

CONVEGNO DI PRIMAVERA DELL'ASSOCIAZIONE ITALIANA DI EPIDEMIOLOGIA (AIE)

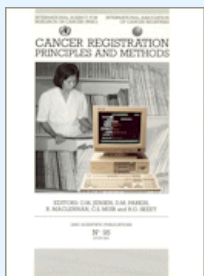
***L'integrazione di archivi elettronici per l'epidemiologia e la
sanità pubblica: finalità e metodi***

***Evoluzione dell'uso degli archivi elettronici
per la registrazione dei tumori***

***Antonio Russo
Servizio di Epidemiologia
ASL Città di Milano***

Roma 17-18 maggio 2007





Purpose of Cancer Registration

“ – is to collect and classify information on all cancer cases in order to produce statistics on the occurrence of cancer in a defined population and to provide a framework for assessing and controlling the impact of cancer on the community.” – *O.M.Jensen and H.H.Storm in “Cancer Registration: Principles and Methods.” IARC Publications No.95 Lyon 1991*

Cancer Incidence in Five Continents

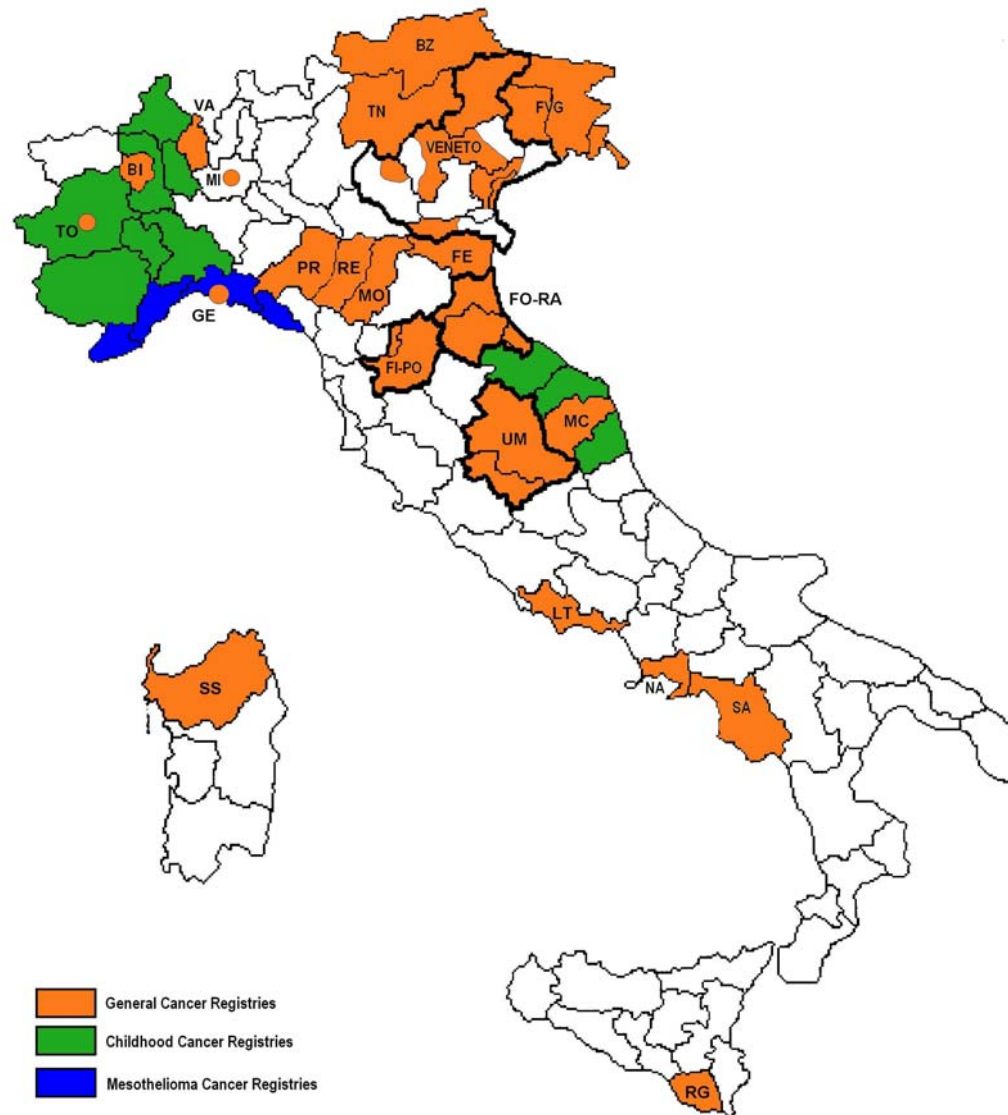
VII edition



VIII edition

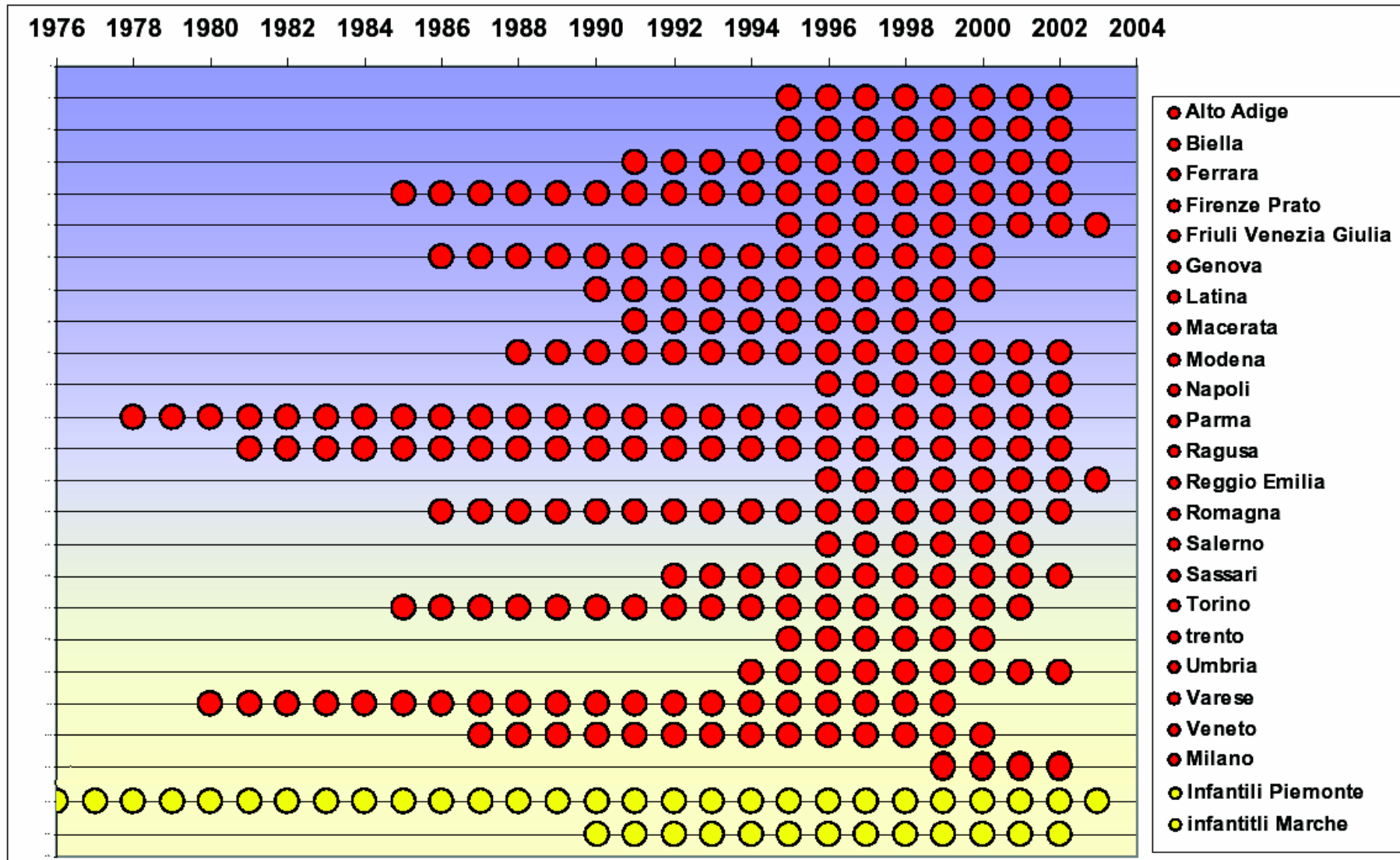


I Registri Tumori in Italia 2006

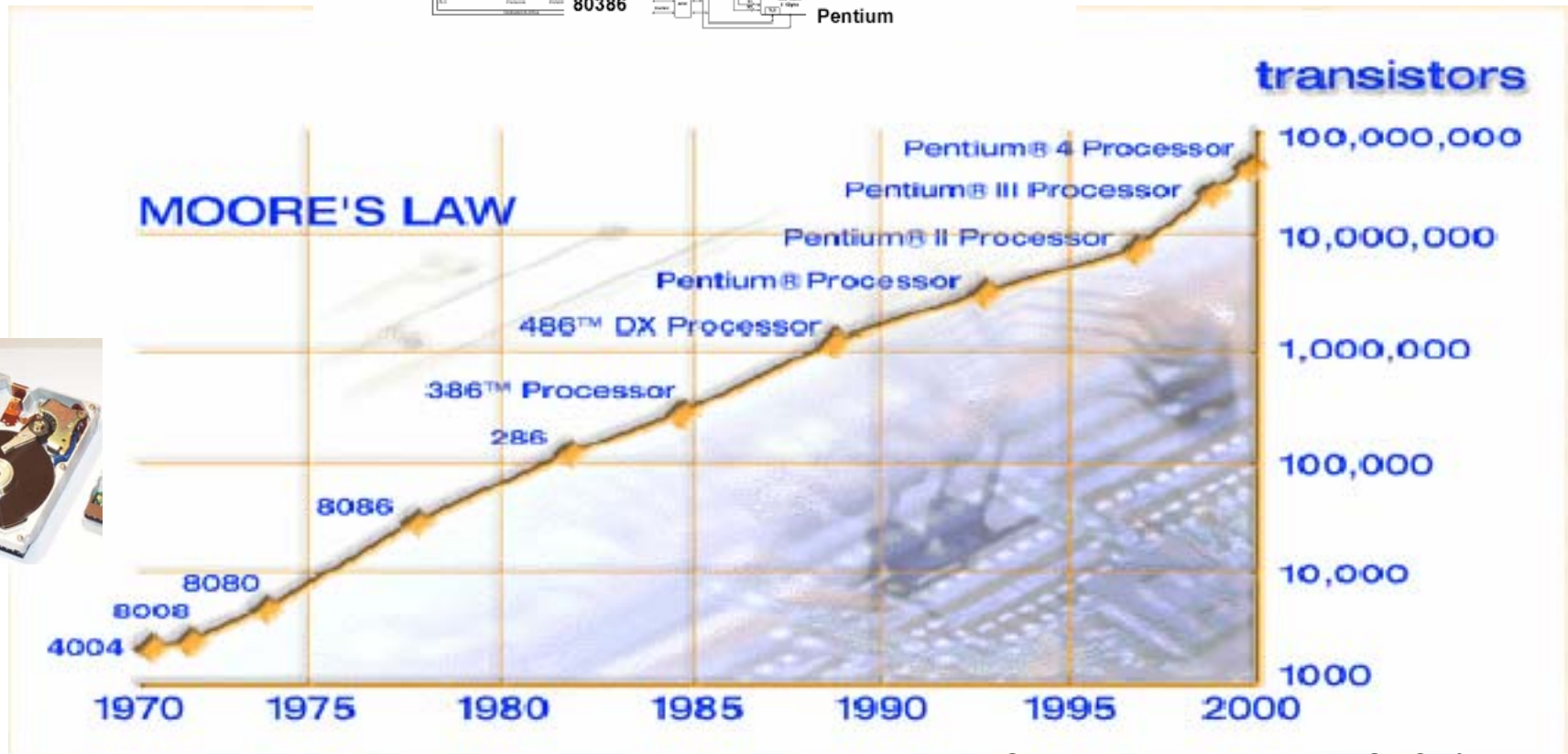
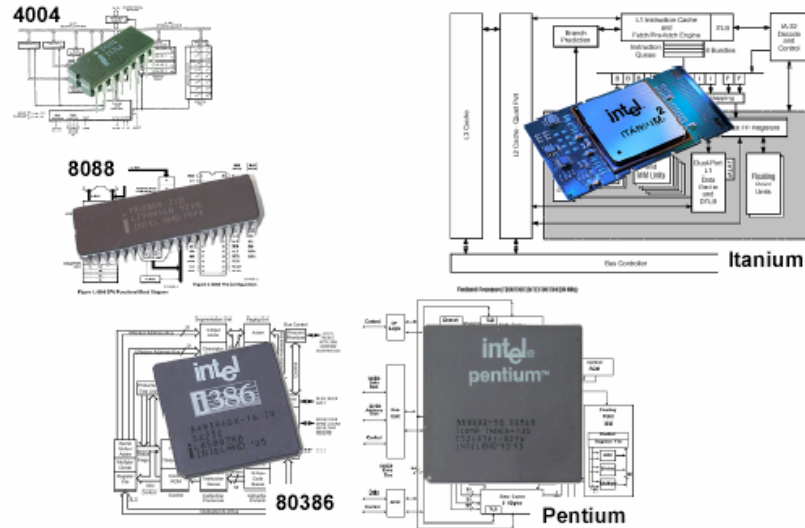




