



In the name of God

DEVELOPING STANDARDS TOOL AND EVALUATION OF POPULATION BASED CANCER REGISTRY IN IRAN

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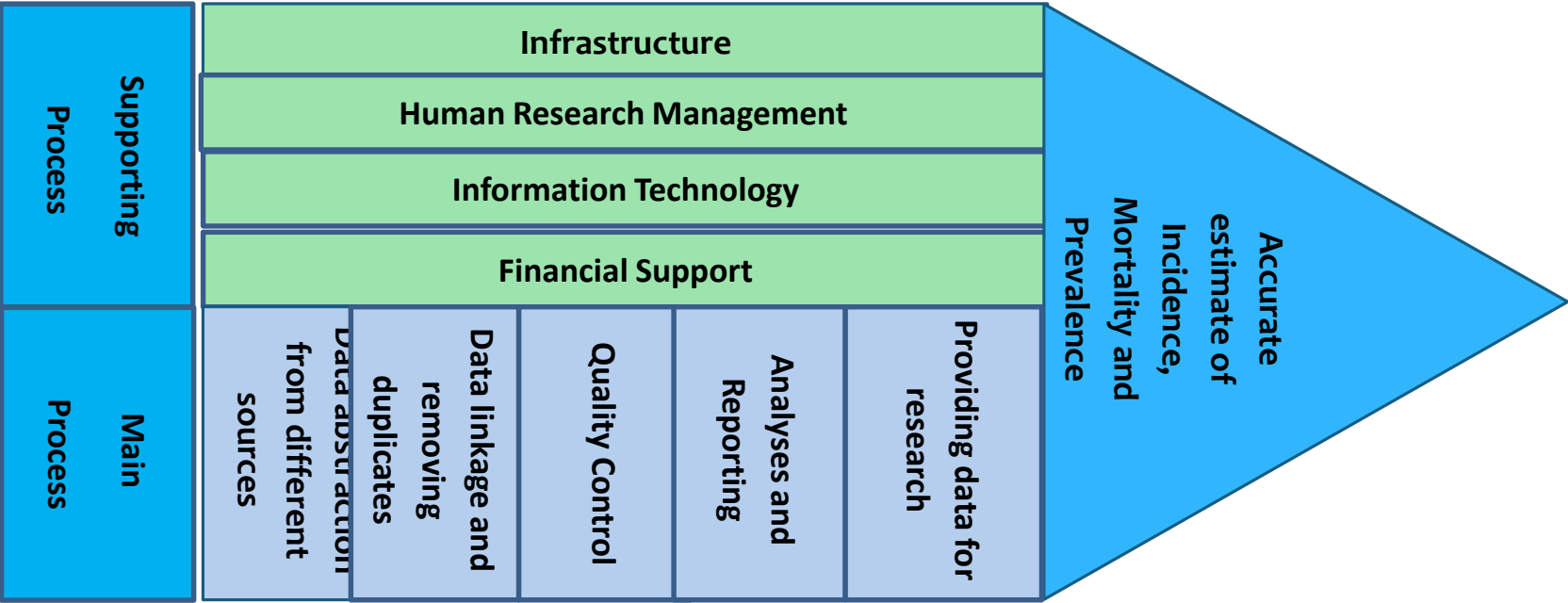
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Importance of CR

- * Cancer registry (CR) is one of the main infrastructures for National Cancer Control Program (NCCP).
- * Iran has run a national program for pathology based cancer registry
- * Recently, a few provinces updated the program and performed population based cancer registry (PBCR).
- * **Evaluation of quality of PBCR is important**

Cancer Registry Processes



طرح ارزیابی ثبت سرطان د رایران

- * با پیشنهاد اداره سرطان، وزارت بهداشت
- * به سفارش دفتر سازمان بهداشت جهانی (در غالب طرح های JPRM)
- * با همکاری مراکز تحقیقاتی، معاونتهای بهداشتی، و خبرگان ثبت سرطان



Purpose of the study

- * To **comprehensively evaluate** the Iranian PBCR

Specific Objectives:

