



**Ministry of Health, Deputy of Public Health
Center for Non-communicable Disease Control, Cancer Office
INPCR secretariat**

**Introduction to
Iranian National
Population-based Cancer Registry
(INPCR)**

Dr Gholamreza Roshandel, MD, PhD
Director, INPCR

History of INPCR

- 1340s
 - Cancer registry activities in Iran
- 1360s
 - National Pathology-based cancer registry
 - Limitation: underestimation
- 1380s
 - Regional Population-based Cancer Registries (PBCRs)
 - Ardabil and Golestan PBCRs were accepted as voting members of the IACR
 - Publication of Golestan PBCR data in CI5 (Volumes X and XI)

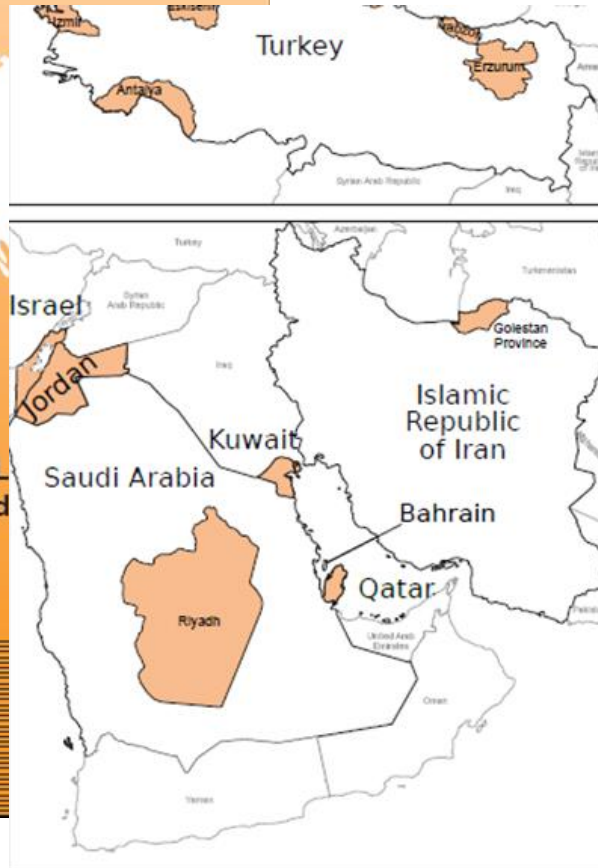
Publication of the GPCR data in the CI5_XI

International Agency for Research on Cancer

IACR
International Association of Cancer Registries



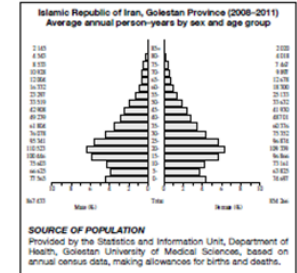
Cancer Incidence in Five Continents Vol. XI



Asia

Islamic Republic of Iran, Golestan Province

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20 major cancers, ASR (World) per 100 000

Male	Female		
Stomach	25.5	Breast	30.5
Oesophagus	22.3	Oesophagus	16.2
Trachea, bronchus, and lung	15.1	Stomach	12.3
Prostate	11.8	Colon	9.3
Non-melanoma skin cancer	11.5	Trachea, bronchus, and lung	6.5
Colon	11.3	Non-melanoma skin cancer	6.1
Bladder	9.9	Ovary	6.0
Brain and nervous system	6.6	Other and unspecified	5.5
Non-Hodgkin lymphoma	6.6	Brain and nervous system	5.3
Other and unspecified	6.1	Cervix uteri	5.2
Larynx	5.3	Non-Hodgkin lymphoma	3.2
Lymphoid leukaemia	4.8	Rectum	3.1
Rectum	4.5	Bladder	2.9
Liver	3.9	Thyroid	2.8
Pancreas	3.2	Lymphoid leukaemia	2.6
Myeloid leukaemia	2.9	Liver	2.5
Kidney	2.8	Leukaemia unspecified	2.3
Multiple myeloma	2.8	Pancreas	2.2
Leukaemia unspecified	2.1	Multiple myeloma	2.2
Testis	1.7	Myeloid leukaemia	2.1
All sites	175.5	All sites	146.4

612

Edited by F. Bray, M. Colombet, L. M. Piñeros, A. Znaor, R. Zanetti and

IARC Scientific Publications
No. 166

History of cancer registration in Iran

- 1380s (cont'd)
 - Regional PBCRs in other provinces
 - Great infrastructures (human resources, software, guidelines)
- The major limitations of these regional PBCRs included:
 - Lack of organizational structures
 - Poor access to financial support
 - Possible discrepancies in operational plans and methods of data collection
- Therefore, in early 1390s, the MOHME planned to establish an integrated Iranian national population-based cancer registry (INPCR).

