

Translating local quality assurance to the global community

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Local quality assurance...

From CIS-IX

IACR 2010 - Yokohama

Local quality assurance...

From CIS-IX

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German speaking region coverage 47%

Switzerland (Confederation)
7.5 million inh.
26 cantons
11 registries covering 17 cantons

French & Italian speaking regions coverage 92%

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Quality assurance

Cancer registry datasets and networks

Data flow : requirements

Sources	Registry Individual file
Name, surname, sex, date and place of birth, national identifier, address, SES status	Administrative
Topography, Morphology, investigations, basis of diagnosis, staging, comorbidity,	Disease & Treatment
Relapse or disease-free, comorbidities, moving, regular deadlalive status, ...	Follow-up

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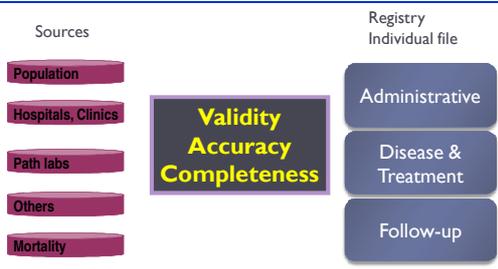
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Data flow : requirements



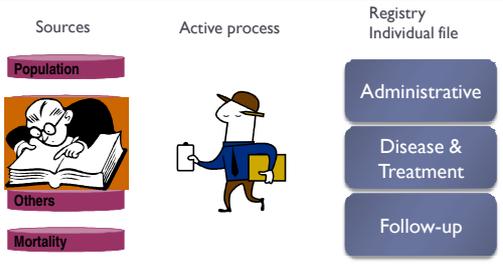
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Data flow : requirements



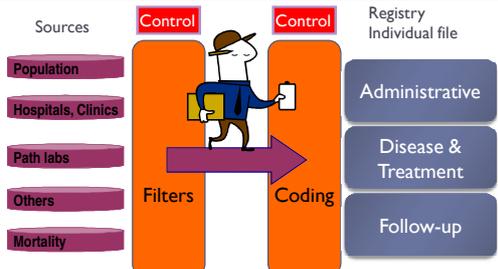
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Data flow : 1. historical management



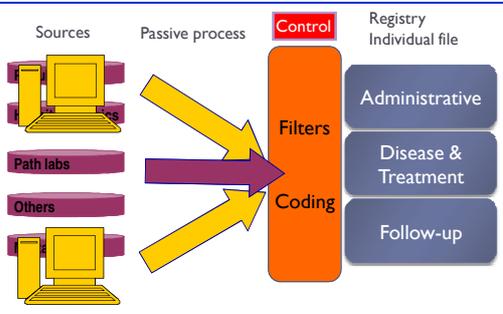
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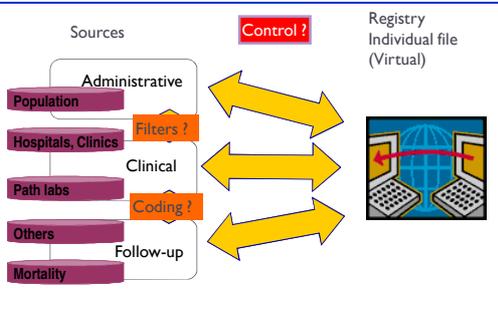
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2. +/- advanced computerized systems



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Data flow : 3. Data base integration



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Reminder :

- ▶ Routine registration requires finding a balance between three types of constraint:
 - ▶ Completeness
 - ▶ Level of detail and accuracy
 - ▶ Timeliness
- ▶ Data output only are under control of the central coordination. Locally, registries must adapt their processes for data collection to the local reality

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Reminder :

- ▶ Quality of any combined dataset is at the level of the poorest component
- ▶ **Quality control for a pooled dataset requires different objectives than for a single database** in order to transform a miscellaneous patchwork into a coherent and representative sample

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Optimal data quality for a network...

- ▶ Seeking maximal comparability :
 - ▶ Unbiased information sources for diagnosis and death
 - ▶ Agreement to use the same international classification systems and a common set of population weights for age-standardising incidence and survival

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Optimal data quality for a network...

