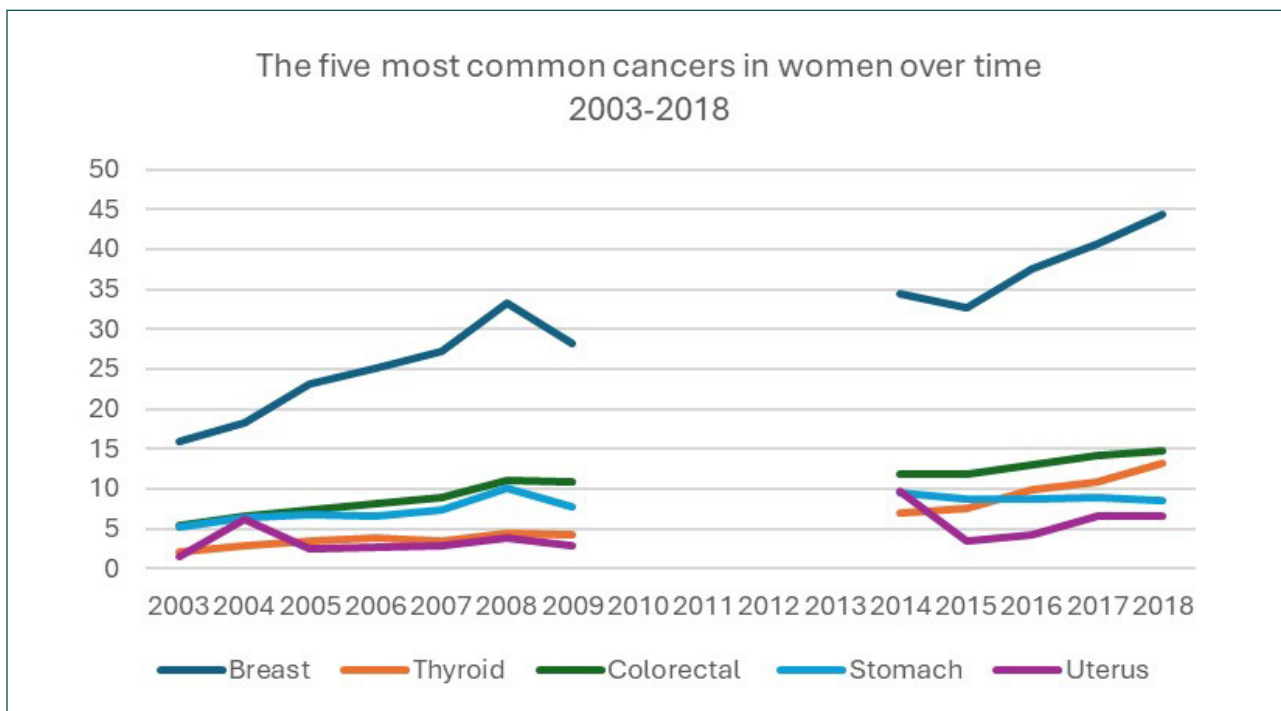


Figure 2: The five most common cancer in women

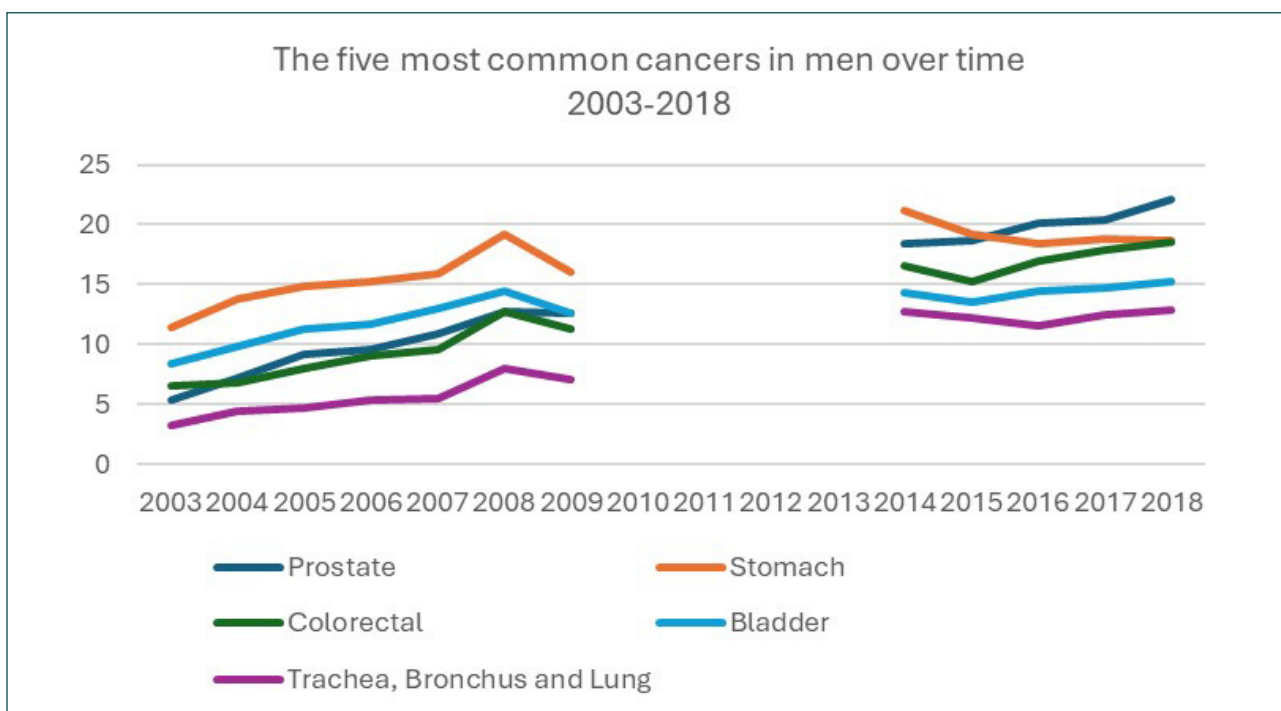


Figure 3: The five most common cancers in Men

The most recent national PBCR report documented approximately 141,000 new cancer cases with age-standardized incidence rates of 182.8 and 165.3 per 100,000 for men and women in 2018, respectively (19). The national PBCR program revealed significant regional differences in cancer incidence across Iran. Higher rates of oesophageal, stomach, and lung cancers were observed in the northern and northwestern provinces. In contrast, central provinces showed higher incidence rates of breast, colorectal, and prostate cancers. Furthermore, it was shown that, by 2025, new cancer cases are predicted to increase by 42.6% to approximately 160,400 cases. Most cancer types are expected to rise significantly, including thyroid cancer (113.8% increase), prostate (66.7%), female breast (62.9%), colorectal (54.1%), and lung cancer (49.1%). Notably, oesophageal cancer (EC) is predicted to decrease by 17.5%. This projected increase underscores the growing cancer burden in Iran and highlights the need for enhanced cancer control strategies (20).

A national study of cancer survival in Iran, based on data from nine provincial population-based cancer registries, estimated 5-year net survival rates for 15 common cancers among adults diagnosed in 2014-2015. The highest 5-year survival rates were observed for prostate cancer (74.9%), breast cancer (74.4%), bladder cancer (70.4%), and cervical cancer (65.2%). In contrast, survival was below 25% for aggressive cancers such as pancreas, lung, liver, stomach, and oesophagus (28). The study also revealed significant geographical disparities, with provinces having higher Human Development Index (HDI) showing better survival outcomes; for example, Western Azerbaijan had a 60% higher excess hazard of death compared to Tehran. These findings highlight the need for improved early detection and quality of care across Iran to reduce survival disparities (29).

A study utilized the national PBCR results in 2020 and revealed that about 32.6% of cancers in Iran were attributable to modifiable risk factors, with a higher fraction in men (40.2%) than women (21.1%). The leading causes were cigarette smoking (15.4%), overweight (5.0%), opium use (3.9%), and *H. pylori* infection (3.8%). For men, cigarette smoking (26.3%) and opium use (6.8%) were the top contributors, while for women, overweight (7.2%) and *H. pylori* infection (2.7%) were most significant. Waterpipe smoking and opium use together accounted for nearly 9% of cancers in men and 1.3% in women, highlighting the importance of addressing these emerging risk factors in cancer