Planning for National PBCR

Main requirement for establishment and maintenance of the INPCR:

Comprehensive collaboration between major stakeholders

To ensure **effective and permanent collaborations**:

INPCR agreement

- Signed by Deputy Ministers of Health, Research and Treatment

Approved by the Minister of Health

(September 2016)

تفاهم نامه برنامه ملی ثبت سرطان در ایران

شهریور ماه ۱۳۹۵

- ❖ تبصره ۳- در استان‌هایی که بیش از یک دانشگاه دارند، تصمیم‌گیری درباره فرآیند دسترسی و استفاده از داده‌های یک پارچه استانی به عهده «کمیته مشترک ثبت سرطان استان» خواهد بود.
- ❖ تبصره ۴- اجرایی شدن این تفاهم‌نامه مستلزم بررسی و تصویب آن توسط کمیته ملی پیشگیری و کنترل بیماری‌های غیر واگیر است.
- ❖ تبصره ۵- مکاتبات با رونوشت به هر سه طرف تفاهم‌نامه صورت می‌پذیرد.
- ❖ تبصره ۶- تغییر در مفاد این تفاهم‌نامه یا موافقت هر سه طرف تفاهم‌نامه و پس از تأیید در کمیته ملی سرطان و کمیته ملی پیشگیری و کنترل بیماری‌های غیر واگیر ایجاد خواهد شد.

این تفاهم‌نامه در ۱۲ ماده، ۱۶ بند و ۱۳ تبصره در دو نسخه تنظیم شده که هر دو نسخه حکم واحد دارند.

دکتر علی اکبر سیاری
معاون بهداشت

دکتر رضا ملک‌زاده
معاون تحقیقات و فن آوری

دکتر محمد حاجی آقاچانی
معاون درمان

بسمه تعالی

شماره: ۵/۱۰۱/۱۷۶۵
تاریخ: ۱۳۹۵/۰۷/۲۶
پرست: هارود

مستندت نام دارد

رئیس / سرپرست محترم دانشگاه / دانشکده علوم پزشکی و خدمات بهداشتی، درمانی

بسمه تعالی

به پیوست تفاهم‌نامه مشترک فی‌مابین معاونت‌های تحقیقات و فن‌آوری، بهداشت و درمان در خصوص «برنامه ملی ثبت سرطان در ایران» که به تأیید مقام محترم وزارت نیز رسیده است، جهت اطلاع و اجرا، ابلاغ می‌شود.

دکتر حسین کشاورز
مشاور وزیر و مدیر کل حوزه وزارتی

رونوشت:

- ✓ جناب آقای دکتر ملک‌زاده معاون محترم تحقیقات و فن‌آوری
- ✓ جناب آقای دکتر آقاچانی معاون محترم درمان
- ✓ جناب آقای دکتر سیاری معاون محترم بهداشت
- ✓ جناب آقای دکتر لاریجانی معاون محترم آموزشی

INPCR agreement:

The main aims of the INPCR

- To help and motivate all medical universities to establish high-quality population-based cancer registries (regional registries) on their own population
- To support and supervise regional cancer registries to ensure maintenance of their activities
- To receive and aggregate cancer data from regional registries to produce and publish cancer statistics at national level

