
con il patrocinio:

Comune di Modena

in collaborazione con:

SERVIZIO SANITARIO REGIONALE
EMILIA-ROMAGNA
Azienda Unità Sanitaria Locale di Modena

AIRTUM

XV Corso di aggiornamento
per operatori dei registri tumori

I tumori cerebrali,
i tumori del polmone,
gli screening oncologici,
i registri specializzati e
il manuale di registrazione

MODENA

6-8 ottobre 2015
Sala Oratorio
c/o Palazzo dei Musei
viale Vittorio Veneto, 5 - Modena

La qualità dei dati dei Registri Tumori

Emanuele Crocetti

Segretario Airtum
segretario.airtum@yahoo.it

La qualità dei dati (RT/AIRTUM)

- Airtum ha costruito la propria credibilità intorno alla qualità dei dati (dei Registri)
  - Formazione
  - Accreditamento
  - Banca dati
- E' su questa capacità che abbiamo avuto il riconoscimento del MdS, di AIOM, ecc.
- Questa qualità è messa (legittimamente?) in dubbio

La qualità dei dati (RT/AIRTUM)

- Qualità tradizionale
    - Confrontabilità, Validità, Completezza, Tempestività
- Qualità del tutto e qualità delle parti
- Qualità fra rigore, realtà e mercato

La qualità dei dati (RT/AIRTUM)

- L'esame Iarc avviene ogni 5 anni
- Conosciamo le domande
- Conosciamo il processo di valutazione

EUROPEAN JOURNAL OF CANCER 45 (2009) 747–755

available at www.sciencedirect.com

ScienceDirect

journal homepage: www.ejconline.com

ELSEVIER

Review

Evaluation of data quality in the cancer registry: Principles and methods. Part I: Comparability, validity and timeliness

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Timeliness
Quality control

ABSTRACT

The value of the modern cancer registry and its ability to carry out cancer control activities rely heavily on the underlying quality of its data and the quality control procedures in place. This two-part review provides an update of the practical aspects and techniques for addressing data quality at the cancer registry. This first installment of the review examines the factors influencing three of the four key aspects, namely, the comparability, validity and timeliness of cancer registry data. Comparability of cancer data may be established through a comprehensive review of the registration routines in place. Validity is examined via numerical indices of that permit comparisons with other registries, or, within a registry, over time, or with respect to specified subsets of cases. There are no international guidelines for timeliness at present, although specific standards for the abstraction and reporting of registry have been set out by certain organisations.

1. Introduction

The role of the population-based cancer registry has evolved beyond that of a provider of information on cancer incidence within a defined catchment area.[1] Given sufficient resources, the modern registry is active in a number of areas of cancer control, including epidemiological research on the causes of cancer, the monitoring and evaluation of screening programmes, and the follow-up of cancer patients in relation to the quality of cancer care they receive.[2,3] The value of a cancer registry and its ability to carry out such activities rely heavily on the quality of the data, and the quality control procedures in place.[4,5] Registries with a wide portfolio of activities will tend to improve the quality of their routine statistics simply by utilising the collected data, as well as by activating interest amongst collaborators (clinicians and researchers) in the daily registration procedures.[6]

As Skeet[7] writes in the standard text on registry methodology, 'all registries should be able to quote some objective measure of (ascertainment) rather than relying on received

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journal homepage: www.ejconline.com

ELSEVIER

Review

Evaluation of data quality in the cancer registry: Principles and methods Part II. Completeness

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Data quality
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Quality control

ABSTRACT

The completeness of cancer registry data – the extent to which all of the incident cancers occurring in the population are included in the registry database – is an extremely important attribute of a cancer registry. Only a high degree of completeness in case-finding procedures will ensure cancer incidence rates and survival proportions are close to their true value. This second instalment of a two-part review of data quality methods at the cancer registry, focuses on the principles and techniques available for estimating completeness, separating methods into those that are semi-quantitative – in that they give an indication of the degree of completeness relative to other registries or over time, and more quantitative techniques – those that provide a numerical evaluation of the extent to which all eligible cases have been registered.