prevention efforts (30).

Overall, the Iranian PBCR program has been pivotal in advancing cancer epidemiology knowledge, providing a robust evidence base to guide national cancer control policies and prevention strategies. Continued investment in registry infrastructure and research is crucial to effectively address the country's evolving cancer burden

### Data Quality

The quality of cancer registration data is evaluated using four fundamental criteria: comparability, completeness, validity, and timeliness (31). Iran's national PBCR program follows international standards and definitions for data collection, registration, analysis, and reporting, which facilitates meaningful comparisons with cancer registries worldwide. Despite these efforts, underreporting has been a significant challenge (10). For example, Mohammadi et al. (2016) estimated an underreporting rate of approximately 49% for cancer cases registered between 2008 and 2011, a period when the registry system was still incomplete. (32). Since the implementation of the updated PBCR program in 2014, concerted efforts have been made to enhance data collection from multiple sources—including pathology reports, hospital records, and death certificates—to reduce underreporting (33).

A critical measure of registry completeness is the proportion of cases registered solely based on death certificates, known as Death Certificate Only (DCO) cases. Ideally, the DCO percentage should be zero, with all cases identified through pathology and clinical records. According to global benchmarks, a DCO rate below 10% is considered acceptable for high-quality cancer registration (31, 34). In Iran's most recent national PBCR report (2018), the overall DCO rate was 13%, slightly above the acceptable threshold. However, this report represents a national average across all cancer types and regions. Some provinces and specific cancer types reported DCO rates below 5%, reflecting acceptable registration quality in those areas. Notably, the DCO rate varied widely by cancer type, ranging from less than 1% for thyroid cancer to as high as 28% for brain and nervous system cancers (Table 4). Continuous quality control measures, including adherence to International Agency for Research on Cancer (IARC) guidelines, periodic data audits, and validation studies, have improved the accuracy and completeness of the PBCR data (35). Nonetheless, challenges remain in achieving optimal timeliness and validity across all