Organization of the INPCR

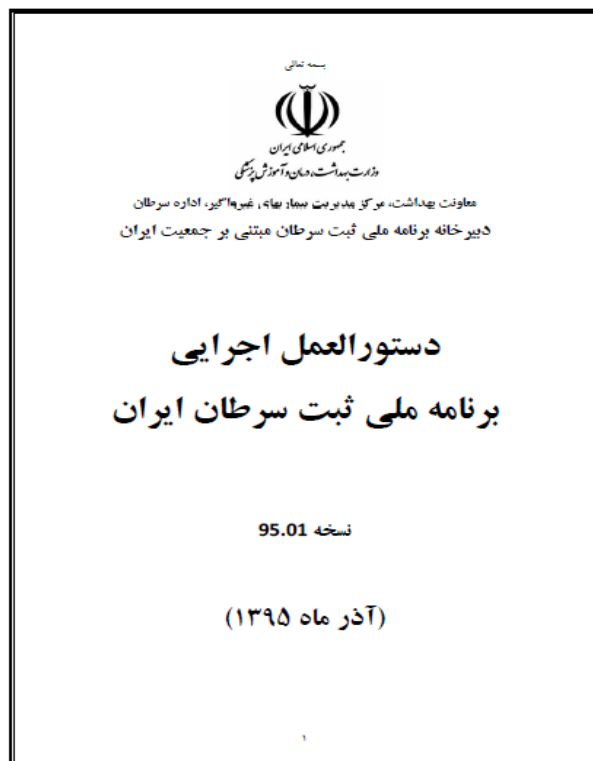
- Iran consists of 31 provinces and there are more than 60 medical universities
- To cover all Iranian population (100% coverage), we considered all medical universities as administrative units of the MOH
- The INPCR includes a national-level secretariat (the INPCR secretariat) and university-level secretariats
- The INPCR secretariat is located in cancer office of the MOH

اداره سرطان
Cancer office

دبیرخانه برنامه ملی ثبت سرطان
Secretariat of the
National Cancer registry
Program

The first step of the INPCR activity: Development of INPCR guideline (December 2016)

- To ensure comparability of data
- Considering IARC and IACR protocols and rules
- To define mandatory and optional items
- ICD-O coding



Training programs (Early 2017)



اولین همایش



برنامه ملی ثبت سرطان ایران

1st Iranian National Population-based Cancer Registry Conference

۱۸-۲۰ اردیبهشت ۹۶
دانشگاه علوم پزشکی گلستان



برگزارکنندگان:

- دبیرخانه برنامه ملی ثبت سرطان ایران
- دبیرخانه برنامه ثبت سرطان دانشگاه علوم پزشکی گلستان

با همکاری:

- معاونت بهداشت معاونت تحقیقات و فن آوری و معاونت درمان وزارت بهداشت، درمان و آموزش پزشکی
- اداره سرطان معاونت بهداشت وزارت بهداشت، درمان و آموزش پزشکی
- مدیریت آمار و فناوری اطلاعات وزارت بهداشت، درمان و آموزش پزشکی
- معاونت های بهداشت، توسعه مدیریت و منابع آموزش درمان و تحقیقات و فن آوری دانشگاه علوم پزشکی گلستان
- مرکز تحقیقات کوآریش و کبد دانشگاه علوم پزشکی گلستان
- مدیریت آمار و فناوری اطلاعات دانشگاه علوم پزشکی گلستان
- پژوهشکده بیماریهای کوآریش و کبد دانشگاه علوم پزشکی تهران
- مرکز تحقیقات سرطان دانشگاه علوم پزشکی شهید بهشتی

وب سایت: www.cancer.goums.ac.ir



Collection of data (June 2017)

- Starting year: 2014
- Main sources:
 1. Pathology labs
 2. Hospitals (from hospital medical records)
 3. Death Registry Programs

INPCR online data collection tool: [Sima-ye-Saratan]

فرم ثبت نام فرد

نام خانوادگی	نام	کد ملی
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مشخصات محل سکونت

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آدرس منزل		

- مشخصات فردی
 - ثبت فرد
 - مستجوی فرد
 - ثبت افراد یا فایل Excel
- مشخصات سرطان
 - لیست سالیانه ی بیماران
 - فرم بیماران ثبت شده
 - دریافت فایل اکسل
- ملی تنظیمات
 - مردود

INPCR online data collection tool: [Sima-ye-Saratan]

- A specific web-based application for data collection
- Advantages:
 - Online tool for data collection
 - To facilitate and secure transmission of data from the university cancer registry secretariats to the INPCR secretariat
 - To facilitate data processing (especially, person search, checking for duplicate records at national level,...)

