

Evaluation and Monitoring of National Cancer Control Plans

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The role of cancer registries





National cancer control plans require surveillance and monitoring

- What is the cancer burden in the country?
- How is it likely to evolve? Where to invest?
- How successful are the implemented cancer control policies?
- Two cancer surveillance mechanisms available (and complementary):
 - For mortality: vital statistics on deaths (by cause)
 - For morbidity: disease (cancer) registers



Types of Cancer Registries

Characteritics, purposes and uses of different types of cancer registries

Registry type	Characteristics	Purpose	Can this type of registry be used in formulating cancer plans?
Hospital-based cancer registry	Collects information on all cases of cancer treated in one or more hospitals	Useful for administrative purposes and for reviewing clinical performance	NO
Pathology- based cancer registry	Collects information from one or more laboratories on histologically diagnosed cancers	Supports the need for laboratory-based services and serves as a quick "snapshot" of the cancer profile	NO
Population- based cancer registry	Systematically collects information on all reportable neoplasms occurring in a geographically defined population from multiple sources	The comparison and interpretation of population- based cancer incidence data to support population- based actions aimed at reducing the cancer burden in the community	YES

Source: Bray et al. (2014) Planning and Developing Population-Based Cancer Registration in Low- and Middle-Income Settings. IARC Technical Publication No. 43. Lyon: International Agency for Research on Cancer. Available from: http://publications.iarc.fr



What is a **PBCR**?

A Population-Based Cancer Registry (PBCR) is an ongoing surveillance system to collect, store, manage, analyse and disseminate information on the **occurrence of cancer in a defined population.**



Cancer incidence rates by type of cancer for the defined population.

Source: Piñeros et al. A Global Cancer Surveillance Framework Within Noncommunicable Disease Surveillance: Making the Case for Population-Based Cancer Registries. Epidemiol Rev. 2017 Jan 1;39(1):161-169



Role of PBCR in Cancer Surveillance

Population-Based Cancer Registry (PBCR)

Cancer Control Measures

Basic



Source: Piñeros et al. A Global Cancer Surveillance Framework Within Noncommunicable Disease Surveillance: Making the Case for Population-Based Cancer Registries. Epidemiol Rev. 2017 Jan 1;39(1):161-169

Associated economic costs



Surveillance for cancer control



Different stakeholders involved in data production & data use for cancer control

Adapted from: Remington P. In: Lee et al. Principles and Practice of Public Health Surveillance; Oxford 2010.

PBCR data and Primary prevention



- Swedish National Cancer Register
- National Vaccination Register

Lei J, Ploner A, Elfström et al. <u>HPV Vaccination and the</u> <u>Risk of Invasive Cervical Cancer.</u> Engl J Med. 2020 Oct 1;383(14):1340-1348. doi: 10.1056/NEJMoa1917338

PBCR and primary prevention



*Age-adjusted to 2000 US standard population.

Source: Death rates: US Mortality Data, 1960-2006, US Mortality Volumes, 1930-1959, National Center for Health Statistics, Centers for Disease Control and Prevention, 2009. Cigarette consumption: US Department of Agriculture, 1900-2007.

PBCR to monitor screening programmes

Main criteria to monitor and evaluate screening programmes are

1. Outcome measures

- Changes in mortality
- Changes in the incidence rate of advanced disease, termed stage migration

2. Performance indicators (quality control)

- Rate of interval cancers: cancers diagnosed between screening episodes
- Prevalence rate at first screen
- Expected incidence



PBCR in evaluating and monitoring screening programmes – Outcomes (1) Breast cancer incidence rates and implementation of

mammography screening in Germany 2003-2014



Changes in invasive carcinoma vs in situ

Changes in stage



Information from 16 Federal State PBCR



Surveillance and cancer control planning, monitoring and evaluation: integration

- Cancer registry advisory committee
 - Multidisciplinary, focus on use of data to inform NCCP
- Linkage with national cancer control committee / plans
 - Joint appointments of members, regular communication
- Reporting and dissemination
 - Consider different formats targeting audience, use of knowledge translation methods for engagement
- Development of targets and indicators
 - May require specific data collection outside of the registry



Thank you!

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