
Milan, 18 February 2019



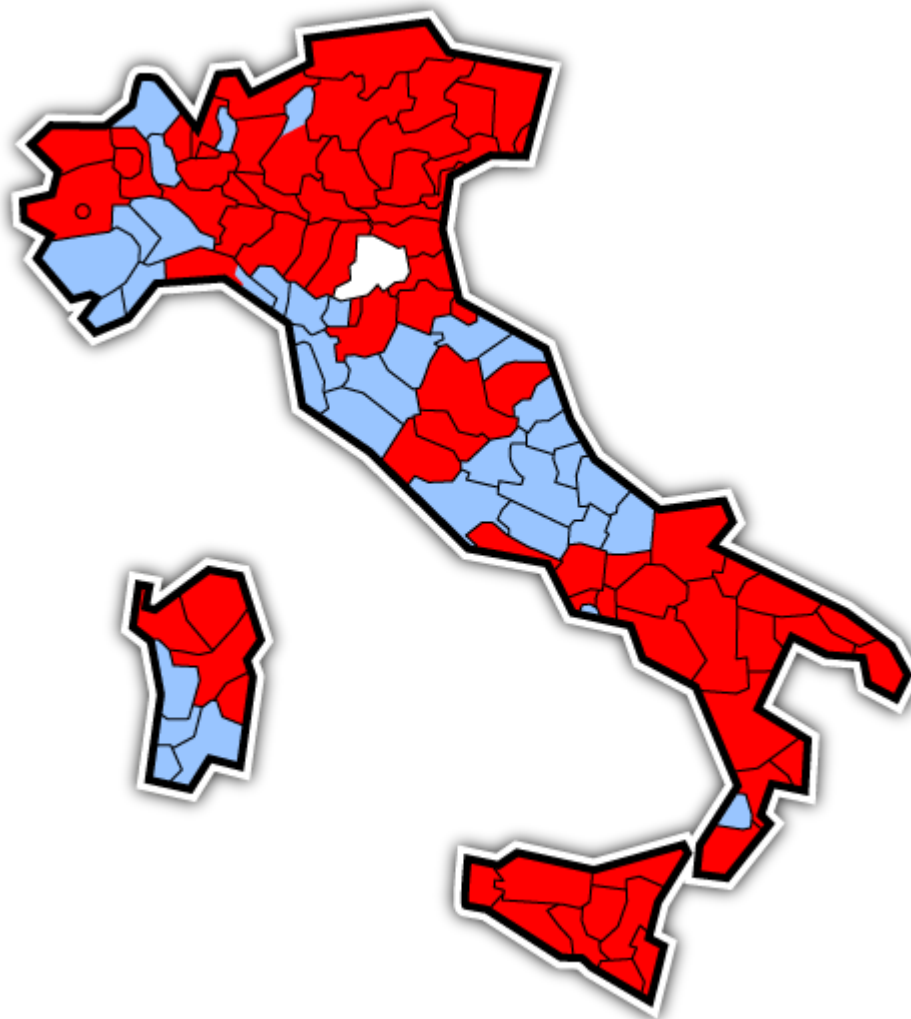
Cancer registry quality: the Italian experience

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Italy, national CR coverage

- Certified registries (red):
70% of the population
- Uncertified registries (blue):
28% of the population
- Not covered (white):
2% of the population



What is quality

?



Definitions

- American National Standards Institute (ANSI)
- American Society for Quality

“Quality is customer satisfaction”

“Quality is fitness for use”



Customer satisfaction

- **Product design:** “the characteristic of a product or service that bears on its ability to satisfy stated or implied needs”
- **Product manufacturing:** “a product or services free of deficiencies”

American Society for Quality, 2000



Cancer registry quality:

Data are:

