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POPULATION-BASED CANCER REGISTRIES AND RISK FACTOR SURVEILLANCE

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A. INTRODUCTION

Surveillance refers to any ongoing systematic collection, analysis, interpretation and dissemination of data for use in public health action to reduce mortality and morbidity.[1] Surveillance systems enable governments and organizations to set and measure progress towards targets for health improvement.[2]

Historically, disease surveillance referred to monitoring and tracking cases of infectious disease to contain spread. In recent decades, surveillance for non-communicable diseases (NCD) has grown in importance, given that these diseases are growing causes of mortality worldwide. In 2000, the World Health Assembly's *Global Strategy for the Prevention and Control of NCDs* included three components, one of which was the use of surveillance to track and monitor the major risk factors for NCDs.[3] In 2008, the World Health Organization's *Action Plan for the Global Strategy* asked member states to commit to developing surveillance and monitoring systems that produce, at a minimum, high-quality mortality statistics and standardized data on NCDs, key risk factors and behavioural patterns.[4] In 2011, the United Nations High Level Meeting on Non-Communicable Disease reiterated the commitment to strengthen surveillance by building and expanding effective NCD surveillance systems as an integral component of the fight against NCDs.

Planning and providing effective and efficient cancer control services requires a thorough understanding of a population's current and predicted future burden of cancer, and its cancer risk factors. Chronic disease surveillance systems can focus on assessing the extent of disease in the population, the prevalence of risk factors for disease in the population, or both.

Data on the extent of cancer in the population are collected through centralized, population-based cancer registries. These include information on the number, characteristics and status of people who have a cancer diagnosis. This information can be used to determine the burden of disease in a population, such as cancer incidence, prevalence and mortality.

Data on risk factors for cancer in the population are commonly collected through population-wide surveys. This surveillance information can be used to predict the future burden of disease, inform targets for cancer prevention strategies and monitor progress toward those targets.

This chapter defines and describes the main features of population-based cancer registries and risk factor surveillance systems.

B. POPULATION-BASED CANCER REGISTRIES

A population-based cancer registry is a system that collects, codes and classifies information about all cancers diagnosed within a defined catchment area (e.g., country, province or state, region). A hospital-based registry conducts the same activities, but focuses on patients diagnosed or treated for cancer in one or a few facilities. See the *Cancerpedia: Hospital Registry* chapter for more information.

Historically, population-based cancer registries produced data on cancer incidence and mortality in a population.[5] With the evolution of computer-based systems, the capacity of these registries to collect and code more information and link to other data sources has increased. A population-based registry is the best, and perhaps only, tool to quantify the burden of cancer within a population and is essential to any national cancer control strategy.[6,7]

Population-based cancer registries provide a framework for assessing and controlling the impact of cancer on the community. This rich repository of information is valued across the cancer control continuum, from prevention to treatment, and from healthcare planning to evaluation. Registries play a key role in developing and modifying public health policies. Their information is used for planning and defining cancer control and prevention services and priorities, evaluating screening programs, assessing the quality of care, studying the etiological aspects of cancer (i.e., the factors that produce or predispose individuals to get cancer), and conducting population-based research.

1. DEVELOPMENT

Globally, there is wide variability in the populations covered by cancer registries. In 2007, 83 per cent of the North American population was covered by a population-based cancer registry, compared to only six per cent of South America's population and one per cent of Africa's population.[8] Resources and education have increased to address this discrepancy and enable countries to build new or improve existing registries.

Two international organizations that help to facilitate the development and improvement of quality registries include the following:

- The International Agency for Research on Cancer (IARC) provides resources and support for registry improvement and development, including the especially valuable publication *Cancer Registration: Principles and Methods.*[9]
- The International Association of Cancer Registries (IACR) fosters the exchange of information between cancer registries internationally, thereby helping to improve data quality and comparability between registries.[10]

Both organizations collaborated to produce CanReg, a free program that includes software for collecting, validating, cleaning and analyzing cancer data.[11]

The basic elements that need to be considered when developing a new cancer registry include: determining which cases get registered; selecting the data elements to be collected for each case; and identifying data sources.