- ▶ Achieving optimal quality requires transparency from every member and routine publication of standard quality indices
- ▶ The goal is **NOT** excellence for a minority, but a high standard for the entire network

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Some classic quality indices (all sites)

	M/I		MV %	DCO %	Stage X* %	
	M	F			C18-20	C50
BA	0.52	0.57	100	0.0	91	90
GE	0.41	0.36	93	0.6	88	93
GG	0.49	0.45	93	0.3	91	77
NE	0.50	0.44	94	0.7	-	-
SGA	0.46	0.44	96	0.2	75-90	75-92
VD	0.42	0.42	96	1.4	-	-
VS	0.47	0.41	93	0.9	85	88
TI	0.47	0.44	93	1.9	89	89
ZH	0.43	0.42	93	2.1	88	88
All	0.46	0.44	95	1.1		

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* Stage X : At least T and N are known, M including M? and Mx

Number of morphologies used by site

	GR	GL	NE	VS	TI	GE	GA	BA	VD	ZH
Nb of cases per year	1'039	947	1'421	1'736	2'664	2'613	2'825	3'646	5'339	
Stomach	48	14	9	13	21	16	23	23	17	21
Colon	41	11	5	10	13	13	19	15	12	13
Rectum	30	8	4	10	11	12	13	14	8	16
Pancreas	37	10	5	6	9	11	15	17	12	14
Lung	62	17	13	18	19	26	36	28	21	19
Pleura	14	6	4	6	7	6	8	6	5	8
Breast F	57	15	9	17	25	19	31	30	20	15
Cervix uteri	28	8	5	7	5	7	10	15	5	9
Corpus uteri	33	11	6	8	12	9	13	17	9	14
Ovary	51	17	8	10	20	19	24	28	14	17
Prostate	25	7	5	3	6	3	6	8	8	8
Bladder	34	8	5	10	12	8	11	11	10	12
Kidney & others	33	7	4	6	10	11	17	14	10	14
Thyroid	34	5	2	5	14	9	14	14	8	14
NHLymphomas	38	11	7	15	20	24	21	19	20	17

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Heterogeneity in the coding of "adenocarcinoma" (ADK: M8140-M8381) for colon and rectum

ICD-O-3 code and description	Average	Local %
8140 Adenocarcinoma NOS	68%	TI 1.7%
8210 ADK in adenomatous polyp	2%	BA:17%, GE:9%
8211 Tubular ADK	0%	TI 73%
8220 ADK in adenomatous polyposis	<1%	GE:9%
8221 ADK in multiple adenomatous polyps	0%	GE:1% (n=48)
8261 ADK in villous adenoma	<1%	NE:9%
8481 Mucin-producing ADK	1-4%	SGA:22%, NE:19%

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Translating to global community

I. Data analysis



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Data analysis requires...

1. Technical means
 - ▶ Best to adopt standard processes for data management, (hardware, software, data transfer, quality controls, output formats,...)
2. Competence
 - ▶ Education and training

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CDC Home
Centers for Disease Control and Prevention
Your Online Source for Credible Health Information

National Program of Cancer Registries (NPCR)

Training

<http://www.cdc.gov/cancer/npcr>

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NPCR
Cancer Data and Statistics

Modules

- Building a Quality Presentation**
This three-part module is designed for education coordinators within the central registries and helps trainees identify what training is needed, improve training methods, build presentations using Microsoft® PowerPoint 2003, and develop exercises.
- Abstracting for the Beginner**
This three-part module for beginning reporters explains why cancer data is collected, how information flows from the facility level to the national level, and how to maintain the confidentiality of health data, perform casefinding, and complete the electronic cancer reporting form.
- Quality Control for Central Registries**
This module has nine parts: five that provide an overview of total quality management and continuous quality improvement, and four separate stand-alone modules for audits, reliability studies, and data quality management reports. Exercises are provided for several of the sessions.
- Validating Data with Text**
This module provides instructions for reporters on the importance of text to validate coded data, how to record text, and what text to include. The exercises help students determine necessary text.
- Head and Neck Malignancies**
The head and neck cancer abstracting module consists of three parts: Overview (incidence and multiple rules), Putting the Pieces Together, and Treatment and Survival.
- Gynecological Malignancies**
The female genital cancers advanced abstracting module consists of three parts covering Introduction, Work-up, Stage of Disease, Treatment, and Follow-up and Outcomes.

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Advanced Abstracting
Gynecologic Cancers

III. STAGE OF DISEASE
TNM and Collaborative Staging

This section of advanced abstracting for gynecologic cancers discusses the TNM and FIGO staging of gynecologic cancers, as well as Collaborative Staging for the various GYN sites.