1. Introduction

In Part I of this review, we considered the importance of comparability, validity and timeliness in the evaluation of cancer registry quality.[1] Here we review the evaluation of *completeness* – the extent to which all of the incident cancers occurring in the population are included in the registry database. Completeness is a very important attribute – only with maximum completeness in case-finding procedures will incidence rates and survival proportions be close to their true values. We present the principles and methods available for determining the extent to which this ideal is achieved.

These methods may be used to evaluate overall completeness of the registry database, or subsets within it, defined, for example, by type of cancer, area of residence, or age group. This is useful in identifying areas for improvement in registry procedures. Case-finding is often more problematical in the elderly, for example, since multiple pathologies may make hospital admission less likely, and extracting a cancer diagnosis from hospital information systems (or death certificates) less certain. The evaluation of completeness is important for all registries, but may be of special relevance to those making extensive use of automated data capture procedures, when case finding relies upon the accuracy (and complete-

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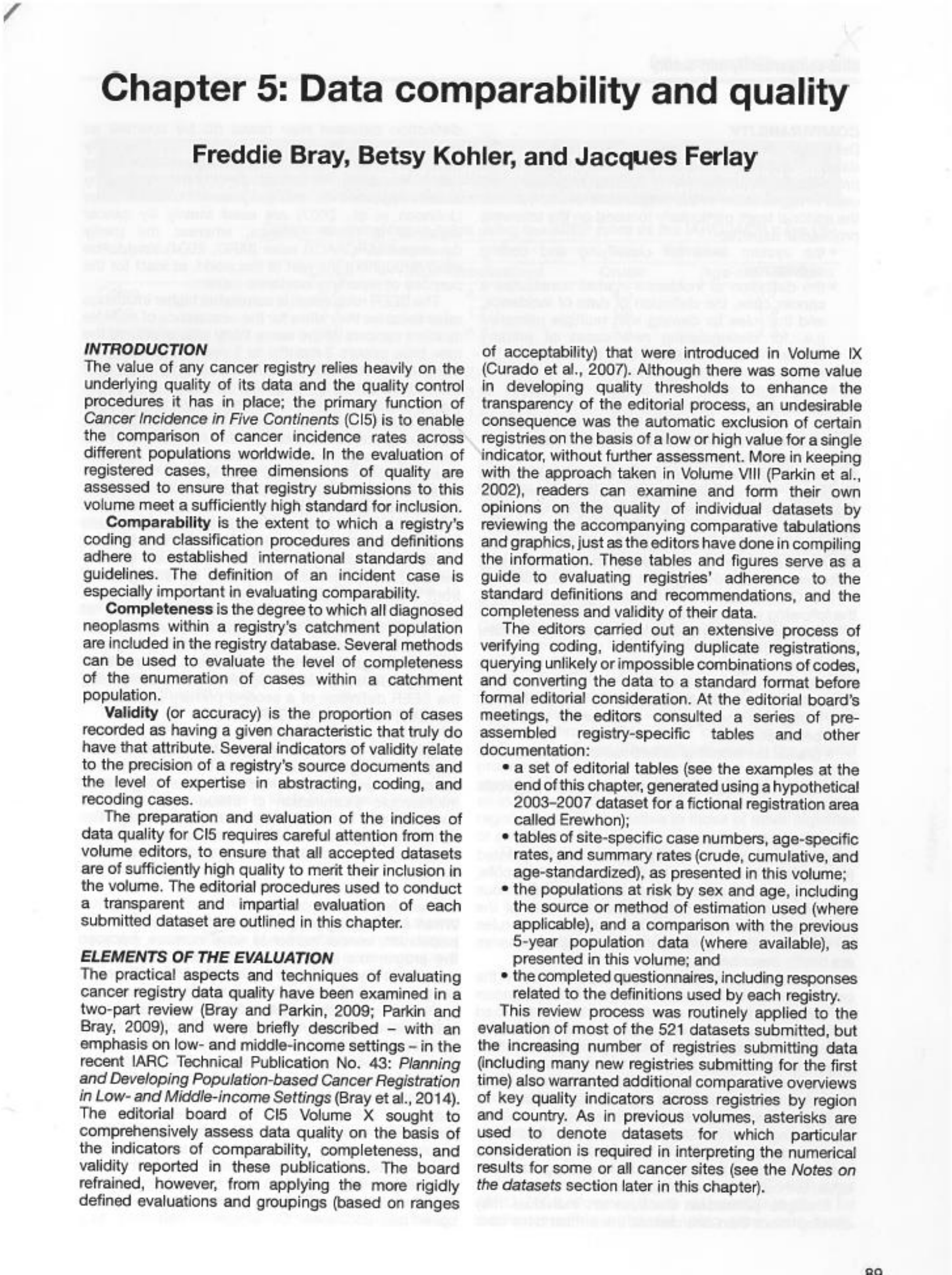
Editorial tables