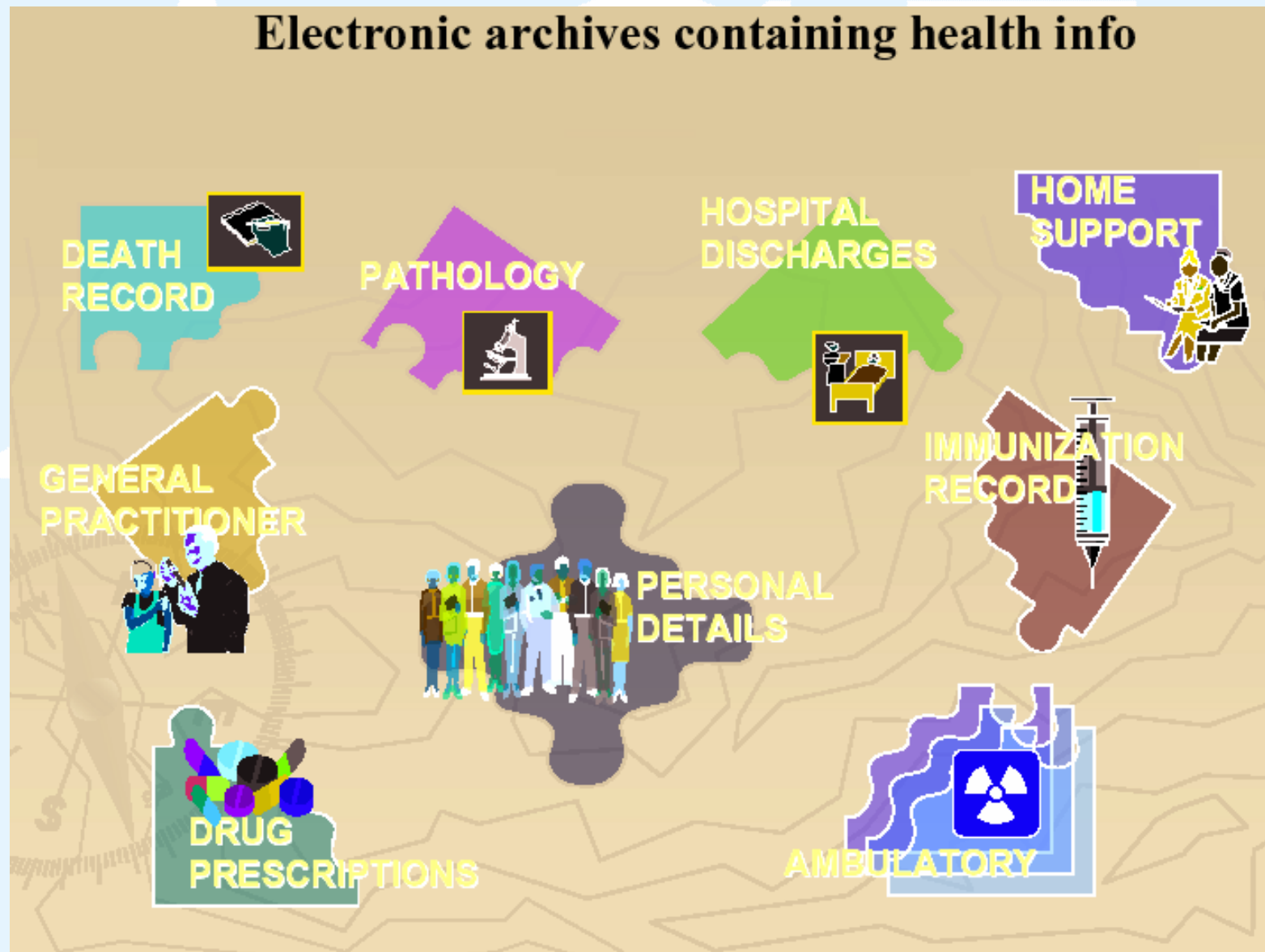
Banca Dati AIRTum: lo stato al 2006



ARCHITETTURA DEI PROCESSORI



Electronic archives containing health info



METHODS OF DATA COLLECTION:

- **ACTIVE** collection at source by registry staff (visit, abstract, copy)
- **PASSIVE** notification by health-care workers from copies of discharge forms, abstracts, reports etc
- **AUTOMATED** use of data already stored in other information systems «down the wire»

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Uso delle fonti informative per definire completezza e qualità della registrazione

- Confronto con gli archivi SDO per identificare casi persi: **es. mobilità passiva**;
- Confronto con gli archivi di anatomia patologica per identificare casi mai ricoverati con diagnosi di tumore: es. cute, prostata;
- Confronto con archivi di mortalità per identificare i DCO



Using Hospital Discharge Files to Enhance Cancer Surveillance

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Use of the traditional mechanism for cancer surveillance, hospital-based registries, may limit ascertainment of incident cases. In this study, the authors evaluated the ability of a statewide hospital discharge file (HDF) to enhance central cancer registry reporting. Incident cancers from a Virginia cancer registry were linked with an HDF for 1995. Medical record abstractions for over 2,000 cancers verified HDF and registry data. There were 19,740 unique cases ascertained from the two combined data sources. The registry captured approximately 83% of cases, while the HDF captured 62%. Although the HDF missed a substantial number of registry cases, the HDF positive predictive value for identifying the correct cancer site was 94%. Logistic regression was used to identify significant characteristics of cases likely to be captured only by the HDF; these characteristics included hospital cancer program certification, the position of the cancer diagnosis on the claim, and cancer surgery. This study represents the evaluation of a novel approach to enhancing registry completeness and accuracy using statewide HDFs. The results strongly suggest that neither a central cancer registry nor an HDF is a sufficient source for complete capture of cases. Using HDFs to supplement a central cancer registry may be a valuable and efficient method for improving registry completeness of reporting.

hospital records; neoplasms; population surveillance; registries

Abbreviations: ACOS, American College of Surgeons; HDF, hospital discharge file; ICD-9-CM, *International Classification of Diseases, Ninth Revision, Clinical Modification*; VCR, Virginia Cancer Registry.