- * To develop **standard questionnaire/checlists** for evaluation of the PBCR
- * To evaluate the **guideline, annual reports, IT, organizational structure** of the cancer registry in Iran
- * To evaluate **Knowledge, Attitude, and Performance** of the cancer registry staff in different level, including national, university, health center, and laboratories.
- * To evaluate **quality of cancer registry data** and assessment of the **coverage** of cancer registry in Iran

Methods:

Objective 1:

Developing checklist/questionnaire

a **task force** for **reviewing** the existence standards

- * cancer epidemiology
- * information technology
- * health management and policy
- * health information management

- * With experiences in running and executing population-based cancer registries

- * Task force selected the **NAACCR standards**

North American Association of Central Cancer Registries, Inc. (NAACCR)



North American Association of Central Cancer Registries



Is responsible for:

- * (1) promote **uniform data standards** for cancer registration
- * (2) provide **education and training**,
- * (3) **certify** population-based registries
- * (4) aggregate and **publish data** from central cancer registries,
- * (5) **promote the use** of cancer surveillance data and systems for cancer control and epidemiologic research

Standards for Cancer Registries Volume III

STANDARDS FOR COMPLETENESS, QUALITY, ANALYSIS, MANAGEMENT, SECURITY AND CONFIDENTIALITY OF DATA

Edited by Jim Hofferkamp, CTR

August 2008



Why NAACCR standards?

- * A comprehensive set of standards (190 pages)
- * Applied for the best cancer registries in the world (USA, SEER, CDC, Canada)
- * Based on the PBCR
- * Organized and defined strictness (Must, Should, May)
- * Used and tested in other countries (Spain, Argentina, Ecuador, Uruguay, Cuba and Panamá)

Why NAACCR standards?

Coverage of different aspect of PBCR

1. Access to data source and completeness of reporting (20%)
2. Data quality assurance (11%)
3. Data analysis and dissemination (18%)
4. Data management(32%)
5. Security and confidentiality (19%)

2.2.5.1. Standards

The central registry **MUST** include all reportable tumors occurring in residents of its coverage area, regardless of where the tumors are diagnosed or treated.

The central registry also **SHOULD** include all residents and non-residents diagnosed or treated in its coverage area to allow for sharing of tumor records with other population-based registries, facilitate death clearance and other record linkages, and allow for the preparation of reports to individual facilities that include all of their tumor records. The registry **SHOULD** record the complete address at diagnosis for its non-resident tumor records as well as resident tumor records in a form that allows for electronic sharing of the full address.

The central registry **SHOULD** provide information on a non-resident to the population-based registry covering the patient's place of residence when the required components listed in Section 2.2.5.2. are in place. The shared information **SHOULD** include confidential and non-confidential data and abstracted text summaries as described in the current NAACCR *Standards for Cancer Registries Volume II: Data Standards and Data Dictionary*.

The central registry **SHOULD** analyze the results of case sharing and data exchange (see NAACCR's *Procedure Guidelines for Cancer Registries Series I: Interstate Data Exchange*).

- * The task force extracted **standards**
- * **Translated to Farsi language (1000 main standards and sub standards)**
- * **Consensus building** among the task force members
- * Organized by selected criteria (structure, guideline, IT, Process, Quality control, reports)
- * Developed the **first draft of checklist and questionnaires** for evaluation of guideline, documents and reports, and processes, IT and structure

Validation

- * We invited **10 national experts** to rate the importance and clarity of the questions (based on 0-4 indicated no importance/clarity to very high importance/clarity)
- * We selected those items with **at least 75% agreement**
- * Items with 50-75% agreement were discussed **in several expert panel meetings** for building consensus

Objective 2 : evaluate the guideline, annual reports, IT, organizational structure

- * One of the member of task force for each section
- * He/she carefully evaluated the guidelines and reports of the national cancer registry and answered the standard questionnaire
- * Some questions were discussed among the experts and the decision was made after discussion (if the assigned expert could not answer)

Objective 3 : KAP study

- * the **central cancer registry** (Cancer Office, Ministry of Health),
- * **5 universities that were responsible** to manage the PBCR in the provincial level.
- * we selected **some health centers** from each university that are responsible to collect data and submit to the cancer registry office in the university,
- * We selected **some laboratories** from each province that are responsible to report cancer cases to the cancer registry program

Objective 4: Estimation of the coverage of cancer registry

- * We performed a capture recapture analysis in the pathology departments in Tehran province to estimate the underreporting rate by laboratories
- * we used the available data from the few PBCR to estimate the percentage of Death Certificate Only Cases (DCO).