Complete

Accurate

Available promptly

Comparable and compatible with those of
other registries



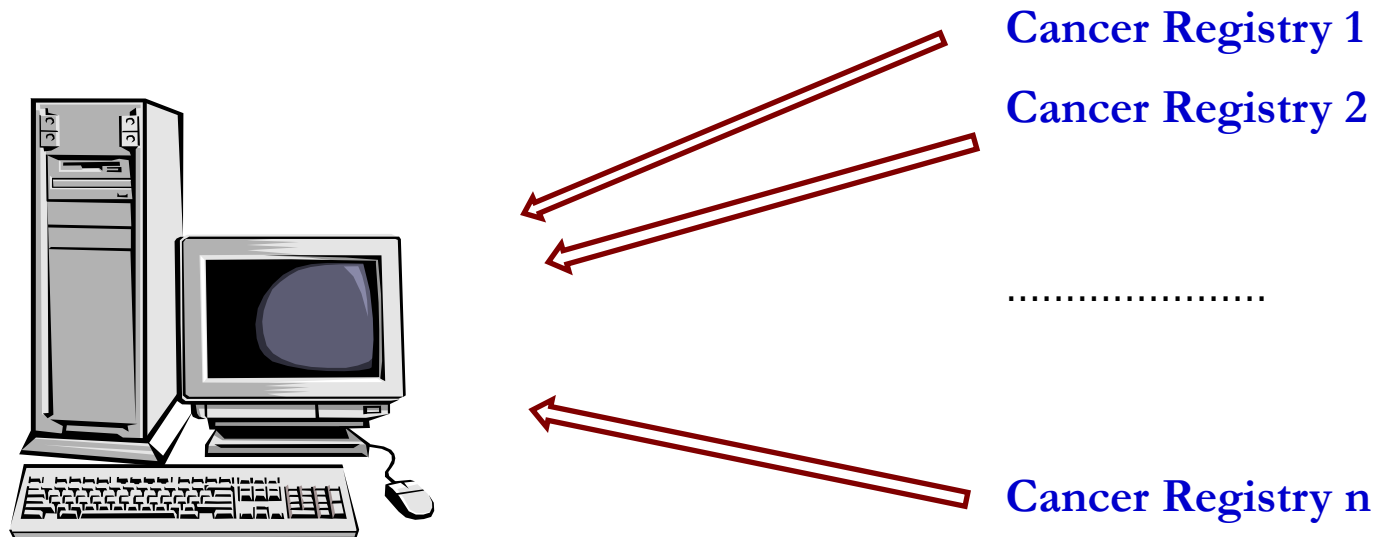
**How AIRTUM tries to help its registries
improve and maintain quality data**

AIRTUM workgroups concerned with:

- Database
- Certification
- Training



The AIRTUM database



The Airtum common database uses
standardized checks and error
corrections



Certification: assesses the quality of the cancer registry structure and its data before admission to AIRTUM

