Direction de l'Observation, des Sciences des données, et de l'Evaluation

SECONDARY USE OF CANCER DATA EXAMPLE OF FRENCH DATA HUB

Cancer in France - Overview

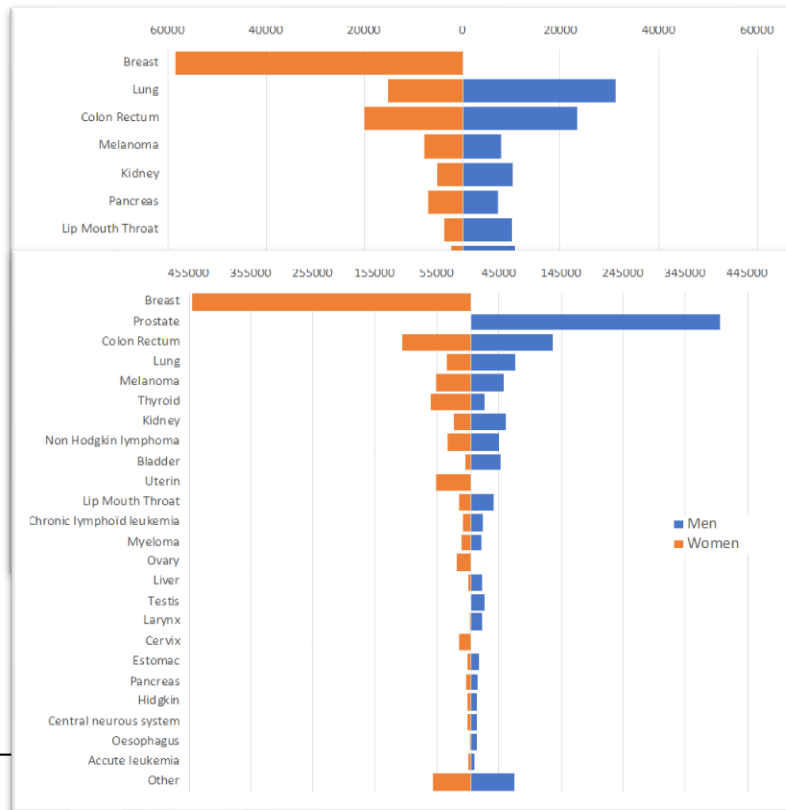68 M of inhabitants

382 000 cancers newly diagnosed every year

- 205 000 men

- 177 000 women

158 000 deaths

- 90 000 men

- 68 000 women

2,1 M 10 years prevalence
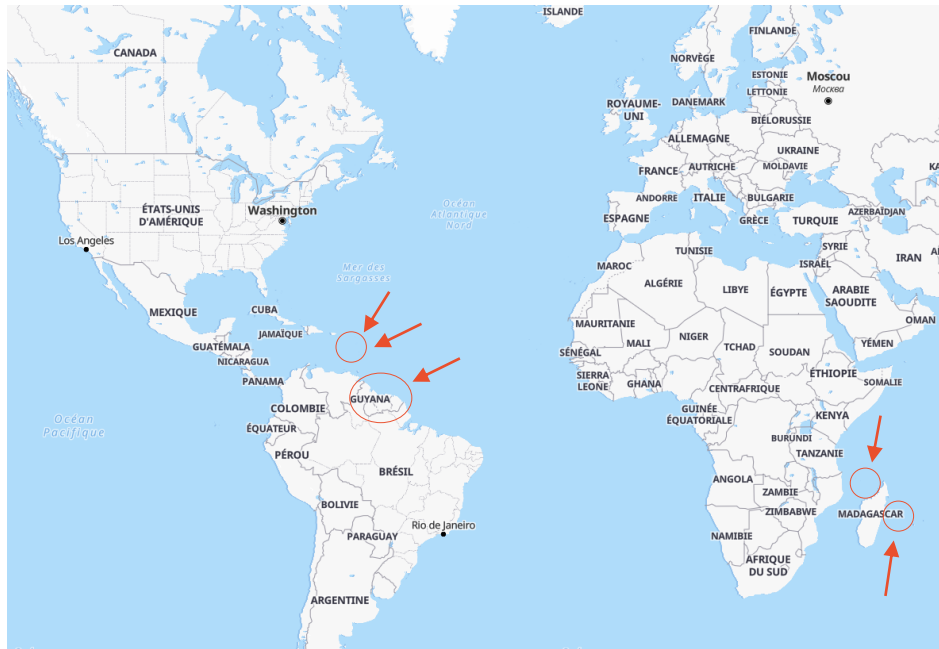
- 1,07 M men

- 1,03 M women

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Cancer in France - Overview

Metropolitan
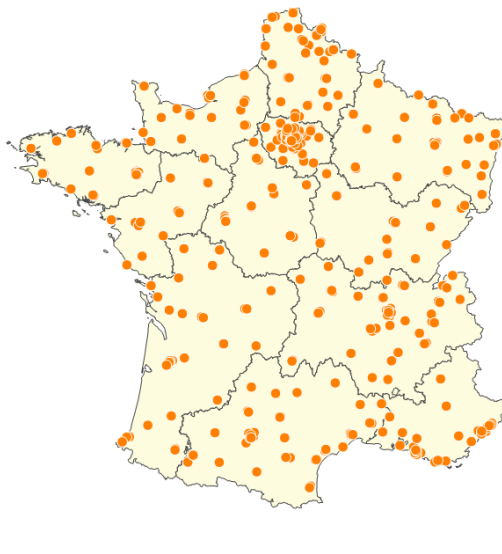
Oversea departments

Cancer in France – A large variety of treatment offers
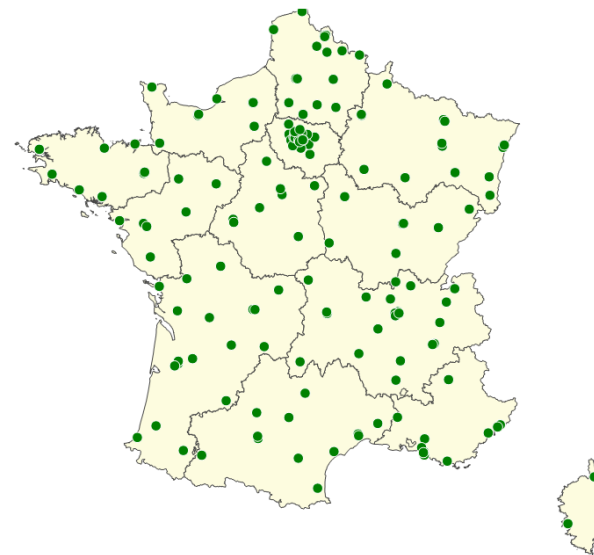
Surgery (723)   Chemotherapy (461)   Radiotherapy (172)

Our vision

A better life without cancer