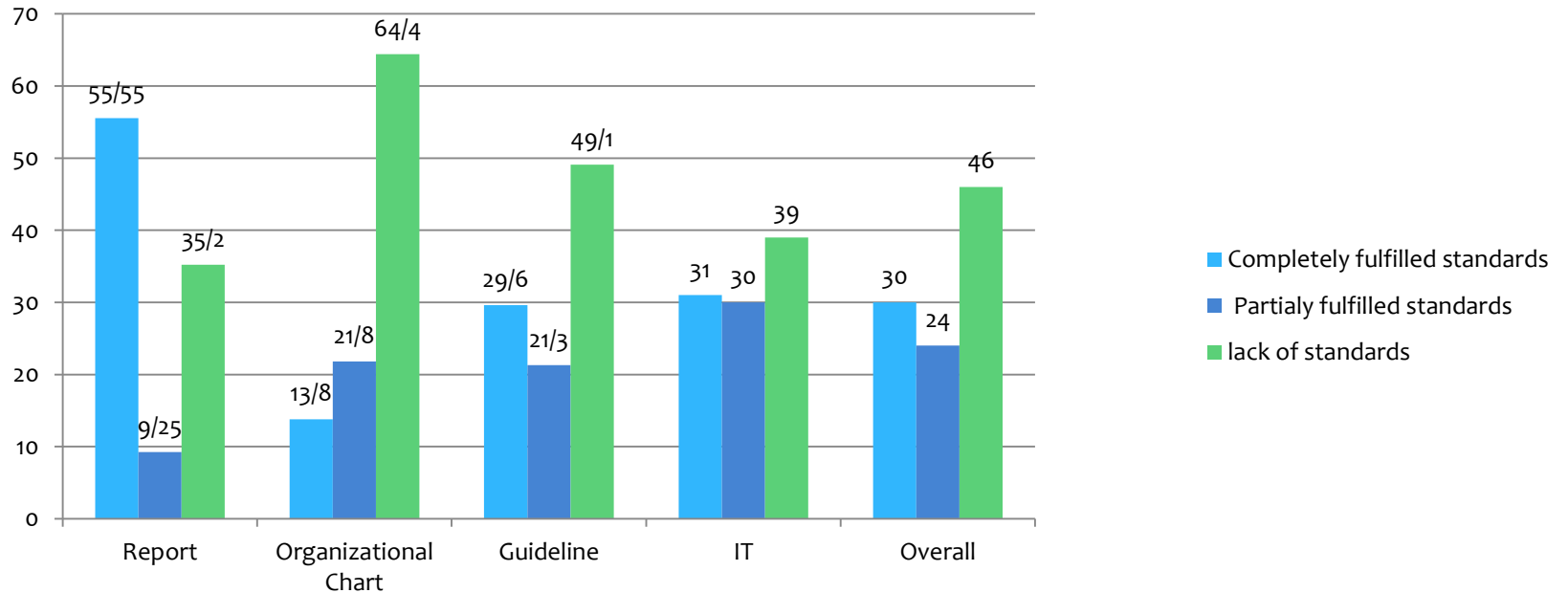
Results objective 1

Final instruments

- * Cancer Registry Guideline (108 Questions)
- * Organizational Chart and Infrastructure (87 Questions)
- * Annual Report (54 Questions)
- * IT (155 questions)
- * KAP