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Réseau Français des Registres de Cancer
FRANCIM
INVS
INSTITUT DE VEILLE SANITAIRE

Discussions - Tumeurs pulmonaires et de la plèvre

Discussions	Réponses	Vues	dernier message
Moderateurs : Patricia DELAFOSSE / Guy LAIBIN / Florence HOLLNÉE de Vincennes	0	7	14/06/2007 17:58 sbrissot@cur
carcinome neuro-endoctrine de Gauthier Delafosse	2	19	29/09/2010 14:39 Gauthier Delafosse
Lymphangite carcino-mateuse de Gauthier Delafosse	0	25	02/08/2010 10:49 Gauthier Delafosse
pt de la pulmonaire de Vincent Demaret	2	21	14/02/2010 11:13 Vincent Demaret
cas de lymphangite carcino-mateuse de Vincent Dufour	1	21	29/06/2009 16:03 Florence Rolland
Enregistrement d'un cas ou non ? de Vincent Demaret	1	20	26/09/2009 15:56 Patricia Delafosse
code morpho de stromectus	1	23	09/03/2009 15:30 Florence Rolland
base d'ant...			09/03/2009 15:04

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Question :

Clinical history :
"Phylloid tumour" in 1999 (surgery).
Relapse in 2000, grade 2, and infiltrating ductal carcinoma, SBR II, N+ (new tumour).
In 2002, "evolution of phylloid tumour, high grade"

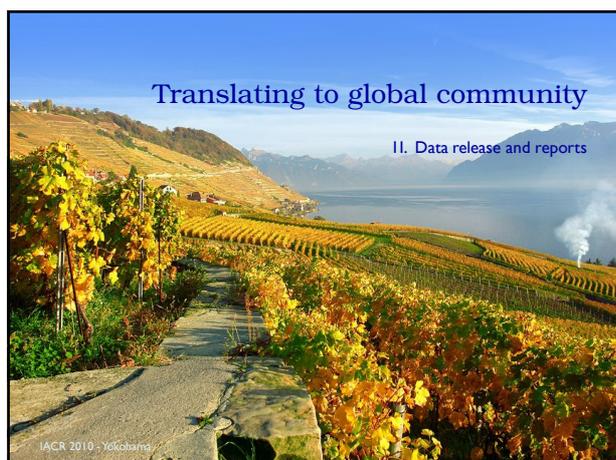
Which code ? relapse or new tumour ?

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Answer :

"You must know the grade of Phylloide tumour diagnosed in 1999. If grade 1 (9020/0) or grade 2 (borderline 9020/1), then 2002 tumour is incident, because high grade (9020/3). However, if it was a grade 3, it's a relapse grade 2 in 2000, not a new tumour. Invasive ductal carcinoma in 2000 was correctly coded new tumour, because not in the same Berg histological group".

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Outcomes and deliverables

Registries are requested to provide

- Reports and figures on **cancer burden** (incidence, prevalence)
- Reports and figures on **quality of care** (survival)
- Reports and figures, interpreting **trends**, geographical **comparisons**
- Reports and figures showing **projections** for the future
- etc.

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The "community" : who, what... ?

- ▶ Governmental bodies, public health managers
- ▶ National Office of Statistics
- ▶ League against cancer
- ▶ Cancer patient associations and families
- ▶ Media
- ▶ ...

Cancer registries' activities and outcomes link epidemiologic research and public health co-actors

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Information should match the needs

- ▶ Information on data collection and definitions must be available easily.
- ▶ Users are regularly informed about existing data

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Data quality at the Cancer Registry of Norway: An overview of comparability, completeness, validity and timeliness

Inger Kristin Larsen^a, Milada Småstuen^a, Tom Borge Johannesen^a, Froydis Langmark^a, Donald Maxwell Parkin^a, Freddie Bray^{a,b}, Bjørn Møller^a

^aDepartment of Clinical and Registry-based Research, Cancer Registry of Norway
^bInternational Agency for Research on Cancer, Lyon, France
^cStatistik Canada, Ottawa, Ontario, Canada
^dDepartment of Biostatistics, Institute of Basic Medical Sciences, University of Oslo, Norway
^eCancer Research UK, Centre for Epidemiology, Mathematics and Statistics

<http://www.ukacr.org/>

NORDCAN
<http://www-dep.iarc.fr/NORDCAN>

Cancer Incidence and Incidence Rates in Japan in 2005: Based on Data from 12 Population-based Cancer Registries in the Monitoring of Cancer Incidence in Japan (MCIJ) Project

Tomohiro Matsuda¹, Tomomi Maruyama¹, Ken-ichi Kamo², Kota Katanoda¹, Wakiko Ajiki¹ and Tomotaka Sobue¹ The Japan Cancer Surveillance Research Group
 * Author Affiliations

¹For reprints and all correspondence: Tomohiro Matsuda, Cancer Surveillance Division, Center for Cancer Control and Informatics Center, 5-1-1 Tsukiji, Chuo-ku, Tokyo 104-0045, Japan. E-mail: matsuda@ccic.ncc.go.jp
 Received July 28, 2010
 Accepted August 2, 2010

<http://www.registri-tumori.it>

Statistique Canada
<http://www.statcan.gc.ca/>

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Do users know that your data exist ?