AIRTUM -

REGISTRI TUMORI -

COMMISSIONI -

PUBBLICAZIONI -

PROGETTI -

Home / Materiali Commissione Accreditamento

Materiali Commissione Accreditamento

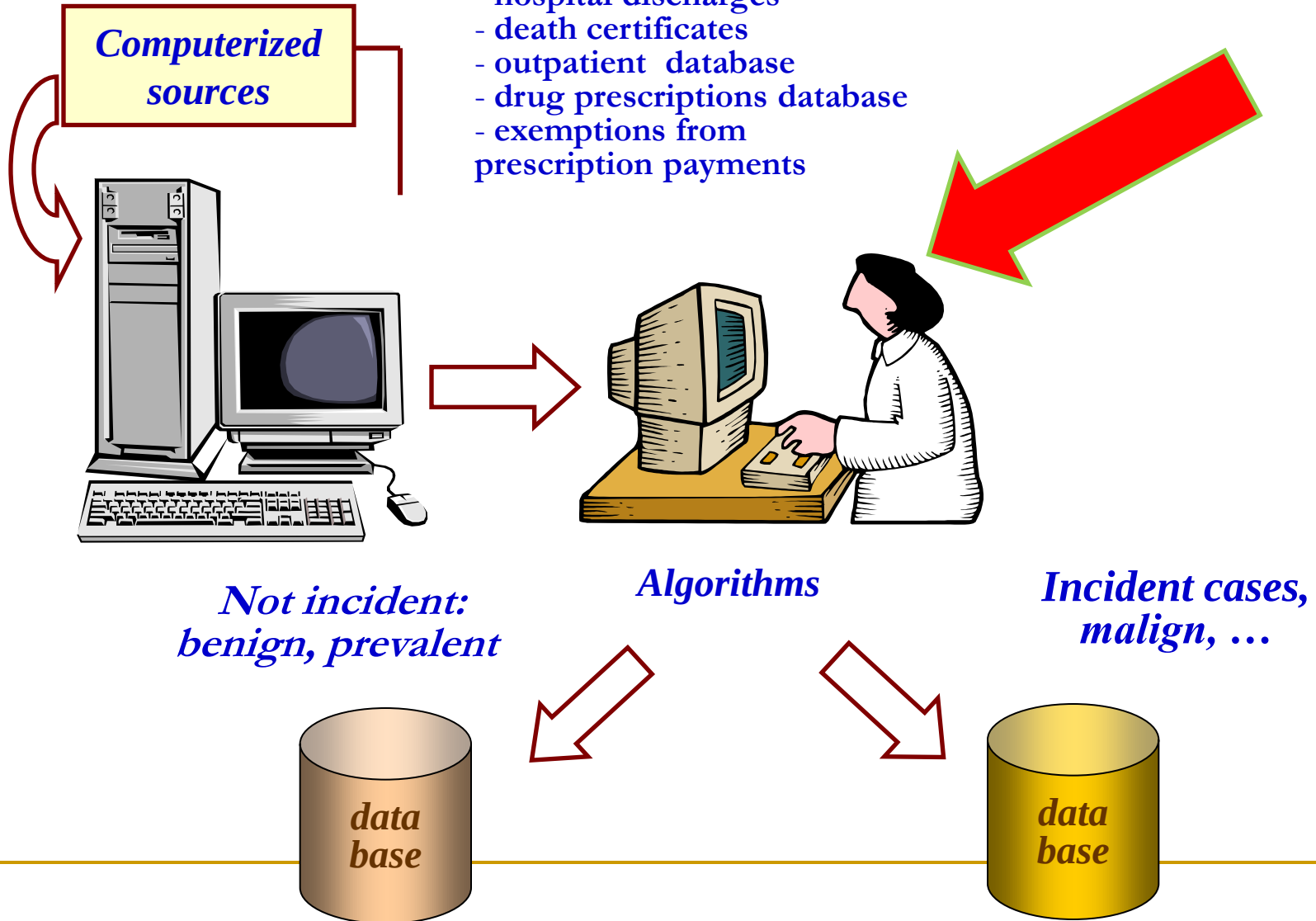
In questa sezione vengono riportati la lista dei documenti e i modelli standard predisposti dalla Commissione Accreditamento, che i registri in attività, devono inoltrare per attivare l'iter procedurale per l'accREDITamento del proprio registro.



Allegato	Dimensione
 Materiali da allegare alla domanda	56.41 KB
 Diagramma di flusso	85 KB
 Questionario AIRTUM	1.28 MB

The CR operatives

- pathology reports
- hospital discharges
- death certificates
- outpatient database
- drug prescriptions database
- exemptions from prescription payments



AIRTUM training initiatives

1998. **Camerino**: corso RT
Salerno: corso RT
2001. **Camerino**: metodologia e statistica
2002. **Camerino**: corso RT
2004. **Camerino**: mesoteliomi
2005. **Civitanova**: corso RT
2006. **Camerino**: corso RT
Termoli: corso base
2007. **Camerino**: infantili
Sassari: corso base
Reggio E: corso RT
2008. **Camerino**: rischio ambientale
2009. **Camerino**: indicatori qualità
Reggio E: corso linfomi
2010. **Mantova**: corso RT
Rho: corso RT
Camerino: RT e colon-retto
Reggio E: corso emolinfopoietico
Tarquinia: corso RT
2011. **Firenze**: SEER STAT
Camerino: sopravvivenza
2012. **Camerino**: ICD_03, qualità, comunicazione
2013. **Camerino**: tumori cerebrali, markers
Napoli: corso RT



2014.

1. Taranto, ambiente e tumori
2. Campobasso, corso base
3. Reggio Emilia, corso per accreditatori
4. Ancona, corso base
5. Modena, corso per operatori RT (ex Camerino)
6. Bologna, corso SEER STAT
7. Foggia, corso base



Coding rules for AIRTUM registries

Derived from:

- IARC
- ENCR
- AIRTUM



Registration technique manual by AIRTUM



Cancer Registration

... good if

- All in
- Malignant
- Infiltrative
- Date of diagnosis
- Residence

Where are the problems?