TABLE 1. Breast, cervical, colon/rectal, lung, and prostate cancer cases captured by the Virginia Cancer Registry and the Virginia hospital discharge file, by cancer site and age group, 1995

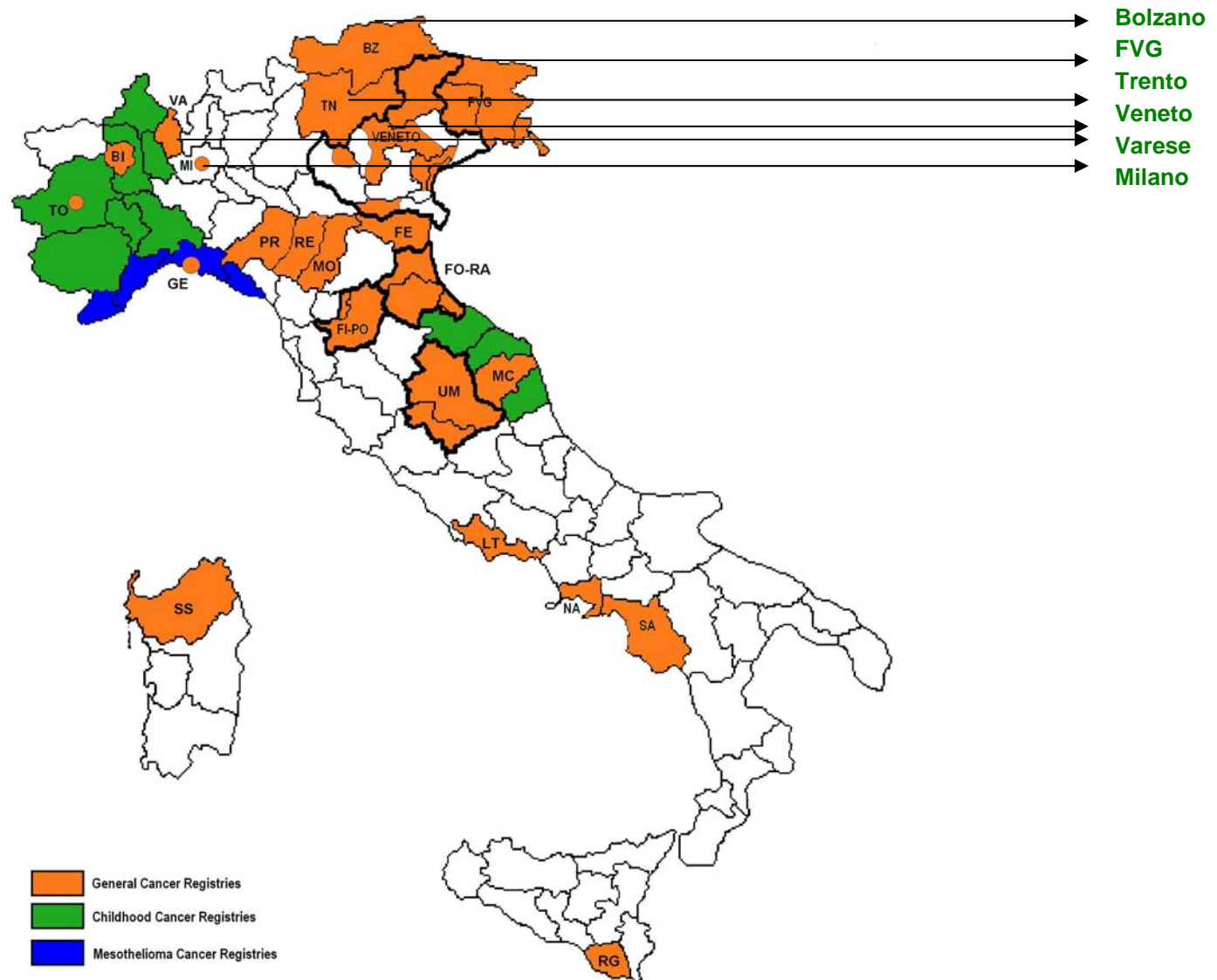
Cancer site and age group (years)	No. of VCR* cases	No. of HDF* cases	Total no. of unique cases	No. of cases captured by VCR and HDF	% of total cases captured by VCR	% of total cases captured by HDF	% added to VCR by HDF
Breast							
<65	2,611	1,631	2,880	1,362	90.7	56.6	10.3
≥65	1,830	1,350	2,143	1,037	85.4	63.0	17.1
Total	4,441	2,981	5,023	2,399	88.4	59.3	13.1
Cervix							
<65	1,194	482	1,358	318	87.9	35.5	13.7
≥65	127	103	171	59	74.3	60.2	34.6
Total	1,321	585	1,529	377	86.4	38.3	15.7
Colorectal							
<65	1,073	922	1,253	742	85.6	73.6	16.8
≥65	1,881	1,835	2,337	1,379	80.5	78.5	24.2
Total	2,954	2,757	3,590	2,121	82.3	76.8	21.5
Lung							
<65	1,536	1,293	1,821	1,008	84.3	71.0	18.6
≥65	2,506	2,325	3,250	1,581	77.1	71.5	29.7
Total	4,042	3,618	5,071	2,589	79.7	71.3	25.5
Prostate							
<65	1,195	628	1,295	528	92.3	48.5	8.4
≥65	2,408	1,605	3,232	781	74.5	49.7	34.2
Total	3,603	2,233	4,527	1,304	79.6	49.3	25.6
Total							
<65	7,609	4,956	8,607	3,958	88.4	57.6	13.1
≥65	8,752	7,218	11,133	4,837	78.6	64.8	27.2
Total	16,361	12,174	19,740	8,795	82.9	61.7	20.7

* VCR, Virginia Cancer Registry; HDF, hospital discharge file.