Chapter 5: Data comparability and quality

Freddie Bray, Betsy Kohler, and Jacques Ferlay

INTRODUCTION

The value of any cancer registry relies heavily on the underlying quality of its data and the quality control procedures it has in place; the primary function of *Cancer Incidence in Five Continents* (CI5) is to enable the comparison of cancer incidence rates across different populations worldwide. In the evaluation of registered cases, three dimensions of quality are assessed to ensure that registry submissions to this volume meet a sufficiently high standard for inclusion.

Comparability is the extent to which a registry's coding and classification procedures and definitions adhere to established international standards and guidelines. The definition of an incident case is especially important in evaluating comparability.

Completeness is the degree to which all diagnosed neoplasms within a registry's catchment population are included in the registry database. Several methods can be used to evaluate the level of completeness of the enumeration of cases within a catchment population.

Validity (or accuracy) is the proportion of cases recorded as having a given characteristic that truly do have that attribute. Several indicators of validity relate to the precision of a registry's source documents and the level of expertise in abstracting, coding, and recoding cases.

The preparation and evaluation of the indices of data quality for CI5 requires careful attention from the volume editors, to ensure that all accepted datasets are of sufficiently high quality to merit their inclusion in the volume. The editorial procedures used to conduct a transparent and impartial evaluation of each submitted dataset are outlined in this chapter.

ELEMENTS OF THE EVALUATION

The practical aspects and techniques of evaluating cancer registry data quality have been examined in a two-part review (Bray and Parkin, 2009; Parkin and Bray, 2009), and were briefly described – with an emphasis on low- and middle-income settings – in the recent IARC Technical Publication No. 43: *Planning and Developing Population-based Cancer Registration in Low- and Middle-income Settings* (Bray et al., 2014). The editorial board of CI5 Volume X sought to comprehensively assess data quality on the basis of the indicators of comparability, completeness, and validity reported in these publications. The board refrained, however, from applying the more rigidly defined evaluations and groupings (based on ranges of acceptability) that were introduced in Volume IX (Curado et al., 2007). Although there was some value in developing quality thresholds to enhance the transparency of the editorial process, an undesirable consequence was the automatic exclusion of certain registries on the basis of a low or high value for a single indicator, without further assessment. More in keeping with the approach taken in Volume VIII (Parkin et al., 2002), readers can examine and form their own opinions on the quality of individual datasets by reviewing the accompanying comparative tabulations and graphics, just as the editors have done in compiling the information. These tables and figures serve as a guide to evaluating registries' adherence to the standard definitions and recommendations, and the completeness and validity of their data.

The editors carried out an extensive process of verifying coding, identifying duplicate registrations, querying unlikely or impossible combinations of codes, and converting the data to a standard format before formal editorial consideration. At the editorial board's meetings, the editors consulted a series of pre-assembled registry-specific tables and other documentation:

- a set of editorial tables (see the examples at the end of this chapter, generated using a hypothetical 2003–2007 dataset for a fictional registration area called Erewhon);
- tables of site-specific case numbers, age-specific rates, and summary rates (crude, cumulative, and age-standardized), as presented in this volume;
- the populations at risk by sex and age, including the source or method of estimation used (where applicable), and a comparison with the previous 5-year population data (where available), as presented in this volume; and
- the completed questionnaires, including responses related to the definitions used by each registry.

This review process was routinely applied to the evaluation of most of the 521 datasets submitted, but the increasing number of registries submitting data (including many new registries submitting for the first time) also warranted additional comparative overviews of key quality indicators across registries by region and country. As in previous volumes, asterisks are used to denote datasets for which particular consideration is required in interpreting the numerical results for some or all cancer sites (see the *Notes on the datasets* section later in this chapter).