Morphology

Incidence date

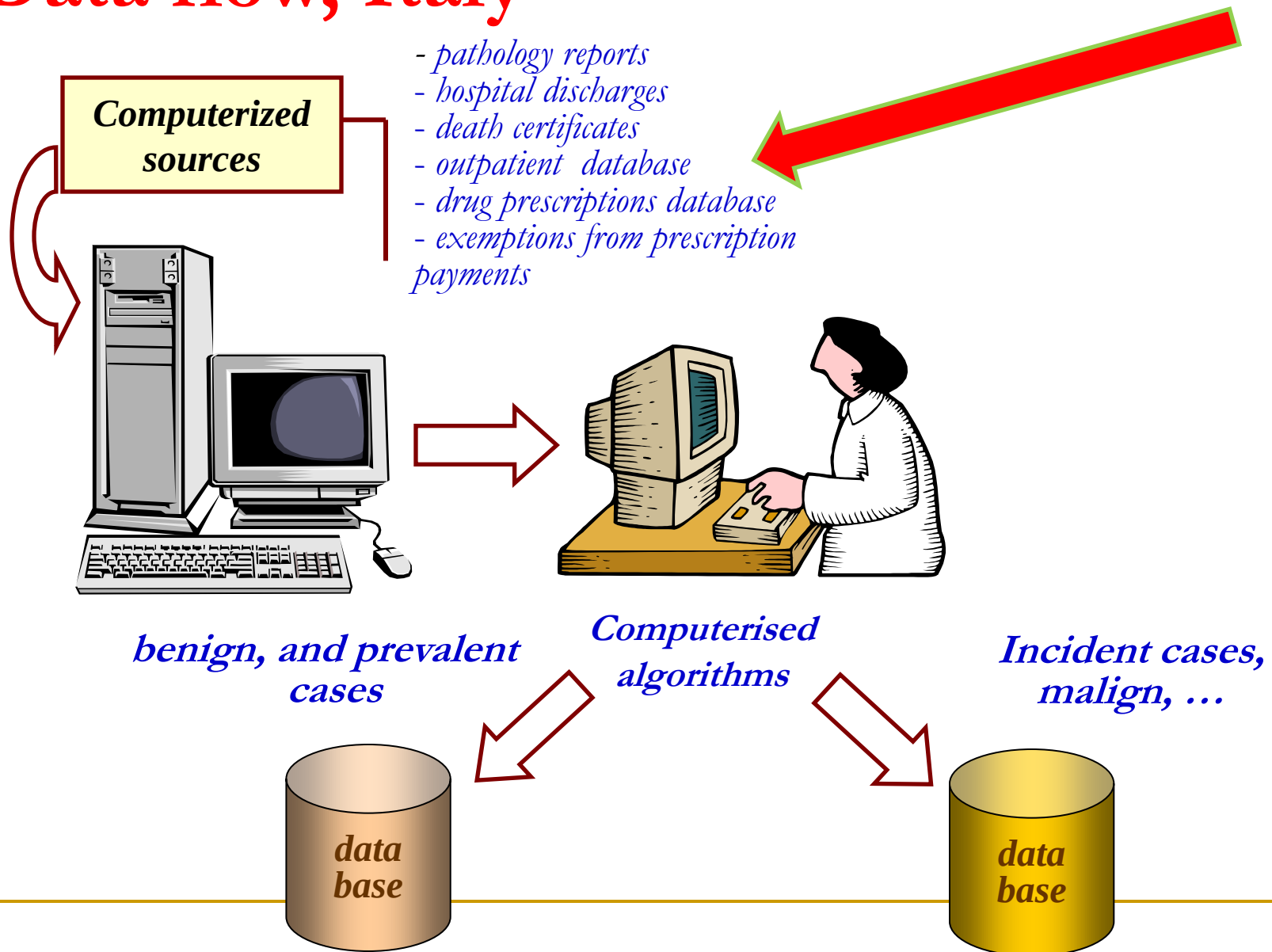
Residence at diagnosis

Privacy legislation



- Privacy legislation creates difficulties for accessing both electronic and paper clinical information sources
- Privacy legislation is interpreted differently according to:
 - region
 - hospital
 - department