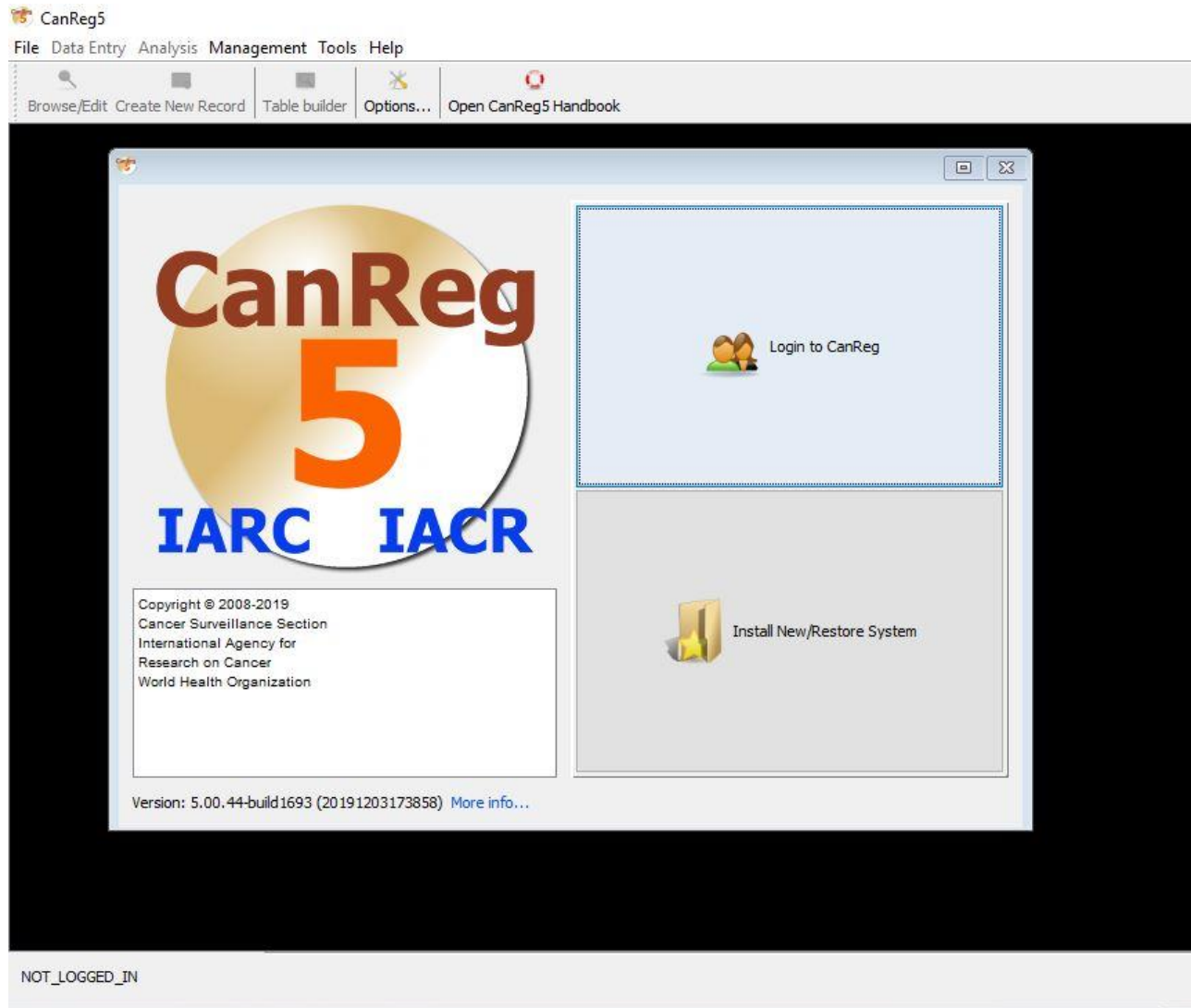
Quality control

- **Regional (University) level**
- **National level**

Quality control

- **Comparability**
- **Validity (or accuracy)**
 - Internal consistency methods (consistency checks)
(IARC-check program)
 - Missing/incorrect information analyses
- **Completeness**
 - The proportion of cases microscopically verified (MV%);
 - Death certificate Only (DCO%)

INPCR Quality control



Indices of data Quality-1:
Distribution of **diagnosis methods in INPCR**

Year	Death Certificate Only (DCO) method	Clinical/ paraclinical methods	Microscopic Verification (MV)
2014	<u>12.99 %</u>	18.73 %	<u>68.28 %</u>
2015	<u>12.60 %</u>	12.80 %	<u>74.59 %</u>
2016	<u>10.27 %</u>	11.75 %	<u>77.98 %</u>
2017	<u>10.84 %</u>	13.66 %	<u>75.50 %</u>
2018	<u>10.38 %</u>	12.27 %	<u>77.35 %</u>

Indices of data Quality-2:

Numbers and proportions (%) of cases with **unknown primary site** in INPCR, 2014-2018