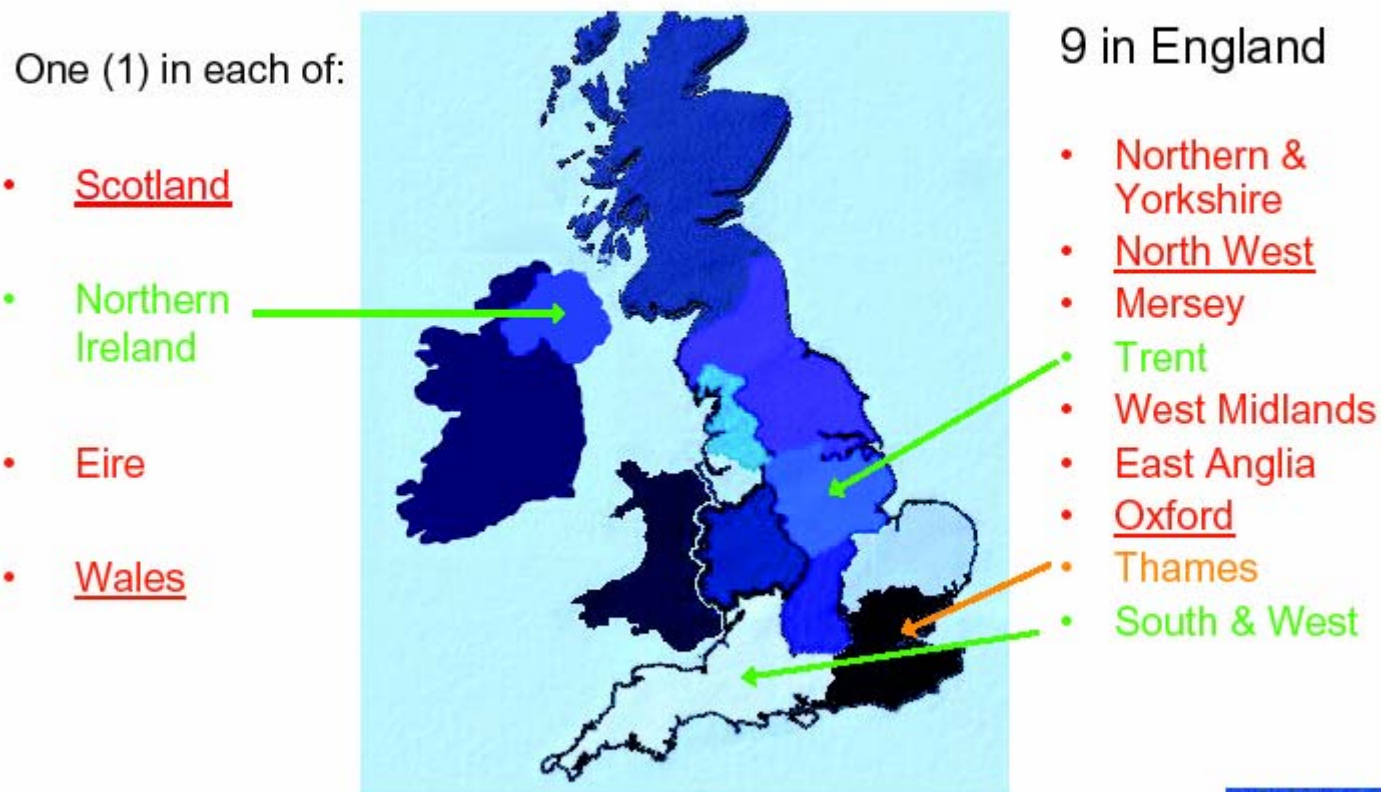
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I Registri Tumori su base automatica in Italia



Automated Registration in the UK&I

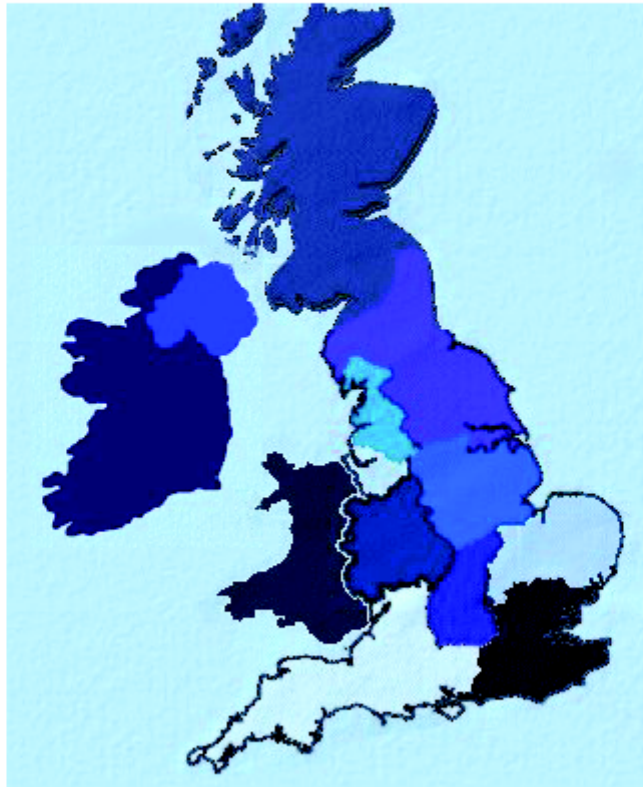


Fonte: Chris Carrigan, UK National Coordinator of Cancer Registration, 2005

Automated Registration in the UK&I

One (1) in each of:

- Scotland
- Northern Ireland
- Eire
- Wales



9 in England

- Northern & Yorkshire
- North West
- Mersey
- Trent
- West Midlands
- East Anglia
- Oxford
- Thames
- South & West



Fonte: Chris Carrigan, UK National Coordinator of Cancer Registration, 2005

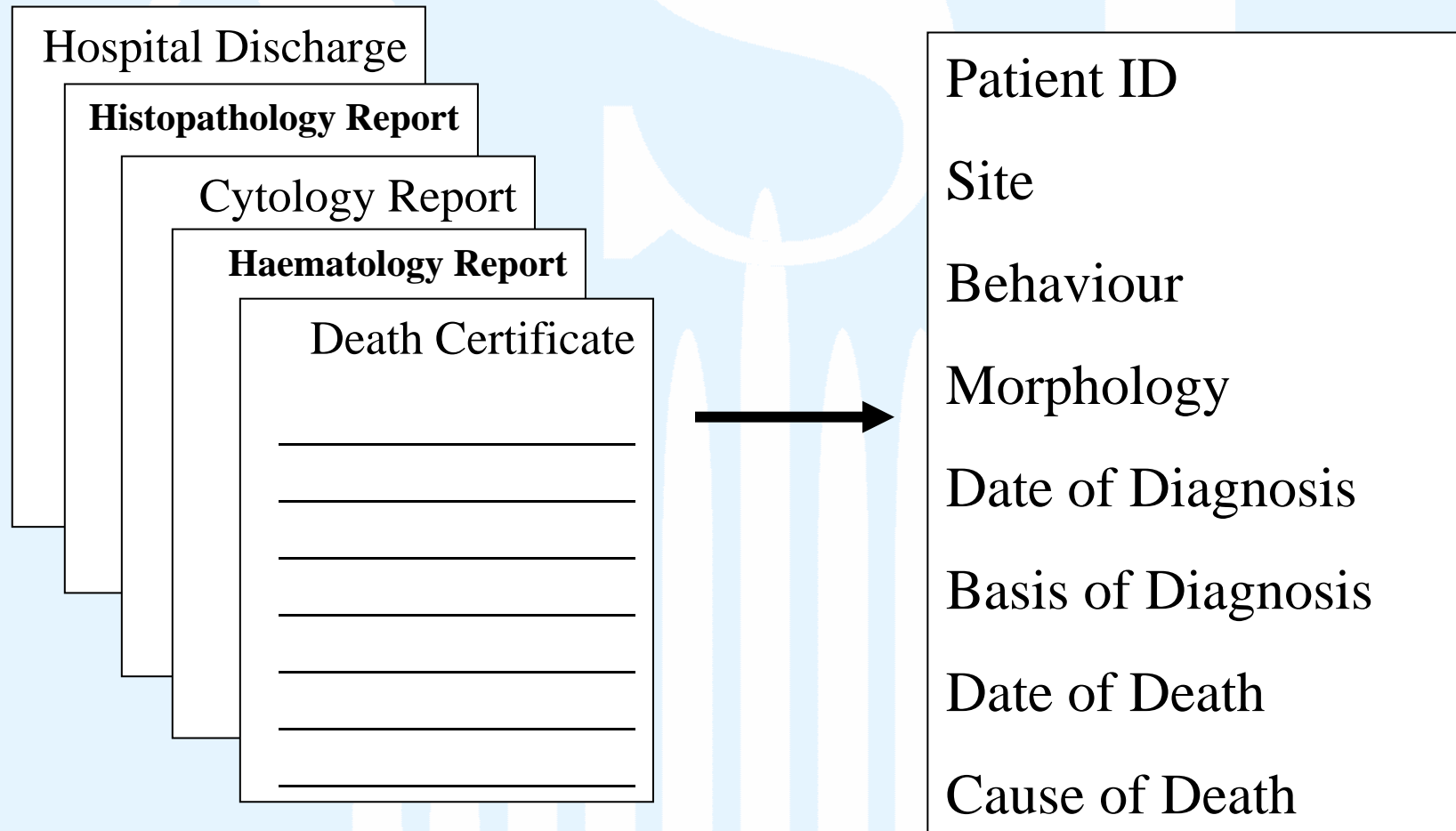
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Registri automatici