Data flow, Italy



Pathology reports

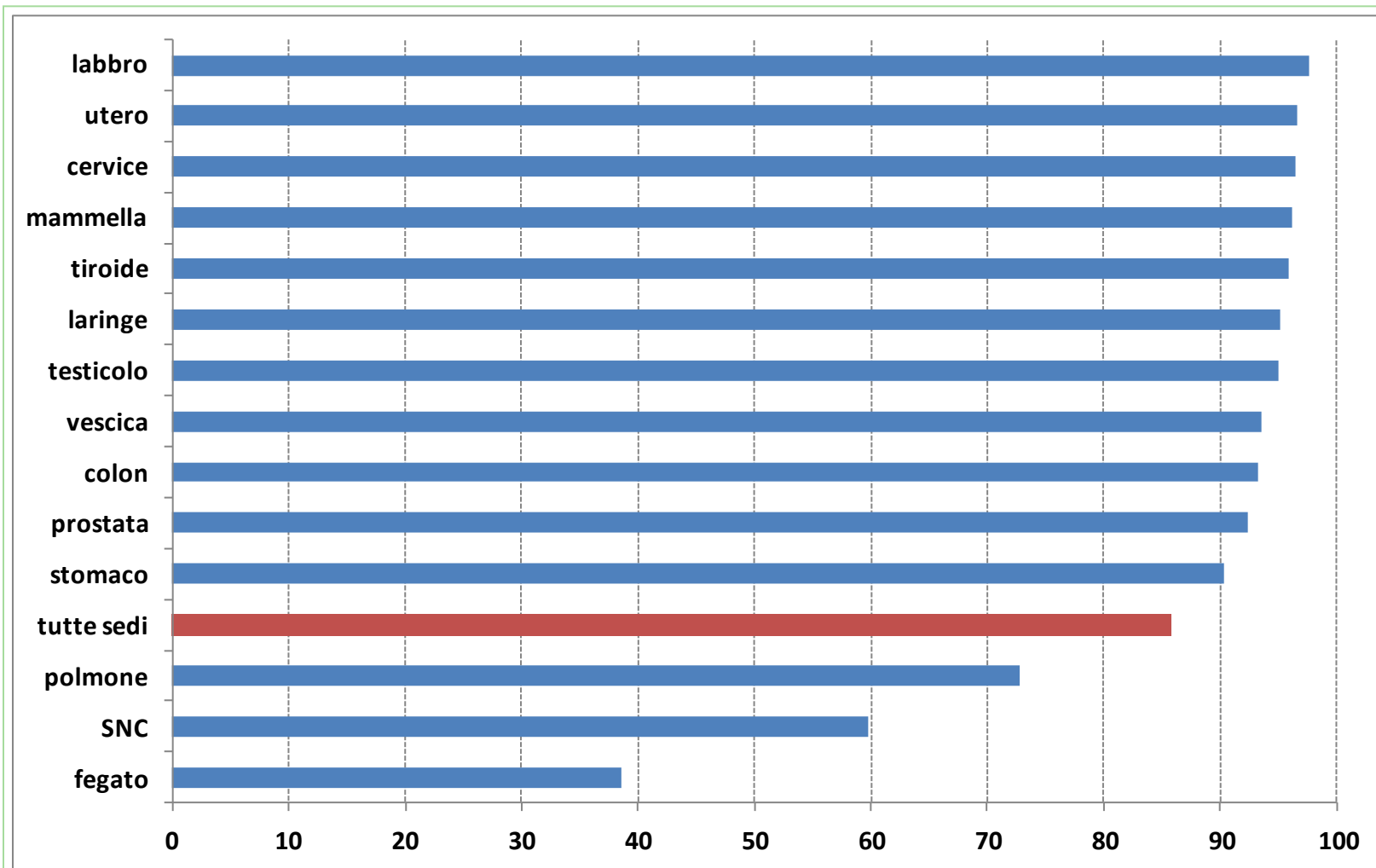
Limits to the
microscopic
verification

- site
- morphology
- age
- residence



AIRTUM CRs

% microscopic verification by cancer site



AIRTUM CRs

% microscopic verification by age

	0-34 years	35-64 years	≥65 years
Pancreas	100	43	31
Lung		73	58
CNS	70	53	36
Thyroid	84	85	71

AIRTUM CRs

% microscopic verification by area of residence Italy

	% Microscopic verification		
	North	Centre	South
Breast	98	97	94
Prostate	94	93	89

	% Microscopic verification			
Liver	Piacenza	Parma	Reggio	Modena
Histological	18	34	46	52
Cytological	13	15	0	1

Hospital discharges

computerised ?
available ?
out of region ?
correct coding ?
...