Objective 2

ارزیابی دستورالعمل، ساختار سازمانی، گزارشها و فن آوری اطلاعات ثبت سرطان جمعیتی

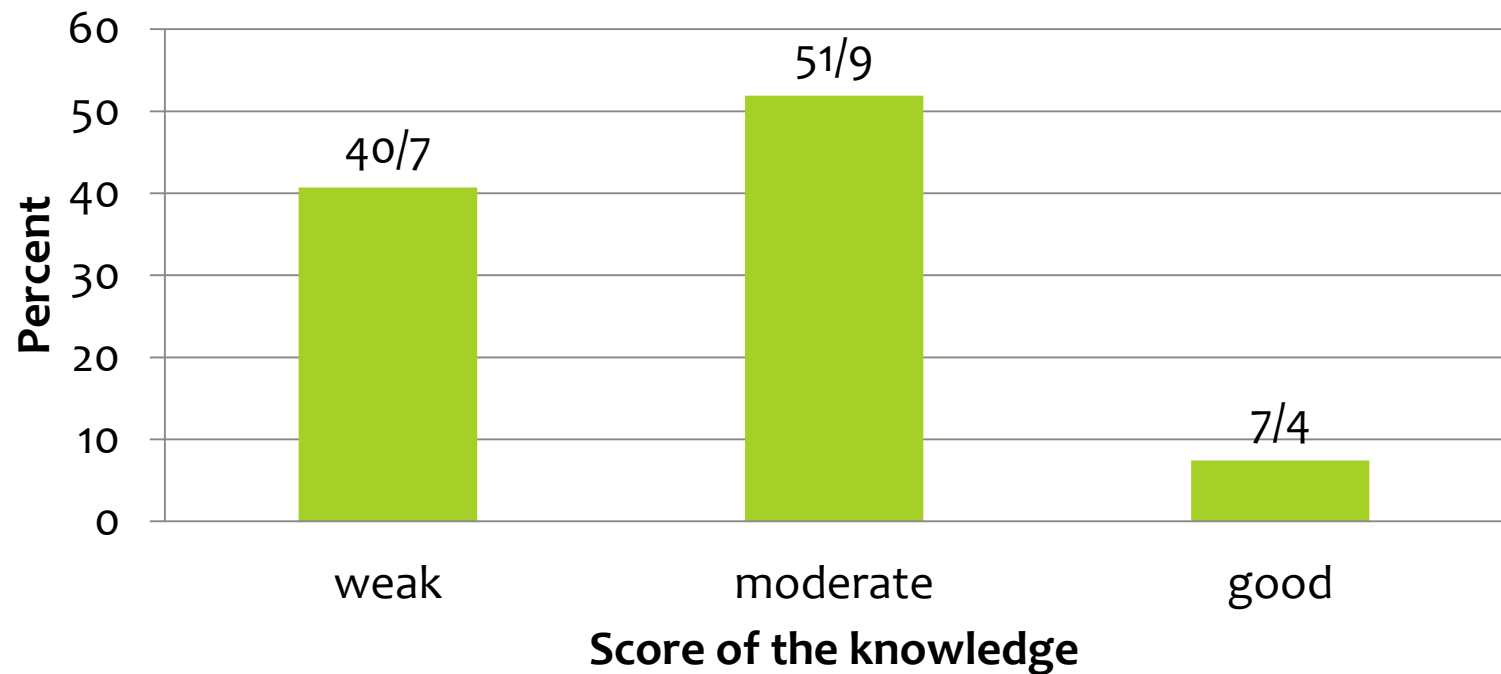


نتایج

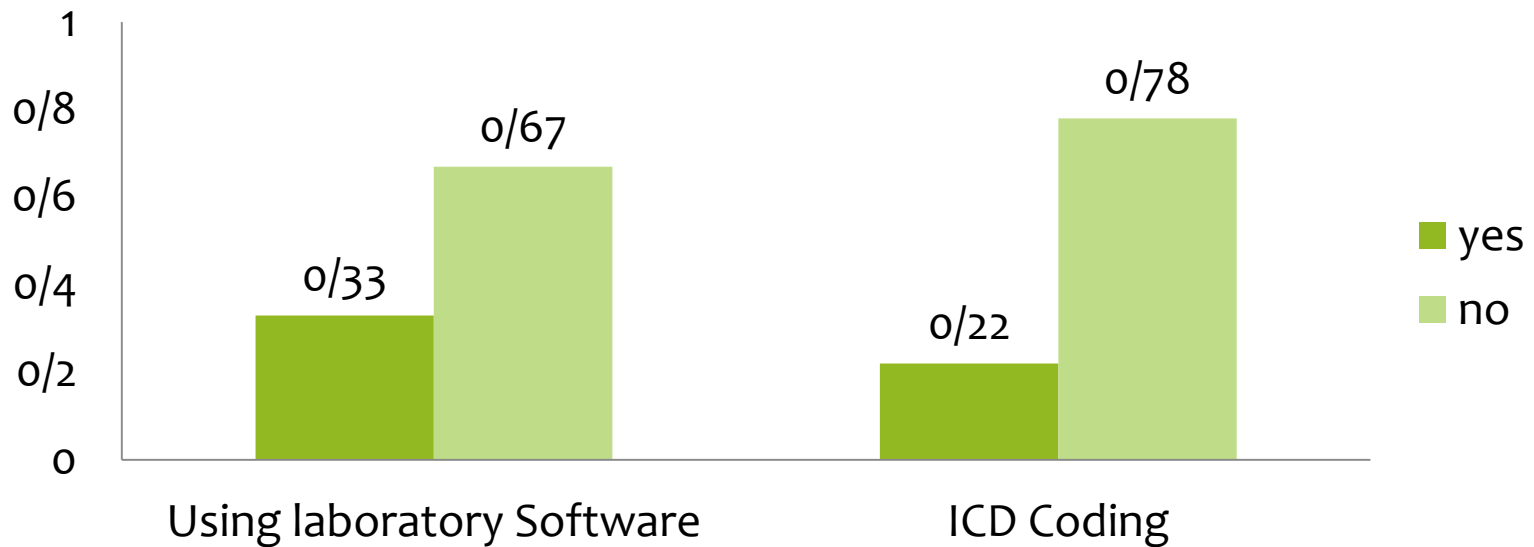
خیر (اصلا اشاره نشده است)	تأحدی ذکر شده است	بلی (کاملاً ذکر شده است)	موضوع مورد بررسی تعداد سوال (استاندارد)
<p>روش تصمیم‌گیری در مورد منابع گزارش دهی</p> <p>گردآوری اطلاعات از موارد اتوپسی</p> <p>تاکید بر اضافه شدن تمام موارد DCO (بعد از پیگیری) به فایل نهایی ثبت</p> <p>روش بررسی علل فوت برای انتخاب علت مرگ</p> <p>تاکید بر لینک داده های ثبت و داده های مرگ پس از تکمیل هر دو فایل</p> <p>تاکید بر اینکه تمام تومورهای تشخیص داده شده بعد از تاریخ مرجع باید ثبت شوند</p> <p>تاکید بر ثبت تومورهای رخ داده در منطقه موردنظر صرف نظر از محل تشخیص یا درمان</p>	<ul style="list-style-type: none"> روش شناسایی مراکز ارایه دهنده خدمات تشخیصی درمانی سرطان روش کنترل تغییرات رخ داده در تعداد و محل موسسات تحت پوشش تاکید بر استفاده از فایل رسمی مرگ و میر (اطلاعات مرگ) روش تعیین تاریخ مرجع ثبت سرطان 	<ul style="list-style-type: none"> منابع گزارش دهی گردآوری اطلاعات از بیمارستان‌ها (مدارک پزشکی)، مراکز سرپایی (مانند مطب‌ها)، آزمایشگاه های پاتولوژی بیمارستانی، مراکز آنکولوژی سرپایی، آزمایشگاه های پاتولوژی مستقل، مراکز رادیوتراپی، موارد فوتی، منطقه جغرافیایی تحت پوشش مشخص بودن تاریخ مرجع (تاریخ شروع پوشش دادن موارد نئوپلاسم) 	<p>منابع داده ها و گردآوری داده (۲۲)</p>