	2014		2015		2016		2017		2018	
	N	%	N	%	N	%	N	%	N	%
Male	3,420	5.66	3,161	5.30	3,226	4.91	3,207	4.58	3,399	4.67
Female	2,889	5.59	2,682	5.14	2,771	4.74	2,729	4.20	2,718	3.93
All	6,309	<u>5.63</u>	5,843	<u>5.23</u>	5,997	<u>4.83</u>	5,936	<u>4.40</u>	6,117	<u>4.31</u>

INPCR progress report

Year	Data Collection	Quality Control	Data Analysis	Report
2014	Complete	Complete	Complete	Complete
2015	Complete	Complete	Complete	Complete
2016	Complete	Complete	Complete	Complete
2017	Complete	Complete	Complete	Complete
2018	Complete	Complete	Complete	Complete
2019	Complete	In progress	To-Do	To-Do
2020	In progress	To-Do	To-Do	To-Do
2021	In progress	To-Do	To-Do	To-Do
2022	In progress	To-Do	To-Do	To-Do

INPCR annual reports

website: cancer.behdasht.gov.ir

گزارش
ملی
سرطان



سال ۱۳۹۳

گزارش
ملی
سرطان



سال ۱۳۹۴

گزارش
ملی
سرطان



سال ۱۳۹۵

گزارش
ملی
سرطان



سال ۱۳۹۶

گزارش کشوری
برنامه ملی
ثبت سرطان



وزارت بهداشت، درمان
و آموزش پزشکی
معاونت بهداشت
دفتر مدیریت بیماری های
غیر واگیر، اداره سرطان
دفتر برنامه ملی
مدیریت سرطان



سال ۱۳۹۷



Cancer incidence in Iran in 2014: Results of the Iranian National Population-based Cancer Registry



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INPCR design paper

*(Cancer Epidemiology,
2019)*

*[Using the data of the year
2014]*

Cancer in Iran 2008 to 2025: Recent incidence trends and short-term predictions of the future burden

Gholamreza Roshandel^{1,2}  | Jacques Ferlay³  | Ali Ghanbari-Motlagh⁴ | Elham Partovipour² | Fereshteh Salavati² | Kimia Aryan¹ | Gohar Mohammadi⁵ | Mostafa Khoshaabi² | Alireza Sadjadi⁶ | Masoud Davanlou⁷ | Fereshteh Asgari² | Hakimeh Abadi⁸ | Abbas Aghaei⁹ | Seyed-Vahid Ahmadi-Tabatabaei¹⁰ | Kazem Alizadeh-Barzian¹¹ | Abbasali Asgari¹² | Noorali Asgari¹³ | Soheyla Azami¹⁴ | Maria Cheraghi¹⁵ | Floria Enferadi¹⁶ | Masoumeh Eslami-Nasab¹⁷ | Jila Fakhery¹⁸ | Mohsen Farahani¹⁹ | Solmaz Farrokhzad²⁰ | Mansooreh Fateh²¹ | Ali Ghasemi²² | Fatemeh Ghasemi-Kebria¹ | Hajar Gholami²³ | Arash Golpazir²⁴ | Susan Hasanpour-Heidari¹ | Narjes Hazar²⁵ | Hosein Hoseini-Hoshyar²⁶ | Mohsen Izadi²⁷ | Mahdi Jahantigh²⁸ | Ahmad Jalilvand²⁹ | Seyed-Mehrdad Jazayeri³⁰ | Yasan Kazemzadeh³¹ | Maryam Khajavi³² | Maryam Khalednejad³³ | Marziyeh Khanloghi³⁴ | Maryam Kooshki³⁵ | Amineh Madani³⁶ | Mahdi Mirheidari³⁷ | Hosein Mohammadifar³⁸ | Zeinab Moinfar³⁹ | Yasaman Mojtahedzadeh⁴⁰ | Ali Morsali⁴¹ | Rita Motidost-Komleh⁴² | Tahereh Mousavi⁴³ | Maboobeh Narooei⁴⁴ | Mohammad Nasin⁴⁵ | Sharareh Niksari⁴⁶ | Mehdi Pabaghi⁴⁷ | Habibollah Pimejad⁴⁸ | Azadeh Pournajaf⁴⁹ | Gita Pourshahi⁵⁰ | Amir Rahnama⁵¹ | Bahman Rashidpoor⁵² | Zahra Ravankhah⁵³ | Khadijeh Rezaei⁵⁴ | Abbas Rezaianzadeh⁵⁵ | Gholamreza Sadeghi⁵⁶ | Mohammad Salehifar⁵⁷ | Athareh Shahdadi⁵⁸ | Mehraban Shahi⁵⁹ | Farrokh Sharifi-Moghaddam⁶⁰ | Roya Sherafati⁶¹ | Ali Soleimani⁶² | Maryam Soltany-hojatabad⁶³ | Mohammad-Hossein Somi⁶⁴ | Sohrab Yadollahi⁶⁵ | Majid Yaghoubi-Ashrafi⁶⁶ | Aliakbar Zareiyan⁶⁷ | Hossein Poustchi⁶ | Kazem Zendehtdel⁶⁸ | Afshin Ostovar⁶⁹ | Ghasem Janbabaei⁷⁰ | Alireza Raeisi⁷¹ | Elisabete Weiderpass⁷²  | Reza Malekzadeh⁶ | Freddie Bray³ 