In that context, The French National cancer institute aimed to develop a knowledge platform in order to better address ins and outs and to promote researches

→ The French cancer data platform

Cancer registries – A backbone of cancer information

Around 30 registries federated in a scientific and administrative partenership

    INCa – SP France – Francim – Hospices civils de Lyon
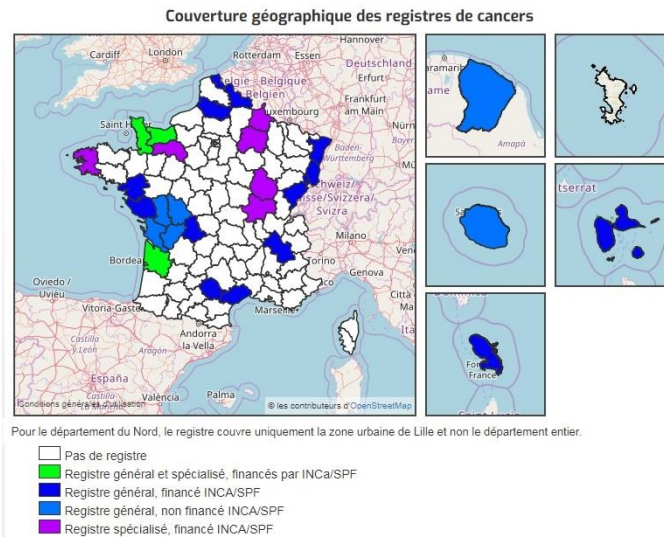
Coverage:

- Adults: 22% of the French metropolitan population
- Children: 100%

Allows to focus on sub-type of cancer

Trends over the time by sub-type and age-class

Observe inequities (*EDI*) on incidence and survival

(*in line with the European inequalities registry*)

Couverture géographique des registres de cancers

Pour le département du Nord, le registre couvre uniquement la zone urbaine de Lille et non le département entier.