Sappiamo in anticipo le domande.

Non possiamo essere bocciati.

Di chi è la colpa?

Vostra!

di Airtum

La qualità dei dati (RT/AIRTUM)

- I metodi per valutare la qualità sono affidabili?
- Riescono a identificare dati di bassa qualità ma non ad assicurare che i dati siano di qualità elevata

La qualità dei dati (RT/AIRTUM)

- La qualità del tutto non è espressione della qualità delle parti

ACCIS: Automated Childhood Cancer Information System

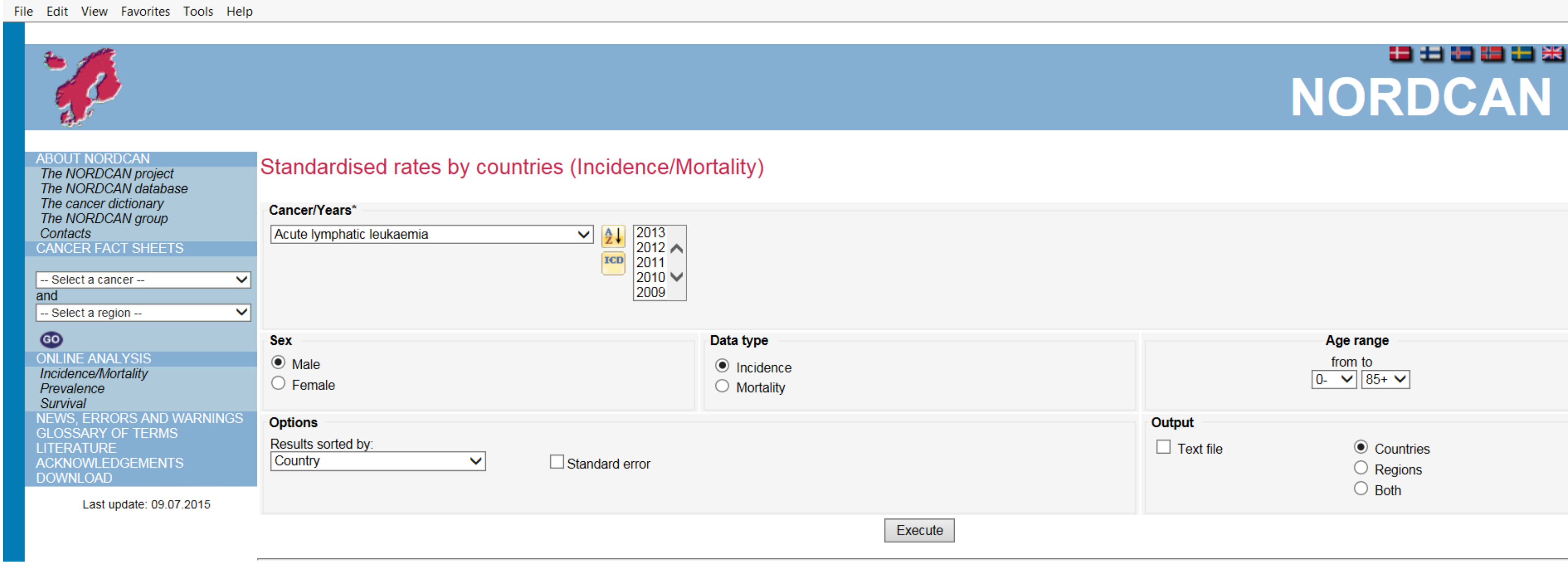
- I metodi per valutare la qualità sono affidabili?

L'effetto Ötzi

Museo Archeologico dell'Alto Adige
www.iceman.it/it

Call e disponibilità dei dati

EUROCARE	2012
CI5C-XI	2008-2012



Last update: 09.07.2015

Standardised rates by countries (Incidence/Mortality)

Cancer/Years*

Acute lymphatic leukaemia

2013
2012
2011
2010
2009

Sex

● Male
○ Female

Data type

● Incidence
○ Mortality

Age range

from 0- to 85+

Options

Results sorted by: Country

☐ Standard error

Output

☐ Text file

● Countries
○ Regions
○ Both

La qualità dei dati (RT/AIRTUM)

- Quanto costa (in tempo e risorse) la qualità?