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³Cancer Surveillance Branch, International Agency for Research on Cancer (IARC), World Health Organization (WHO), Lyon, France

Abbreviations: ASR, age-standardized incidence rates; Brain & CNS, brain and/or other parts of central nervous system; EC, esophageal cancer; IAQI, International Association of Cancer Registries; IARC, International Agency for Research on Cancer; ICD-O-3, third edition of the International Classification of Diseases for Oncology; INH, Iranian National Population-based registry; INPCR, Iranian National Population-based Cancer Registry; MOH, Ministry of Health; NHL, non-Hodgkin lymphoma; NMIBC, non-melanoma skin cancer; PAHs, polycyclic aromatic hydrocarbons; TC, thyroid cancer.

INPCR prediction paper

*(International Journal of Cancer,
2021)*

*[Using the data of the years
2014-2016]*

International collaboration

- Voting member of the IACR/IARC
- Collaboration in the Globocan2018 project

International Agency for Research on Cancer
World Health Organization
GCO
CANCER TODAY
HOME ABOUT DATA & METHODS FACT SHEETS EXPLORE HELP

GLOBOCAN2018_Annex_A - Excel
Gholamreza Roshandel

	A	B	C	D
		Source		Method
121	India	Local	2b	Population estimates: (1) North-Eastern region population (eight states), remaining (2) urban and (3) rural populations were computed by sex and age for 2018 by partitioning proportions from the 2011 census.
122	Iran, Islamic Republic of	Local	2b	Rates from 24 provinces (22 for 2014, 2 for 2015) covering 70% of total population applied to 2018 population. Ref. Reza Malekzadeh, Gholamreza Roshandel, Alireza Raisi, Ghasem Janbabaee, Afshin Ostovar, Ali Ghanbari-Motlagh, Kazem Zendeheidi, Elham Partovipour, Fereshteh Islamic Republic of Iran in 2014. Tehran: Iranian National Population-based Cancer Registry secretariat, Cancer office, Center for Diseases Control, Iranian Ministry of Health and Medical Education, 2015.
123	Kazakhstan	National	2a	Rates (2008-2012) ³ applied to 2018 population.

The methods used to estimate the sex- and age-specific incidence rates of cancer in a specific country fall into the following broad categories, in order of priority:

- 1 Observed national incidence rates were projected to 2018 (45 countries).

CANCER INCIDENCE AND MORTALITY DATA: SOURCES AND METHODS BY COUNTRY

Cancer Today - IARC, 150 Cours Albert Thomas, 69372 Lyon CEDEX 08, France - Tel: +33 (0)4 72 73 84 85 - powered by GLOBOCAN 2018

<https://gco.iarc.fr/today/data-sources-methods>

Use of the data



دستورالعمل

دسترسی و استفاده از داده های
برنامه ملی ثبت سرطان جمعیتی ایران

مهر ماه ۱۳۹۷

- Guideline for use of the INPCR data
- Signed by deputy ministers of Health, Research and Treatment (November 2018)
- Clear plan for access to and using the INPCR data
 - Regional (university/provincial level) data
 - National level data
 - Considering codes of research ethics and publication ethics
- DTA

website: cancer.behdasht.gov.ir

Data requests

(by January, 2023)

- **31** research projects:
 - Mainly student thesis (PhD, MSc, MD)
- **From different Universities:**
 - Tehran, Shahid Beheshti, Iran, Isfahan, Shiraz, Kerman, Yazd, Golestan, Hamedan, Urmia, Azad

Acknowledgments





For more information:

Website: *cancer.behdasht.gov.ir*

Email: *cancer@health.gov.ir*

Thanks for your kind attention