Every patient is not
necessarily hospitalised
cancer site
age
...



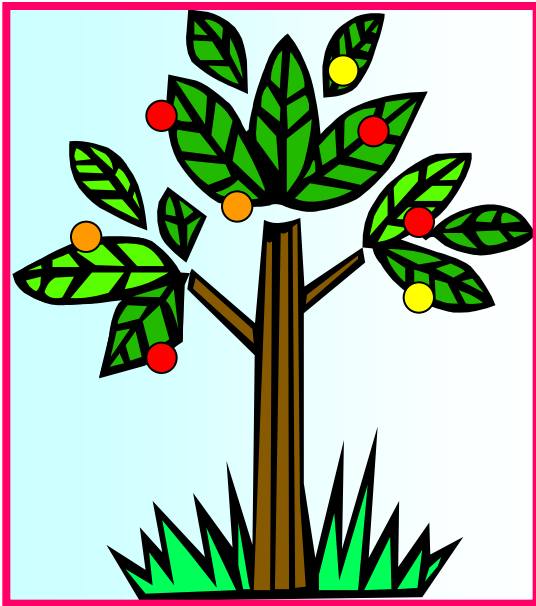
Death certificates

computerised ?
available on paper ?
out of region ?
correctly coded ?
*not all cancer
patient have died !
(so incomplete source)*