Knowledge, Attitude and Performance

دانش کارشناسان و عوامل ثبت سرطان در مورد برنامه ثبت سرطان



کد گذاری در آزمایشگاه های آسیب شناسی و استفاده از نرم افزار جهت ثبت اطلاعات

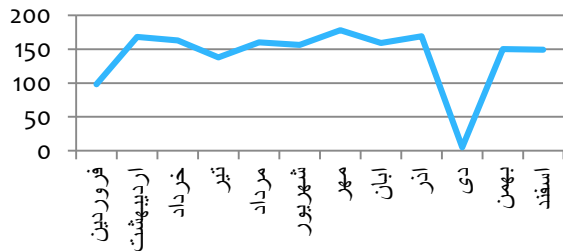


Estimation of the Coverage

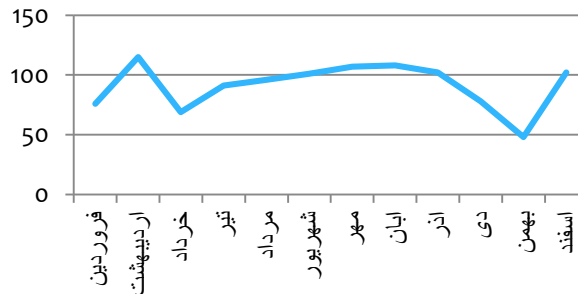
(only no 6 was consistent)

(the low reporting was in Winter, the last 3 months of Iranian calendar)