requisiti

- **accesso alle fonti informative**
- **qualità e completezza delle fonti**
- **identificazione univoca di ogni soggetto**
- **sistema di relazioni tra le fonti informative**
- **regole per l'accettazione automatica di un caso incidente**

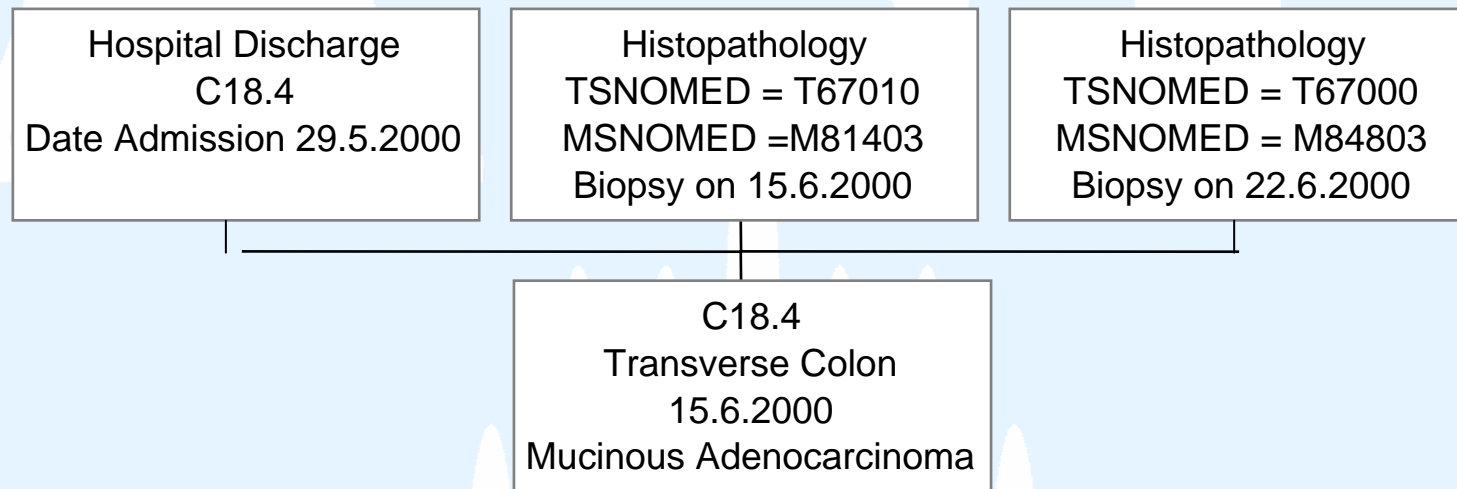
Electronic Sources for Tumour Registration



Types of Tumour Coding

	ICD-9CM	ICD 9	T Snomed	M Snomed
Hospital Discharge	+			
Histopath			+	+
Cytopath			+	+
Haemat				+
Death Cert		+		

