Combining medico-administrative with registry data for the surveillance of cancer with a limited registry population coverage: the experience of France
THE INSTITUT DE VEILLE SANITAIRE

- National public health agency under the Ministry of health
  - created in 1998
  - to support decision and policy making in public health
- Missions:
  - public health surveillance
  - early warning and alert of health authority
  - contribution to management of health crisis
- Covers all fields of health: infectious diseases, chronic diseases, occupational health and environmental health
- From emergency (outbreak, disasters…) to long term programs
- Operates at National and regional levels
- European and international contribution
DATA USED FOR NCD SURVEILLANCE

• Medical causes of death (ICD 10)*
  - all death certificates since 1968
  - number of deaths, crude, specific and standardized death rates

• Morbidity : three sources of information
  - Health Registries:
    • all newly diagnosed cases in a defined territory by active search and matching of several data sources
    • cover 100% of childhood cancers and 18 to 20% of adult cancers
  - Population studies:
    • population surveys at national level or in specific groups
    • ad-hoc and cohorts studies
  - Medico-administrative databases (BMA)
    • hospital discharge data: new diagnosis in all public and private hospitals
    • social security reimbursement and long term diseases (ALD) data
    • ALD: 100% reimbursement for about 30 conditions including cancers
ADULT CANCER REGISTRY COVERAGE, FRANCE, 2014

18 to 20% coverage of France population
TRENDS IN CANCER INCIDENCE (RED) & MORTALITY (BLUE) RATES, FRANCE 1980-2012

Rates standardized on the age structure of the world population

Sources: cancer registries and CépiDC

Tobacco consumption:
- Decrease in men
- Increase in women
FROM NATIONAL TO REGIONAL & DISTRICT INCIDENCE DATA (1)

- Registries provide invaluable data at national level on:
  - incidence, prevalence and survival rates
  - by time, age, gender and cancer site
  - basic clinical and treatment characteristics
- Do not inform on regional and district heterogeneity of cancer morbidity
- In 2004, creation of regional health agencies
- No data on cancer morbidity at regional, district and local levels
- Solutions?
- National registry:
  - best solution,
  - but too expensive at a time when resources are scarce
- hospital discharge & health insurance data:
  - available
  - produce indicators at each level: national, regional and district levels?
  - but heterogeneous validity by cancer site
SENSITIVITY & PVP OF HOSPITAL DISCHARGE AND ALD BY CANCER SITE IN REFERENCE TO CANCER REGISTRIES IN DISTRICTS COVERED BY A REGISTRY
FROM NATIONAL TO REGIONAL & DISTRICT INCIDENCE DATA

- Direct use of ALD and hospital discharge data is of limited validity
- Combination of medical administrative and registry databases
- Calibration and validation of incidence indicators by cancer sites in districts with a registry
- Production of routine validated indicators for specific cancer sites
METHOD PRINCIPLES

- Modeling of the ratio of cancer in either ALD, hospital discharge or mortality data base to registry incidence in district covered by registries.
- Calibration & validation
- Estimates in region/districts with no registry
THE “MODEL”

- Poisson model of ratio data from medico-administrative data base (BMA: ALD, Hospital discharge or mortality) to registry incidence in districts with a registry as a function of age and district (random effect)

\[ \frac{A_{ij}}{C_{ij}} = f(a_i) \cdot \exp(b_j), \text{ where } b_j \sim N(0, \sigma_d^2). \]

- Pancreatic cancer: ratio BMA/I by age & district in districts with a registry

\[ A_{ij} : \text{number of cancer patients of age } a_i \text{ in BMA in districts } j \]
\[ C_{ij} : \text{number of registry incident cancer cases of age } a_i \text{ in district } j \]
\[ f(a_i) : \text{average ratio according to age} \]
\[ b_j : \text{term specific to district} \]
\[ \sigma_d : \text{variability of } b_j \text{ by district} \]

CRITERIA FOR USING DISTRICT MODEL ESTIMATES

• Relative error = (predicted - observed incidence)/observed incidence
• If relative error <15% in each districts covered by registries : A++
• If relative error between 15 and 30% in > 2 districts or > 30% for > 1 district: B--
• If relative error between 15 and 30% in < 2 districts and <15% for other districts
  – Comparison of variability of ratio BMA/I to variability of estimated incidence by district
  – If variability of estimated incidence by district > twice the variability of BMA/I: A+
  – If variability of ratio incidence by district < twice the variability of BMA/I: B-
• Estimates used for cancer sites with method A++ or at least A+
Ovary Cancer

Ovaires 2008-2010 à partir des ALD: $\sigma_d = 0.0002$, $\sigma_k = 0.08$, ERA max = 12%
MELANOMA AMONG MALES

- Wide variability of BMA/I between estimated incidence in districts covered by a registry
- Low precision of estimates
- Variability of incidence estimate in all district falsely constrained
CANCERS SITES FOR WHICH DISTRICT INCIDENCE ESTIMATES WERE JUDGED APPROPRIATE

<table>
<thead>
<tr>
<th>Localisation</th>
<th>Hommes</th>
<th>Femmes</th>
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<tbody>
<tr>
<td>Gêsophage</td>
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<td>M/I</td>
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<td>M/I, ALD/I, PMSI/I</td>
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- **Regional incidence**
  - 8 cancer site/19 for male
  - 9 cancer site/21 for female

- **District incidence**
  - 8 cancer sites/19 for males
  - 8 cancer sites/21 for females

- **Limitations**
  - Cancers with low incidence
  - Number of districts
  - Choice of sites that are appropriately estimated (matter of debate)
EXAMPLE OF OVARY CANCER INCIDENCE ESTIMATES BY REGION AND DISTRICTS

Regional age standardized incidence rate for Ovary Cancer (model using ALD/I ratio)

District age standardized incidence rate for Ovary Cancer (model using ALD/I ratio)
NATIONAL CANCER ESTIMATES BY AGE AMONG WOMEN WITH 3 RATIO (I/M, I/ALD, I/HD) MODELS
CONCLUSIONS

• Pragmatic approach
• Allows having reasonably valid estimates of cancer incidence at district and regional level
• Clear added value & usefulness for health policy at regional and district levels
• Only for 8/9 cancer sites,
• However the most prevalent cancers are included
• Now in production phase of these basic indicators
• New approach: incorporate pathology results
• Moving to a system with 3 data sources: ALD, Hospital discharge and pathology results
ACKNOWLEDGEMENTS

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