- E' meglio avere dati perfetti del 2010 (2008…2012) o dati imperfetti del 2014?
- O entrambi?

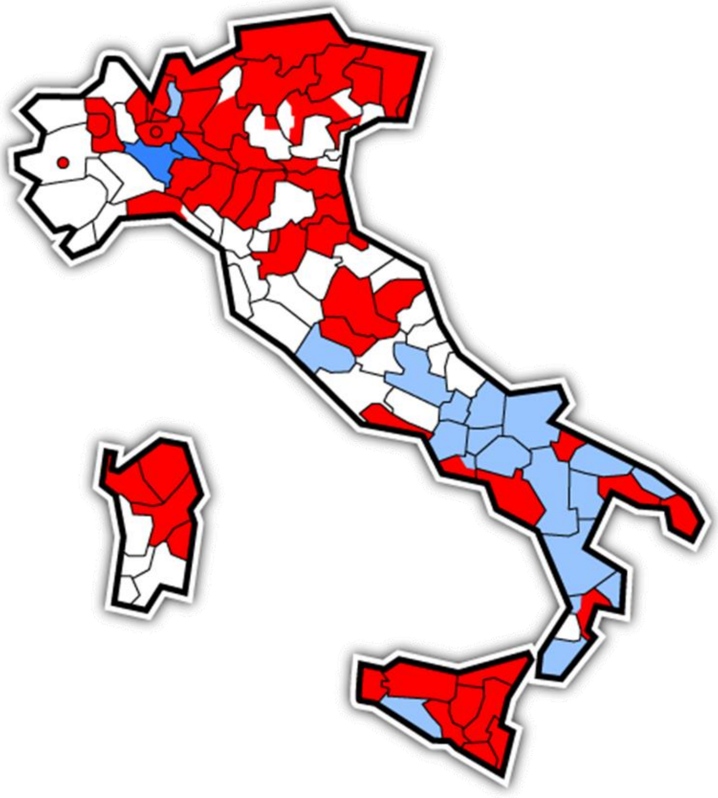
La qualità dei dati (RT/AIRTUM)

- Chi usa i dati del vostro RT?
  - Iarc ogni 5 anni
  - Eurocare ogni X anni, ecc.
  - Airtum
  - Il RT?
- E' abbastanza?
- E i clinici? E i decisori della sanità?

La qualità dei dati (RT/AIRTUM)

- Che senso ha valutare la qualità sulla proporzione di DCI quando non si hanno informazioni sui marker, sul trattamento, sugli outcome intermedi?

Andiamo verso una copertura nazionale del Paese



Un Registro nazionale con articolazioni (pluri) regionali

La qualità va garantita (livello 0)

Alcuni degli (altri) articoli che trovate in PubMed

Dimitrova N, Parkin DM. Data quality at the Bulgarian National Cancer Registry: An overview of comparability, completeness, validity and timeliness. Cancer Epidemiol. 2015 Jun;39(3):405-13.

Zanetti R, Schmidtmann I, Sacchetto L, Binder-Foucard F, Bordoni A, Coza D, Ferretti S, Galceran J, Gavin A, Larranaga N, Robinson D, Tryggvadottir L, Van Eycken E, Zadnik V, Coebergh JW, Rosso S. Completeness and timeliness: Cancer registries could/should improve their performance. Eur J Cancer. 2015 Jun;51(9):1091-8.

Pardo C, Bravo LE, Uribe C, Lopez G, Yepez MC, Navarro E, de Vries E, Pineros M. Comprehensive assessment of population-based cancer registries: an experience in Colombia. J Registry Manag. 2014 Fall;41(3):128-34.

Cendales R, Pardo C, Uribe C, López G, Yepez MC, Bravo LE. Data quality at population-based cancer registries in Colombia. Biomedica. 2012 Oct-Dec;32(4):536-44.