Information flow

... good if



Complete

Available

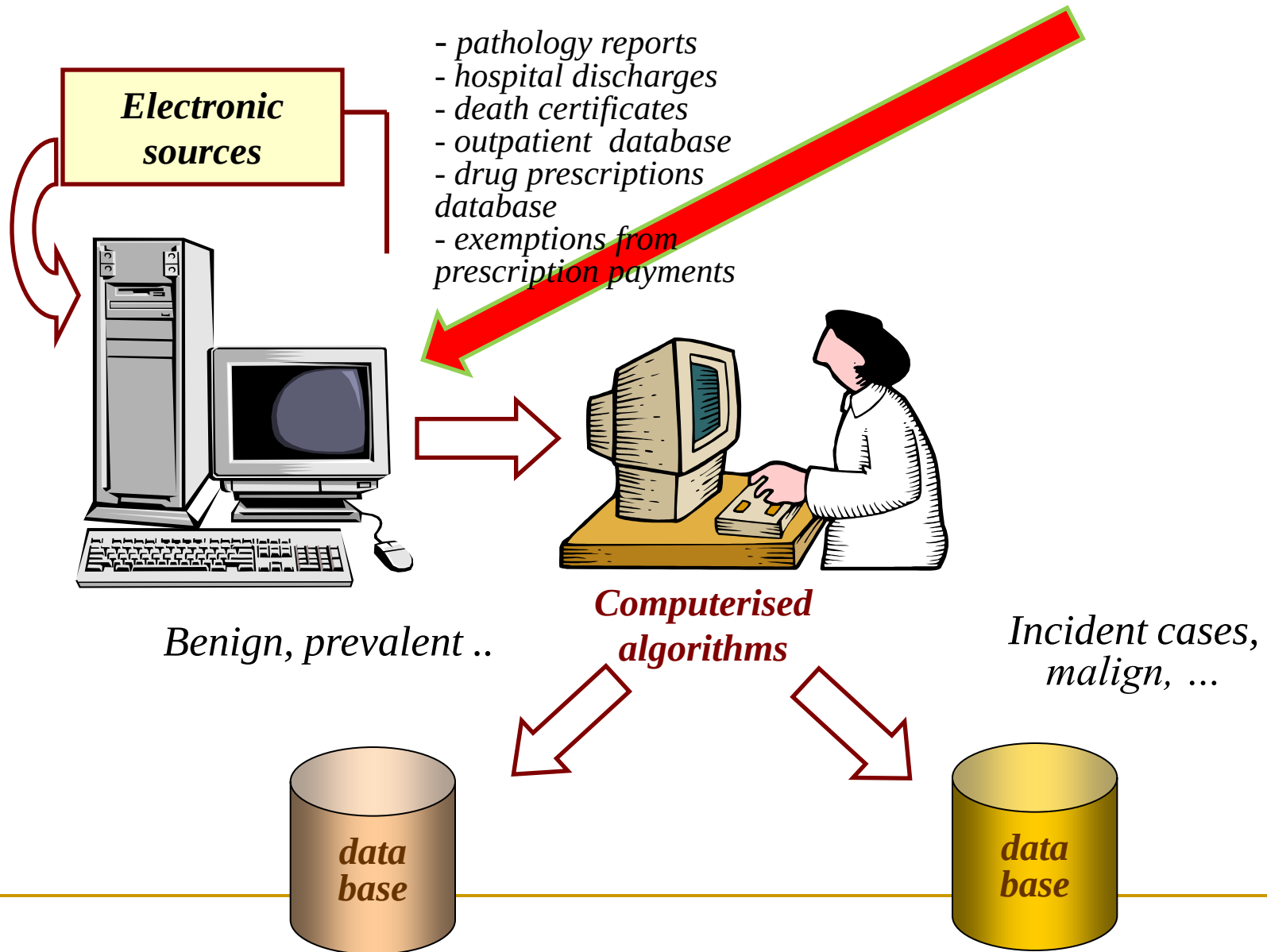
Computerised

Accessible

Correctly coded

Out-of-region data available

The SOFTWARE



Software

...once upon a time



...today

**CANREG (IARC)
OpenRegistry (INT)
GeCo
REPOCI
CRTOOL
Torino, ATS Milano
Romagna**

What has changed: example

In 2001 at Reggio Emilia

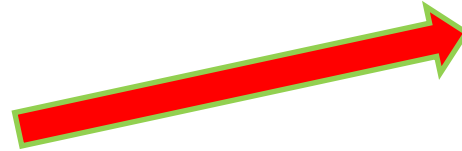
Pathology reports+

Hospital discharge +

Death certificates

10,000 possible cases

to be assessed for inclusion in database



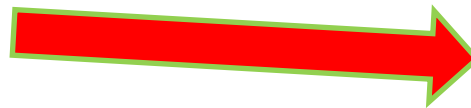
2800
incident
cases

28%

In 2018 at Reggio Emilia

6.000 possible cases

to be assessed for inclusion in database



4600
incident
cases

76%

... is good if



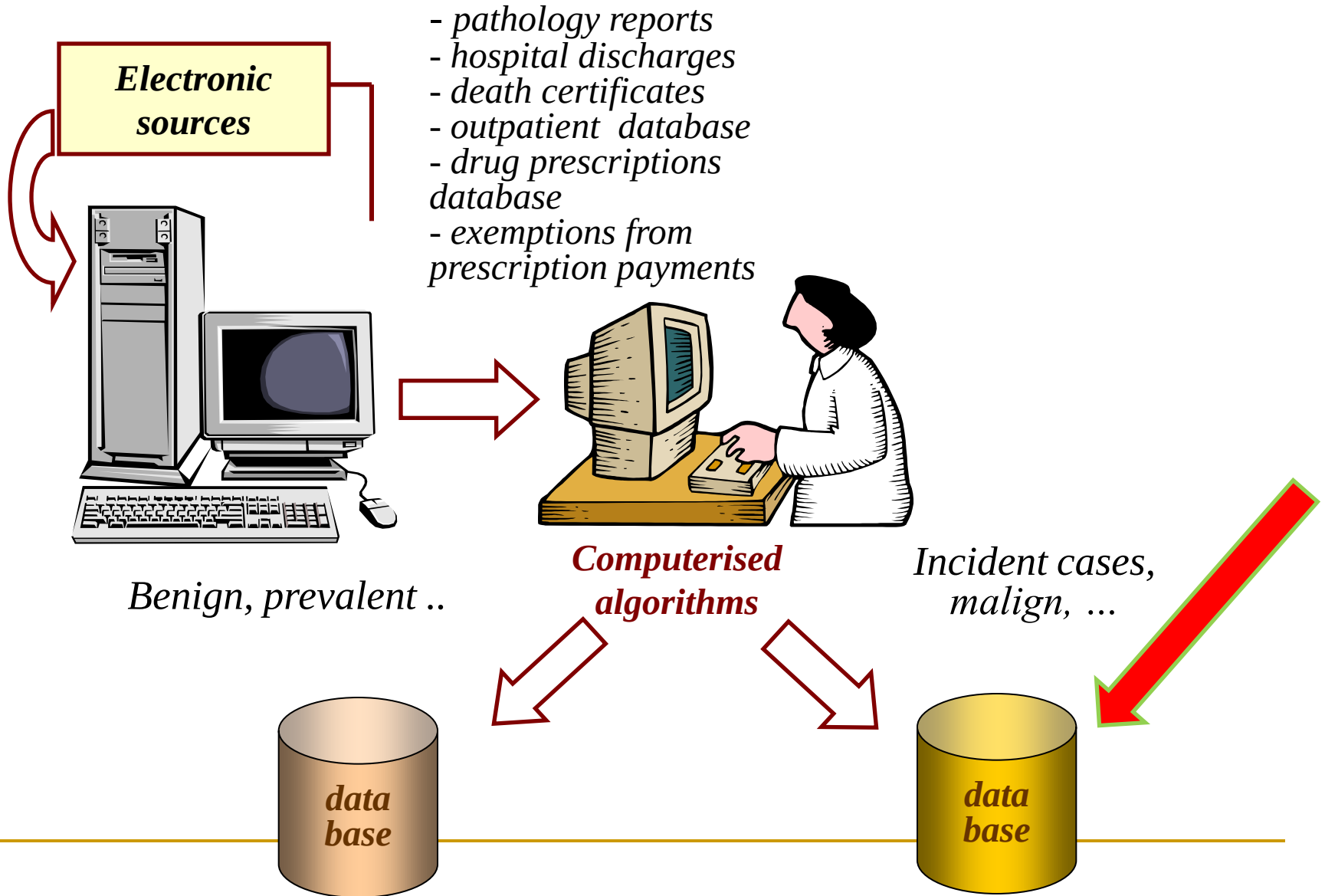
speeds work

reliable

efficient

finds errors

Data quality check



Basic data quality



Distribution of cases by site
% microscopic verifications
% death certificate only
Mortality-incidence ratio

“Check AIRTUM”, a program that performs advanced quality checks

Analisi dei dati

Registro: VARESE Aggiustamento: Nord

Selezione anni

Anno/i da valutare: dal 2009 al 2011 Anni per i trend: dal 2009 al 2011

Elaborazioni

189	8	☒ Topografia (IV cifra)	38	0	☒ Rapporto maschi/femmine
73	10	☒ Sedi mal definite	66	8	☒ Tasso di incidenza età-specifico