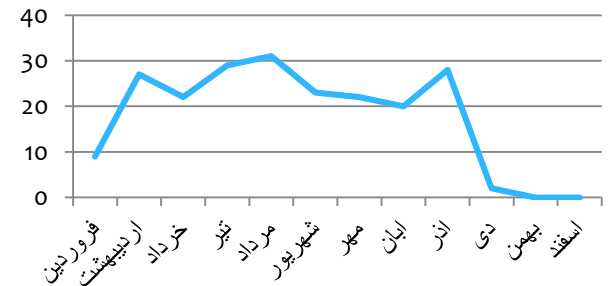
Lab1



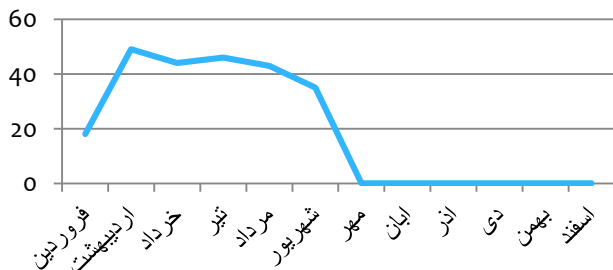
Lab2



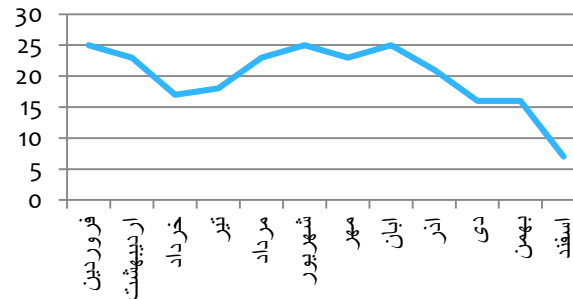
Lab3



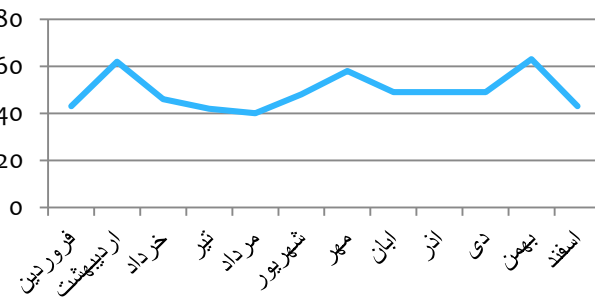
Lab4



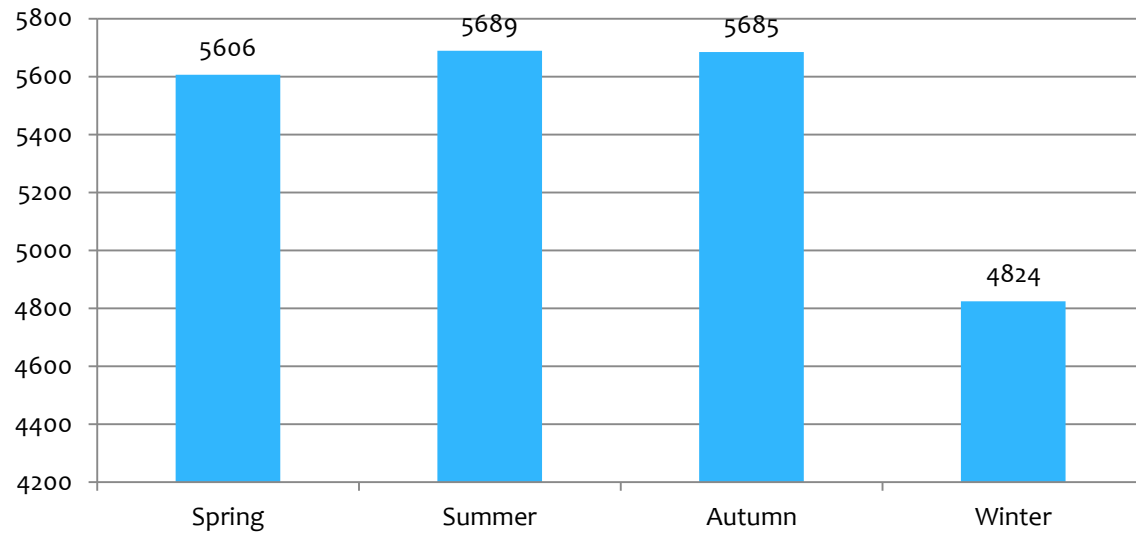
Lab5



Lab6



گزارش دهی به ثبت سرطان بر اساس چهار فصل سال *



کم شماری موارد مرگ ناشی از سرطان در ثبت مرگ استان فارس
در سالهای ۱۳۸۴ الی ۱۳۸۶ (مطالعه صید باز صید)

Percentage of under-registration of the cancer specific mortality rate in the Fars Province mortality registry, Iran, in 2006.

Cancer Type	Underestimation rate (%)
All Cancer	42
Bladder Cancer	60
Colon Cancer	35
Esophageal Cancer	44
Lung Cancer	48
Stomach Cancer	30
Ovarian Cancer**	42
Breast Cancer**	27
Endometrial Cancer**	50
Prostate Cancer**	32


Analyses of data from 5 provinces and estimation of death certificate cases only (DCO %) for Iranian national cancer registry in 2009.

Variable	Ahvaz	Arak	Mashhad	Shiraz	Isfahan	Overall
Number of Data Sources used in Registry	8	9	6	7	3	-
All number of cases in the cancer registry	4834	2182	8900	5137	6515	27568
No. of Cases reported from clinical sources	1408 (29%)	799(36.6%)	1483 (17%)	203 (4%)	28 (0.4%)	3921 (14.2%)
No. Of Cancer Death Reported N (%)	807 (20)	319 (23)	598 (10)	309 (7)	1043 (21)	3076 (11.1)
No. Of Cancer Excluding Non-melanoma Cancer	4097	1398	6048	4745	4987	16288
Death Only Cases in the Cancer Registry Data, N (%)	729 (18)	189 (14)	385(6)	305 (6)	872 (18)	2480 (11.7)

Recommendations

- * The registration system should be revised according the international standards in terms of guideline, organizational structure, annual report, and information technology .
- * The cancer registration guideline needs to be revised.
- * establishment of cancer registry centers in some selected provinces and support them with appropriate budget and infrastructure
- * advisory committees should be established in the central and regional level

- * **little awareness and advocacy for security and confidentiality** exist among the cancer registry personnel. Cancer office should prioritize this issue and add a section to the guideline about safety and confidentiality
- * **Standard training program** should be promoted.
- * **Coding of the cancer reports** had been done variably by pathologist, or other staff. Actions need to be taken to evaluate the coding practice .
- * It is important to run an **ongoing monitoring and quality assurance plan** in the everyday basis

- 
- * Cancer Registry should fund **external quality control** studies periodically
 - * It is important to **send the feedback** to the laboratories, hospitals, death registry, and other data sources regularly
 - * Ministry of health should improve the **Causes of Death Registry**.



**Thank you
for
your kind attention**