- ☐ Pas de registre
- ☐ Registre général et spécialisé, financés par INCa/SPF
- ☐ Registre général, financé INCA/SPF
- ☐ Registre général, non financé INCA/SPF
- ☐ Registre spécialisé, financé INCA/SPF

The french national insurance system – A strength

It is called « *Système national des données de santé* » (SNDS)

Everyone is affiliated to the French national health insurance system

A claim database that gather information based on

- Inpatients
- Outpatients

Without consideration

Strict secure conditions

Some analysis are forbidden

Sovereign space / infrastructure

To date, an extract of

Informations on diagnosis, treatments (chemotherapy, surgery, radiotherapy, palliative cares…), and specific follow-up
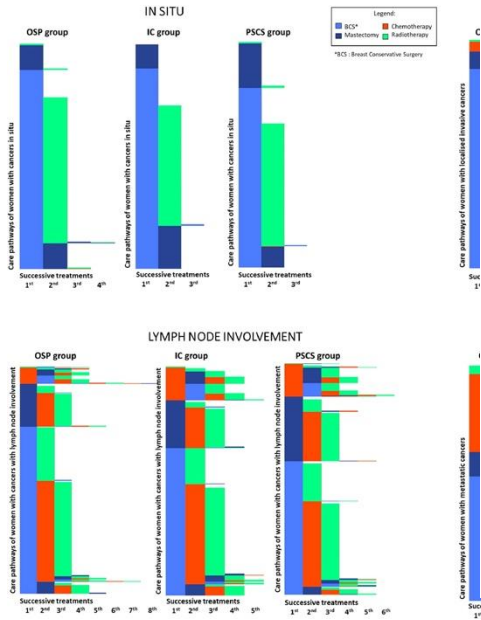
But no medical record
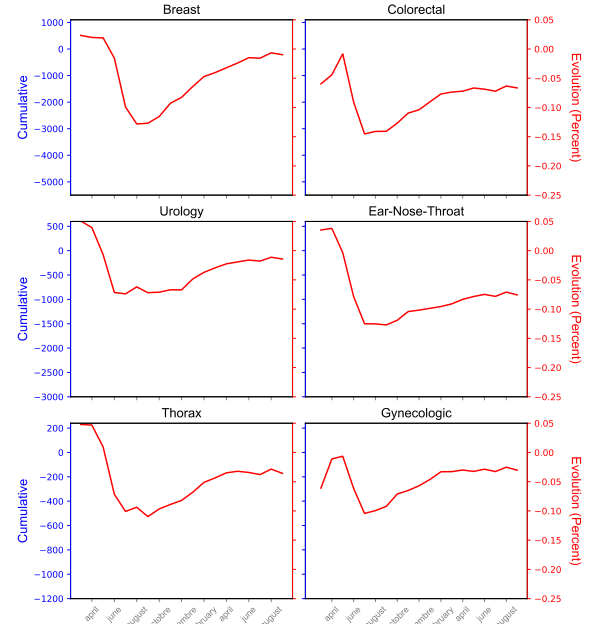
Some examples

Breast cancer - Care pathw[...]
diagnostic [...]

Care Quality, and Sa[...]

Impact of COVID on activities

Using medical records

Expertise from care givers is mandatory

Assume that medical records are of interest for medical research

A huge amount of information provided by clinical practice

    But often a lack of quality (for researchers)

Need for a balance between « structured » and « unstructured » information

→ A multistep approach based on a common set of documents part of « Cancer folder »

1- Defining structured medical documents // electronic health records

   → *Pathology and molecular biology reports ; multidisciplinary staff report ; personalized care program*

Using medical records

2- Integrating these documents into the interoperability domain

- HL7 / CDA (Clinical Document Architecture)

3- « Reuse » for research and assessment purpouse

- A second life for electronic health records
- A wide range of secondary use

At European level : Strong connexions to the European health data space

- Interoperability
- Think about the number of needed interactions (→ *previous slides*)

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Federating other platforms - Networking

We do not believe that a single platform could integrate every data

We do not believe that only federated approach could heighten researches

We believe in both models

Acting as a « platform » control tower

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Federating other platforms - Networking

Connexions between each platform

Set-up minimal datasets

- For each patients

- Adapted to the context and the platform

A common data governance

- Data sharing

- GDPR agreements

- Technical and security aspects

Considering new usages such as Trails based on real world data

Involving private sector

→ The National "Artificial Intelligence and Cancer" project

To Build bridges between public and private sector

To improve knowledge of cancers in order to allow better patient care and more precise medicine

To stimulate innovation in order to promote faster and greater access to it, whatever the field of oncology.

Involving private sector

A new association unifying

- 8 pharmaceutical firms + France BioTech
- INCa and HDH

Approved by the Strategic Committee for Industry Sectors (CSF)

Supported by 3 Ministers: Research, Health and Industry

Aims to

- Reinforce data-sharing
- Allow innovations and studies
- Proof of concept based on real world data

To summarize

For a better life without cancer

 We need to reinforce our capabilities, share our data and innovate

The platform developped at a national level is one example

Allows partnerships

Relies on medical records → European health data space

Studies inequities → European registry on inequalities