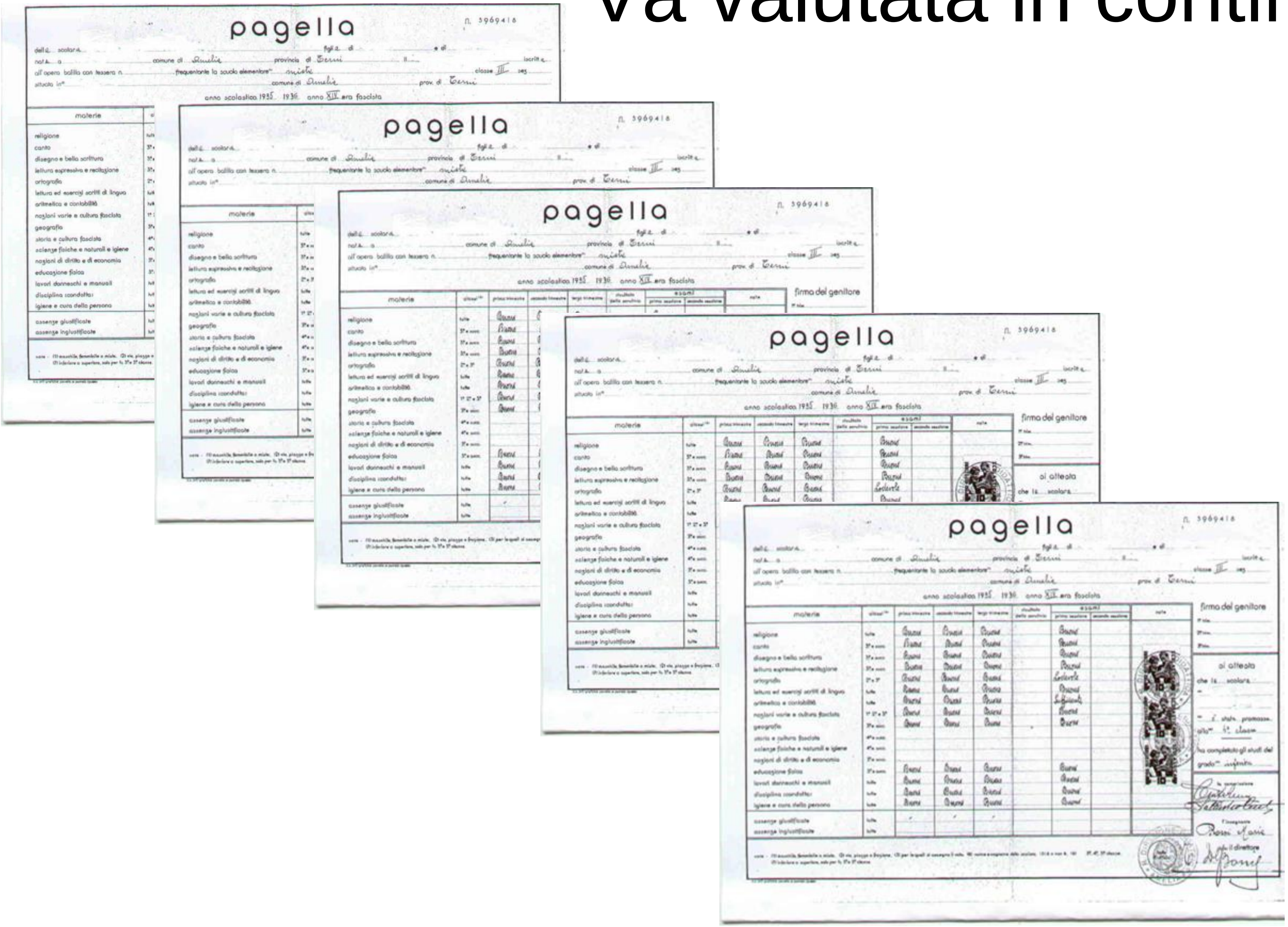
Sigurdardottir LG, Jonasson JG, Stefansdottir S, Jonsdottir A, Olafsdottir GH, Olafsdottir EJ, Tryggvadottir L. Data quality at the Icelandic Cancer Registry: comparability, validity, timeliness and completeness. Acta Oncol. 2012 Sep;51(7):880-9.

