

The partnership for cancer surveillance in France: results of the 2014-2019 working program and perspectives



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BACKGROUND

Cancer is the first cause of death in France. Since 2007, data producers and institutions joined together in a partnership for cancer surveillance.

POPULATION-BASED CANCER REGISTRIES (PBCR), IN FRANCE IN 2020

- 29 district-level PBCR covering 18 to 29% of the national adult population according to cancer site, and contributing to a common database
- 2 national PBCR of childhood cancers
- 1 district-level PBCR of mesothelioma covering 30% of the national population

FRANCIM, THE FRENCH NETWORK OF PBCR

- Continuous quality improvement program
- Coordination of common studies
- Contribution to methodological developments and statistical analysis

THE BIOSTATISTICS-BIOINFORMATICS UNIT OF HOSPICES CIVILS DE LYON (HCL)

- Data-management of the common database
- Methodological developments and statistical analysis

THE FRENCH NATIONAL PUBLIC HEALTH AGENCY (SANTÉ PUBLIQUE FRANCE)

- Contribution to define cancer surveillance needs
- Methodological developments and statistical analysis

THE FRENCH NATIONAL CANCER INSTITUTE (INCa)

- Contribution to define cancer observation needs
- Leader of the National Cancer Plans: the 3rd Plan was ongoing in 2014-2019

As part of this partnership, a joint working program was implemented to provide information to support public health policies.

OBJECTIVES

We present the main results of the 2014-2019 working program.

METHODS

The partnership leans on:

- **A joint working program** comprising 56 projects jointly defined, of which 40 studies and 16 long-term projects
- **Three committees:**
 - A steering committee (members from partners) for the day-to-day management of the studies using data from the common database
 - A monitoring committee (members from partners) for the development and the monitoring of the program
 - An independent international scientific council that gives advices on the scientific projects and methods of the program
- **Grants** partly funded by Santé publique France and INCa, dedicated to PBCR and HCL

RESULTS

In 2020, the common database contained data related to 1,670,000 patients and 1,840,000 cancers:

- Since 1975 for the oldest PBCR
 - Until 2017 (the latest validated year for most of PBCR)
 - Geocoding of cases since 2013
 - Stage at diagnosis for 8 cancers sites
- In 2021, 26 projects were achieved among 56 planned, 23 were still ongoing and 1 was postponed.

AN IMPORTANT PRODUCTION OF ROUTINE INDICATORS THANKS TO INNOVATIVE STATISTICAL DEVELOPMENTS (FIGURE)

- National estimates of incidence, mortality or survival-trends for more than 70 types and sub-types of cancers using multidimensional penalized splines
- National incidence and survival for childhood cancers based on national PBCR, and incidence and survival for adolescents and young adults cancers based on the common database

- District-level incidence estimates, including the French overseas territories, for 24 cancer types using both PBCR data and health care or mortality data

NEW ORIGINAL INDICATORS DIRECTLY RELATED TO PATIENTS' CONDITIONS AND PUBLIC HEALTH

- Conditional net survival study: probability of death returning to low values after critical periods → allowed improving access to insurance coverage of people with a prior cancer history
- Cancer incidence among employees: feasibility study through matching cases from PBCR with occupational administrative data
- Studies addressing directly screening, care pathway and quality of care, including pediatric, adolescent and young adult's cancers
- Studies addressing socio-economic disparities in cancer incidence and survival

OTHER IMPROVEMENTS

- Periodicity of the PBCR funding has evolved from a yearly basis to 5-year periods
- A dedicated visual identity of the main reports (figure); 3 partnership press conferences during the period
- Improving data quality with regular registries' seminars and updating of manuals in line with changes in classifications and reference systems

LIMITATIONS

- Delay and difficulties in accessing data sources in the context of General data protection regulation
- Expensive costs to link vital status with PBCR databases

CONCLUSIONS AND PERSPECTIVES

The 2014-2019 program achieved most of its projects. The partnership is now facing new challenges, mainly relying on data protection, combining PBCR databases with national health databases, and data sharing.

All authors declare that they have no conflicts of interest.

Figure: Main studies of the 2014-2019 French cancer working program according to their date of publication and the topic



REFERENCES:
<https://www.santepubliquefrance.fr/>
<https://geodes.santepubliquefrance.fr/>
<https://www.e-cancer.fr/>