**Table 4.** Number and percentage of diagnostic methods in the 12 most common cancers nationwide in the year 2018

Cancer Site	Pathology & Cytology (MV)		Clinical OR Paraclinical		Dead Certificate Only (DCO)	
	N	%	N	%	N	%
Breast	17117	87.5	1861	9.51	584	2.99
Prostate	6369	76.24	1008	12.07	977	11.69
Colorectal	11097	83.07	1272	9.52	989	7.4
Skin(non-Melanoma)	11617	94.13	594	4.81	131	1.06
Stomach	7922	72.33	1366	12.47	1665	15.2
Thyroid	7057	92.15	528	6.89	73	0.95
Bladder	6458	88.97	534	7.36	267	3.68
Trachea, bronchus and lung	4021	55.62	1531	21.18	1678	23.21
Other & unspecified	2631	43.29	1983	32.63	1463	24.07
Leukemia	4021	73.79	690	12.66	738	13.54
Uterus	2232	85.13	237	9.04	153	5.84
Brain, Nervous system	2689	50.88	1110	21	1486	28.12
All sites	109396	77.21	18063	12.75	14224	10.04

regions and cancer types. Strengthening coder training, improving death registration systems, and expanding data sources are ongoing priorities to enhance the overall quality of cancer registration in Iran.

The validity and accuracy of cancer registry data depend on the correctness of essential variables, including date of diagnosis, cancer type, patient age, gender, and geographic residence. While demographic variables such as age and gender are generally recorded with near 100% accuracy, other variables, especially tumour morphology, present greater challenges. In 2014, the percentage of cases with morphological verification (MV%) was 68%, increasing to 77.2% in the latest 2018 PBCR report (19, 36, 37, 38, 39). However, this remains below the international benchmark set by the International Association of Cancer Registries (IACR) and the International Agency for Research on Cancer (IARC), which recommend that over 90% of cases should be confirmed by pathology or tumour morphology (34).

Additionally, the proportion of cases with unknown tumour types decreased from 5.6% in 2014 to 4.29% in 2018, reflecting improvements in diagnostic precision and data completeness. Nevertheless, data quality varies across provinces, with some regions demonstrating higher accuracy than others (19, 36, 37, 38, 39).

Timeliness is another critical quality indicator. International standards consider a two-year delay between data collection and report publication acceptable, accounting for data cleaning, analysis, and review processes. Unfortunately, despite ongoing efforts, the most recent national PBCR report available is from 2018, indicating a lag that risks data becoming outdated. This delay highlights the need for enhanced management and streamlined processes within the Ministry of Health to ensure more rapid dissemination and updating of cancer incidence data (31, 40, 41). Overall, while significant progress has been made in improving the validity and timeliness of Iran's cancer registry data, continued efforts are essential to meet international quality standards and support effective cancer control planning.

### Conclusion and Recommendations

The Population-Based Cancer Registry (PBCR) program in Iran has been a successful and vital infrastructure for national cancer control efforts. Over the years, these initiatives have provided a clearer picture of the cancer burden in the country, enabling policymakers and health officials to make informed decisions and plan targeted interventions. The accumulated experience, along with the expertise of specialized researchers and professionals

at the Ministry of Health and Medical Education (MOHME) and academic institutions, forms a strong foundation for achieving the program's long-term goals. Despite these achievements, the PBCR program has faced numerous challenges, including interruptions in implementation. Although data quality has improved steadily over time, a significant disruption has occurred since 2018, halting the publication of updated reports. It is crucial that this gap be addressed promptly through renewed commitment from responsible authorities, allowing continuous monitoring of cancer incidence, risk factors, and outcomes across Iran.

**To enhance the national PBCR program, the following strategic recommendations are proposed:**

**Timely Publication of Reports:**

The highest priority is to resume and maintain the timely release of annual cancer registry reports. Delays in reporting hinder effective cancer control planning and program evaluation. Annual reports from 2018 onward should be published without further delay.

**Improvement of Coverage and Data Accuracy:**

Strengthening coverage and accuracy indicators must be a key focus. Aggregating data from provinces with low coverage and data quality can dilute national-level indicators. Establishing an evaluation framework to identify and temporarily exclude provinces with insufficient data quality from national reports can help improve overall metrics. These provinces should be supported to progressively enhance their registry performance before reintegration.

**International Quality Certification and Publication:**

A hallmark of a high-quality PBCR program is the inclusion of its data in the internationally recognized Cancer Incidence in Five Continents (CI5) series, which requires rigorous evaluation by global experts. Currently, only Golestan Province's registry has achieved this certification. Expanding efforts to certify and publish reports from additional Iranian provinces in CI5 should be prioritized to demonstrate and enhance the program's quality on the international stage.

In summary, Iran's PBCR program has made significant strides but requires sustained political will, resource allocation, and technical improvements to fulfil its critical role in cancer control. Addressing these recommendations will strengthen the registry's capacity to provide accurate, timely, and comprehensive cancer data that underpin effective national cancer prevention and control strategies.

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