150	0	☒ Casi D.C.O.	74	0	☒ Stabilità delle verifiche microscopiche
154	0	☒ Casi con verifica microscopica	27	1	☒ Incidenza dei tumori infantili
86	13	☒ Distribuzione delle morfologie	73	1	☒ Sopravvivenza a 1 anno
49	0	☒ Morfologie generiche	75	0	☒ Analisi dei S.I.R. per anno
58	0	☒ Valore del rapporto M/I	60	0	☒ Percentuale di incongruenze sede-morfologia
58	0	☒ Trend del rapporto M/I			☐ Percentuale grading non noto
58	0	☒ Stabilità del rapporto M/I	1	1	☒ Percentuale follow-up non aggiornati
65	10	☒ Tasso di incidenza standardizzato	1354	52	

Seleziona tutti Deseleziona tutti

Risultati

Benchmark totale: 93.8% Completezza: 97.6% Accuratezza: 93.2 Avvisi: 3

Uscita

A photograph of a hand holding a single yellow leaf against a bright blue sky with soft white clouds. The sun is visible behind the leaf, creating a lens flare effect. The text "Further points to consider..." is overlaid in a bold blue font.

**Further points to
consider...**

When can registries be considered to be good quality?

When they have....

- 1. 100% histology ?**
- 2. low % cytology ?**
- 3. low % of DCO ?**
- 4. Good site/morphology concordance?**



Cancer registry data quality also depends on the use to which that data are put, for example

- whether used for standard registration or for high definition studies
- etc., etc.



Many thanks for your attention