Steps to make Electronic Tumour Registration



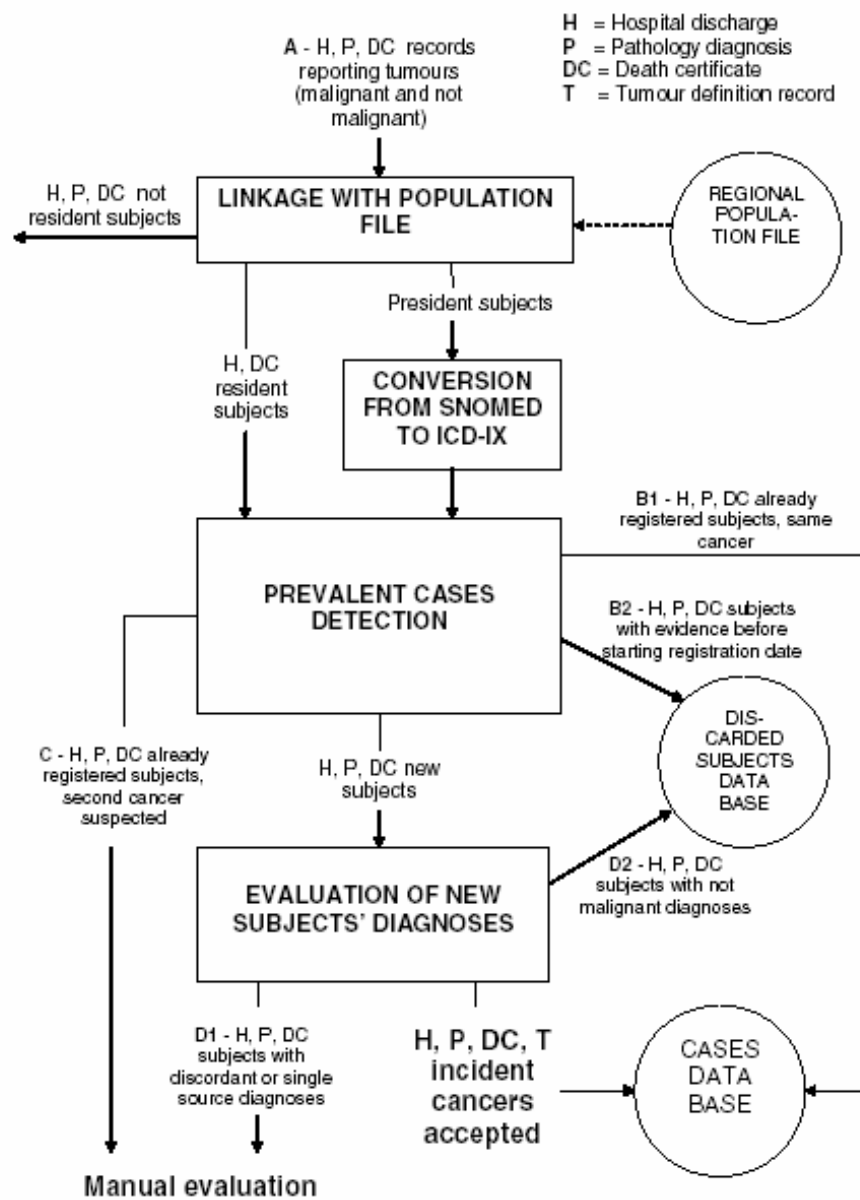


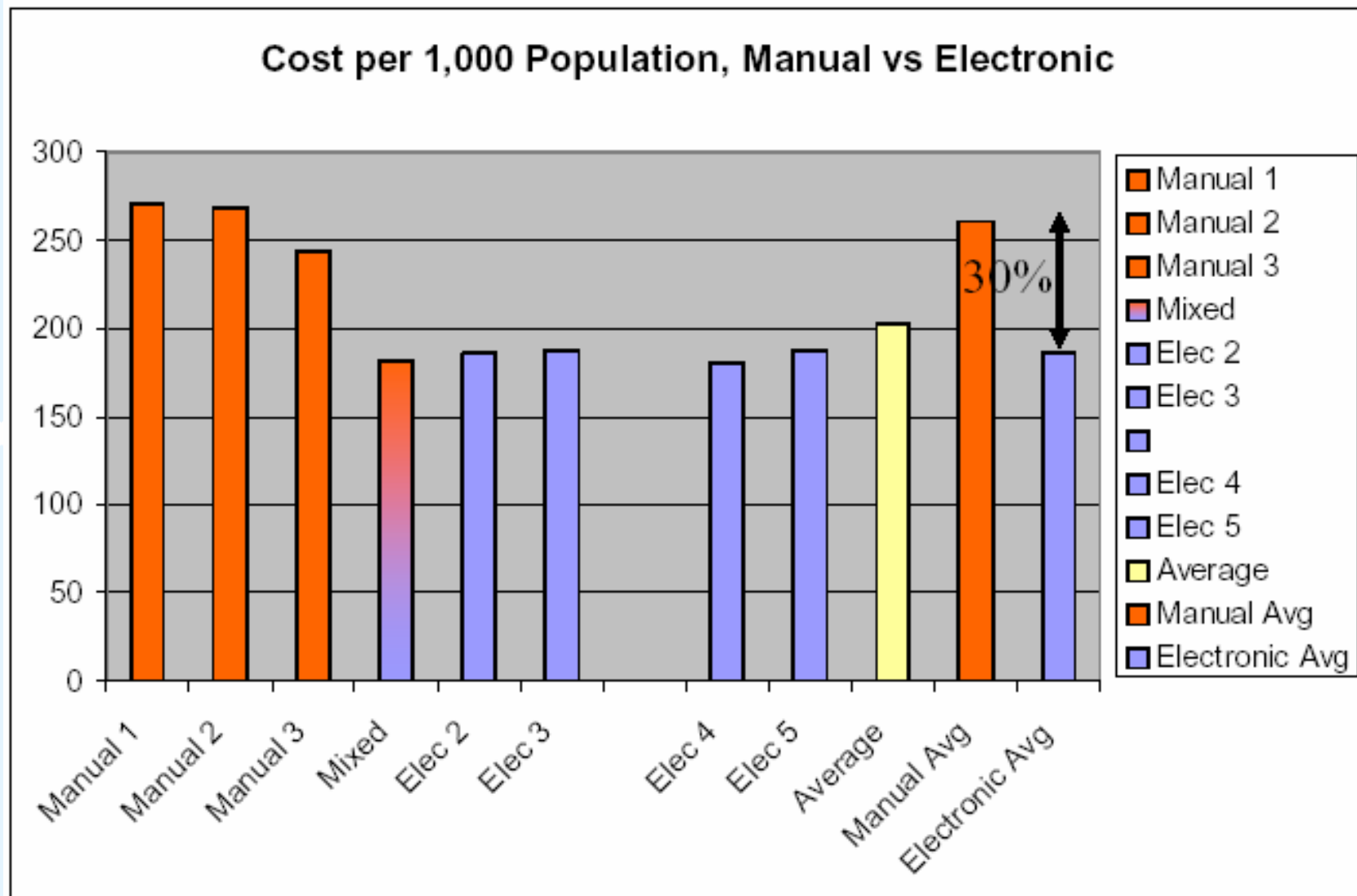
Figure 1 Venetian Tumour Registry data processing flow-chart

AUTOMATICO

- utilizza fonti informative che servono per altri scopi
- meno esposto alla variabilità in quanto basato su di un algoritmo decisionale con regole esplicite
- le variazioni dell'algoritmo richiedono tempi lunghi
- 1 operatori ogni 1.000 casi

MANUALE

- raccoglie informazioni nel formato più utile per il registro
- il controllo della eterogeneità tra operatori di registro è più oneroso e richiede una organizzazione
- Le variazioni delle regole di registrazione sono immediate
- 2 operatore ogni 1.000 casi



Fonte: Chris Carrigan, UK National Coordinator of Cancer Registration, 2005

Antonio Russo – Servizio di Epidemiologia, ASL Città di Milano



Research

Open Access

Consistency and accuracy of diagnostic cancer codes generated by automated registration: comparison with manual registration

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Quality control of automatically defined cancer cases by the automated registration system of the Venetian Tumour Registry

Quality control of cancer cases automatically registered

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Background: In the Venetian Tumour Registry a substantial quota of cases (55%) is accepted using an algorithm that automatically evaluates diagnostic evidence: this study aims at assessing the reliability of the information produced in this way. **Methods:** A reabstraction study was conducted, which put a stratified sample of 1539 automatically accepted cases through a double-blind manual revision. **Results:** A significantly higher proportion of prevalent cases were found among breast, prostate and larynx cancer cases without microscopic confirmation, while there is a clear strong inverse relationship between the number of concordant diagnostic sources and the proportions of discordant diagnoses: cases based only on a single cytology record are particularly unreliable. A small number of multiple cancers are not detected because of one of the rules applied. **Conclusion:** The overall proportion of incorrect decisions is not high and similar to those reported by other registries, but errors are correlated to the diagnostic evidence pattern. As a further check, we decided to revise clinical cases for the three sites mentioned manually, in order to reduce the numbers proportion of both prevalent cases, and all cytology-based diagnoses, so as to reduce the number of 'false positives'. Coverage of hospital discharge source has been extended in order to decrease the proportion of cases based only on pathology records.