Larsen IK, Småstuen M, Johannesen TB, Langmark F, Parkin DM, Bray F, Møller B. Data quality at the Cancer Registry of Norway: an overview of comparability, completeness, validity and timeliness. Eur J Cancer. 2009 May;45(7):1218-31.

Schmidtmann I, Blettner M. How do cancer registries in europe estimate completeness of registration? Methods Inf Med. 2009;48(3):267-71.

…

Va valutata in continuo



pagella

n. 3969418

della scolara ... figlia di ... e di ...
nata a ... comune di Amelia provincia di Terni il ... iscritta
all'opera balilla con tessera n. ... frequentante la scuola elementare mista classe III sez.
situata in ... comune di Amelia prov. di Terni

anno scolastico 1935 1936 anno XIV era fascista

materie	classi	primo trimestre	secondo trimestre	terzo trimestre	risultato dello scrutinio	esami prima sessione	esami seconda sessione	note
religione	tutte	Buono	Buono	Buono		Buono		
canto	3ª e succ.	Buono	Buono	Buono		Buono		
disegno e bella scrittura	3ª e succ.	Buono	Buono	Buono		Buono		
lettura espressiva e recitazione	3ª e succ.	Buono	Buono	Buono		Buono		
ortografia	2ª e 3ª	Buono	Buono	Buono		Lodevole		
lettura ed esercizi scritti di lingua	tutte	Buono	Buono	Buono		Buono		
aritmetica e contabilità	tutte	Buono	Buono	Buono		Sufficiente		
nozioni varie e cultura fascista	1ª 2ª e 3ª	Buono	Buono	Buono		Buono		
geografia	3ª e succ.	Buono	Buono	Buono		Buono		
storia e cultura fascista	4ª e succ.							
scienze fisiche e naturali e igiene	4ª e succ.							
nozioni di diritto e di economia	5ª e succ.							
educazione fisica	3ª e succ.	Buono	Buono	Buono		Buono		
lavori donneschi e manuali	tutte	Buono	Buono	Buono		Buono		
disciplina (condotta)	tutte	Buono	Buono	Buono		Buono		
igiene e cura della persona	tutte	Buono	Buono	Buono		Buono		
assenze giustificate	tutte	–	–	–				
assenze ingiustificate	tutte							

firma del genitore
1º trim.
2º trim.
3º trim.

si attesta
che la scolara
è stata promossa
alla 4ª classe
ha completato gli studi del
grado inferiore

la maestra
l'insegnante
Rossi Maria
il direttore

Gli esami non devono finire mai

La quantità va incrementata (senza indugi)

CONFERENZA DI CONSENSO

DALLA PRATICA DEL **FOLLOW UP** ALLA CULTURA DI **SURVIVORSHIP CARE**

ROMA • 10 - 11 SETTEMBRE 2015

supplemento 1
numero 6
anno 38
novembre dicembre 2014

EPIDEMIOLOGIA & PREVENZIONE

Rivista dell'Associazione italiana di epidemiologia

AIRTUM Working Group

I TUMORI IN ITALIA - **RAPPORTO 2014**

Prevalenza e guarigione da tumore in Italia

ITALIAN CANCER FIGURES - **REPORT 2014**

Prevalence and cure of cancer in Italy

Associazione Italiana Registri Tumori

Centro per la prevenzione e il controllo delle malattie

inferenze

La tempestività va migliorata (2 anni)

Dati osservati e stimati hanno obiettivi diversi

Con buoni dati osservati possiamo avere stime più affidabili

I NUMERI
DEL CANCRO
IN ITALIA
2011

Dati incompleti
per uno scopo
possono essere
sufficienti
per un altro

I singoli flussi vengono già utilizzati non possiamo limitarci a dire che non vanno bene

Bisogna essere molto competenti nel nostro lavoro, non solo per produrre dati di qualità, ma per alzare l'asticella e soprattutto per essere liberi dai limiti di qualità imposti da altri

La registrazione dei tumori può essere
un lavoro noioso, poco interessante,
di bassa professionalità,

ma solo se a svolgerlo è una persona
noiosa, poco interessante,
di bassa professionalità

STAY HUNGRY. STAY FOOLISH