- ▶ Since 2008, the French cancer registry network (FRANCIM) has estimated incidence for the current year based on projections from previous years, available on its website every September. (Ref: Agence France Presse (AFP) on 14 October 2009) <http://www.invs.sante.fr/applications/cancers/projections2010/default.htm>
- ▶ 2 November 2009, when launching the second National Cancer Programme : *"We must improve the quality of cancer data in our country. The USA just published incidence and mortality data for 2006, and we only have those for 2005"*

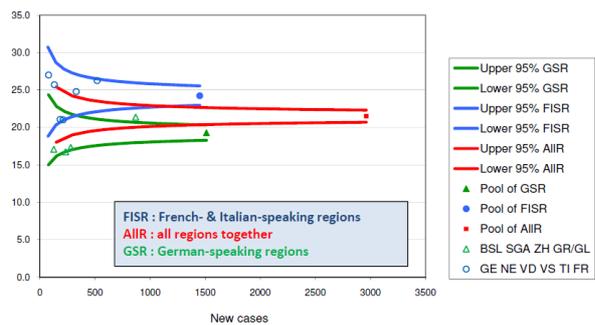
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Information should match the expectations

- ▶ Reporting scientific issues intelligibly for a lay audience is a major challenge
- ▶ Providing unbiased interpretation of the results when they are released helps to reduce inappropriate comments.

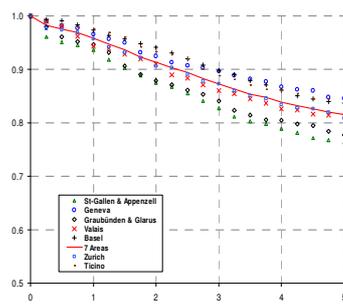
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Age Standardised Incidence Rates (European Population) Female Skin Melanoma - 2003-2007



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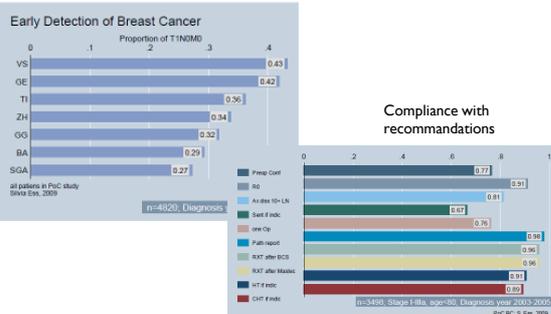
PoC studies, an obvious benefit...



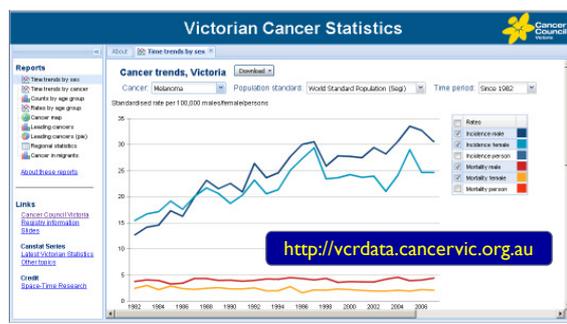
Fisch et al, Annals of Oncology, 2005

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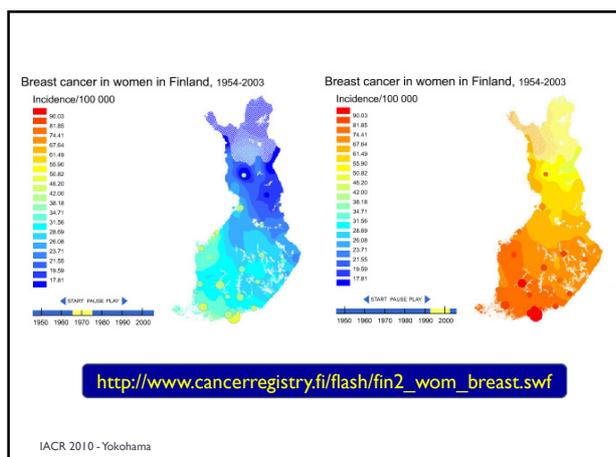
PoC studies, an obvious benefit...



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Conclusion

- ▶ Cancer registration and quality control
 - ▶ Is a dynamic, continuous process
 - ▶ Requires continuous monitoring to improve its efficiency
 - ▶ Requires standardisation in data collection, management analysis and publication.
- ▶ Effective liaison between research and public health makes it possible to promote "profitable cancer registries" for the greater benefit of the community

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