Keywords: automated registration, cancer incidence, quality control

Abstract

Background: Automated procedures are increasingly used in cancer registration, and it is important that the data produced are systematically checked for consistency and accuracy. We evaluated an automated procedure for cancer registration adopted by the Lombardy Cancer Registry in 1997, comparing automatically-generated diagnostic codes with those produced manually over one year (1997).

Methods: The automatically generated cancer cases were produced by Open Registry algorithms. For manual registration, trained staff consulted clinical records, pathology reports and death certificates. The social security code, present and checked in both databases in all cases, was used to match the files in the automatic and manual databases. The cancer cases generated by the two methods were compared by manual revision.

Results: The automated procedure generated 5027 cases: 2959 (59%) were accepted automatically and 2068 (41%) were flagged for manual checking. Among the cases accepted automatically, discrepancies in data items (surname, first name, sex and date of birth) constituted 8.5% of cases, and discrepancies in the first three digits of the ICD-9 code constituted 1.6%. Among flagged cases, cancers of female genital tract, hematopoietic system, metastatic and ill-defined sites, and oropharynx predominated. The usual reasons were use of specific vs. generic codes, presence of multiple primaries, and use of extranodal vs. nodal codes for lymphomas. The percentage of automatically accepted cases ranged from 83% for breast and thyroid cancers to 13% for metastatic and ill-defined cancer sites.

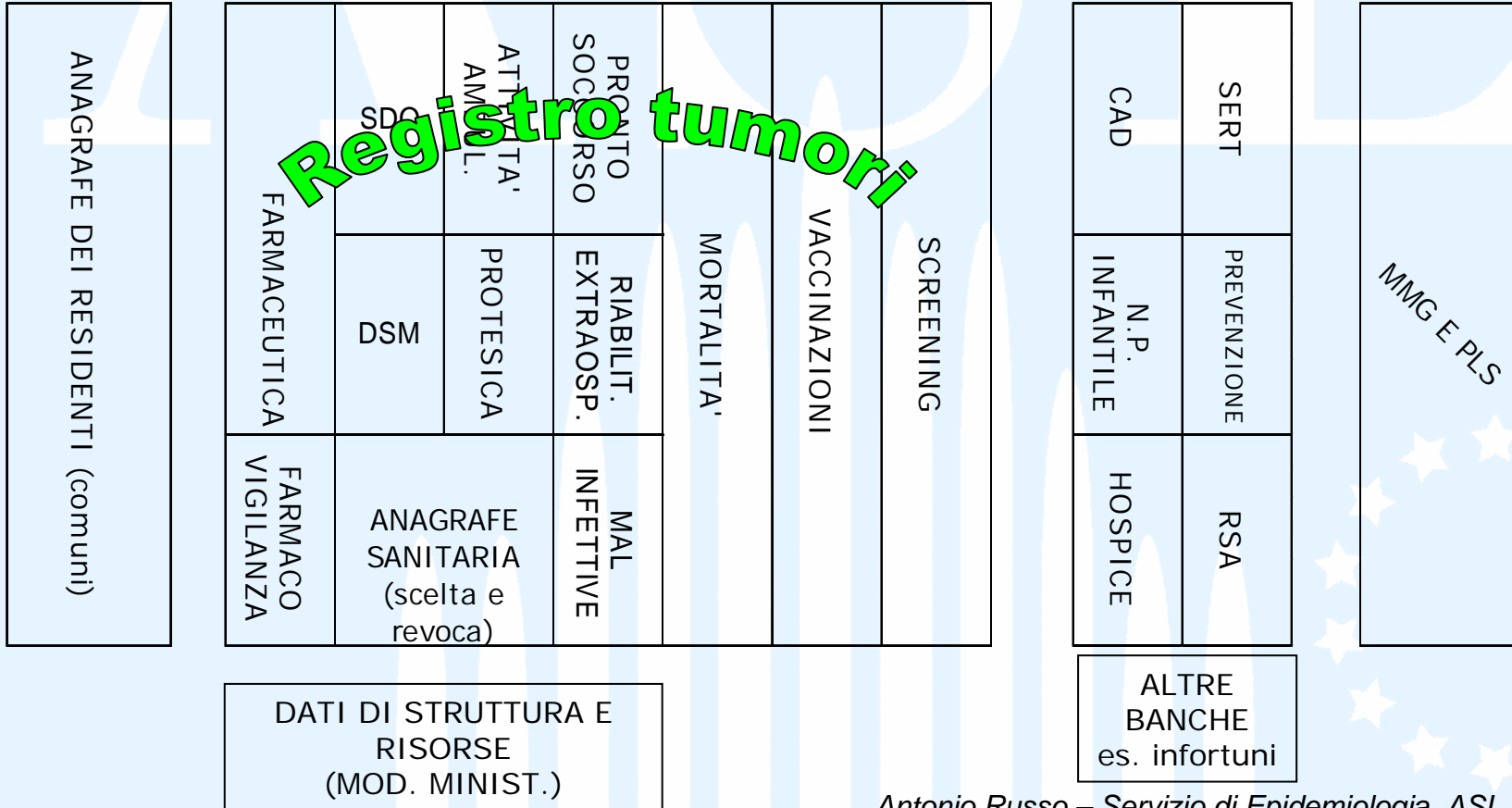
Conclusion: Since 59% of cases were accepted automatically and contained relatively few, mostly trivial discrepancies, the automatic procedure is efficient for routine case generation effectively cutting the workload required for routine case checking by this amount. Among cases not accepted automatically, discrepancies were mainly due to variations in coding practice.

SISTEMI DECISIONALI

DATA WAREHOUSE

DATI ELEMENTARI

DATI AGGREGATI



POTENZIALITÀ DELLA INTEGRAZIONE DEI REGISTRI TUMORI NEI SISTEMI INFORMATIVI SANITARI

- valutare le performance delle strutture ospedaliere: outcome research;
- analizzare l'aderenza ai protocolli di trattamento;
- identificare i percorsi diagnostico-terapeutici;
- creare coorti di esposti a farmaci per valutare il rischio di tumore;
- valutare l'effetto delle comorbidità nel condizionare la prognosi di tumore
- contribuire all'analisi dei costi

Conclusioni

- attualmente tutti i registri utilizzano i flussi informativi (sanitari e non sanitari) e questo richiede un rafforzamento di figure e competenze meno presenti nei vecchi registri (informatici/statistici);
- pochi registri lavorano integrati in strutture di data warehouse
- la registrazione automatica è una strada promettente, ma richiede investimenti continui per:
 - mantenimento e implementazione
 - adeguamento delle fonti alle esigenze informative dei registri

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