Determining Eligible Cases for Registration

Jurisdictions must determine what constitutes an eligible cancer case for registration in the population-based cancer registry. Eligible cases typically include all malignant tumours identified through symptomatic diagnosis, screening and sometimes autopsy within the defined population or catchment area. There are some typical exceptions; for example, most registries exclude non-melanoma skin cancers and include some benign tumours (i.e., intracranial cancers) and/or carcinoma in situ that are detected during screening.[5]

Selecting Data Elements

In the early stages of setting up a population-based cancer registry, a few basic data elements may be selected; these elements may be expanded as the quality of existing elements has been ensured.[6] Table 1 presents a list of essential and recommended data elements to be included in routine data collection for population-based cancer registries.

Table 1: Essential and Recommended Data Elements Recorded by Population-Based Cancer Registries[5]

Essential	Recommended
- Personal identification (names in full and/or unique personal identification numbers) - Sex - Date of birth or age - Address (i.e., usual residence) - Ethnic group (when the population consists of two or more groups) - Incidence date - Most valid basis of diagnosis (enables cases to be registered with a non-histological diagnosis) - Topography (site) of primary cancer - Tumour morphology (histology) - Tumour behaviour (i.e., benign, uncertain, in situ or malignant) - Source of information	- Date of last contact - Status at last contact (i.e., at least dead or alive) - Stage or extent of disease at diagnosis - Initial treatment

Demographic information is essential to ensure that a single case is registered only once, and to produce descriptive statistics. This information is not only necessary for cancer cases, but also for the broader population covered by the cancer registry. Population data provides the denominators required to calculate population-based statistics. It is advisable to select a registry catchment area that overlays with an administrative region that collects reliable vital statistics.

It may be challenging to register and collect demographic information on everyone with cancer because of increasingly strict legislation on collecting medical information. It has proven impossible to establish, maintain and use population registries while meeting the principles of informed consent. As a result, exceptions to these principles have been supported and applied in several jurisdictions, including North America (i.e., Canada and the United States), Japan and the European Union.[5]

Identifying Data Sources

To function effectively and produce valid statistics, a population-based cancer registry relies on data from a variety of sources. These include reports from physicians, radiology services, surgical services, laboratory medicine and pathology services, haematology and cytology laboratories, hospital admissions and discharge departments, and so on.

2. DATA QUALITY

A successful registry requires that strict data quality standards be implemented, monitored and evaluated for compliance. There are four major aspects of data quality in cancer registries: comparability, validity, timeliness and completeness.[12,13] Unless otherwise noted, the description of these aspects presented below reflect the work of.[14]

Comparability is the extent to which coding and classification procedures, definitions, recording and reporting of data elements are consistent within the registry and between registries. With regard to procedures, consistency within the registry permits historical comparisons and surveillance of trends over time. Consistency between registries – achieved with the use of international guidelines – permits valid comparisons between regions covered by different cancer registries. Threats to comparability may occur because of: i) the definition of an incident case; ii) the distinction between a primary cancer and an extension, recurrence or metastasis of an existing cancer; iii) the coding and classifying of data elements to describe the neoplasm; and iv) the coding of cancers detected in asymptomatic individuals (e.g., detected upon screening or by autopsy).

Adherence to international standards and guidelines can help address threats to data comparability. Examples of organizations that provide international standards and guidelines include:

- The International Classification of Diseases for Oncology provides standards for the coding of tumour topography (i.e., anatomical location), morphology (i.e., microscopic appearance), behaviour, grade and basis of diagnosis.[15]
- The European Network of Cancer Registries provides guidelines for defining an incident case and recommends a data field for "method of detection", which allows registries to determine the extent to which cancers detected by screening influence incidence rates and estimate the rate of interval cancers.[16]
- IARC and the Surveillance, Epidemiology and End Results (SEER) Program of the National Cancer Institute each have guidelines for registering first- and higher-order malignancies.[17]
- The North American Association of Central Cancer Registries (NAACCR) develops and promotes uniform data standards for cancer registration, and provides education and training to help meet those standards.[18]

Validity – which means an indicator actually measures what it claims to measure – depends on the precision of source documents and the level of expertise exercised in abstracting, coding and recoding cases. Methods to ensure validity include: i) re-abstracting and recoding; ii) determining the proportion of cases histologically verified; iii) analyzing missing information; and iv) checking internal consistency.

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Timeliness is the rapidity with which a registry can collect, process and report sufficiently reliable and complete cancer data.

Completeness is the extent to which all eligible cancer cases occurring in the population are included in the registry. Maximum completeness is necessary to generate statistics, such as incidence and survival, that are close to their true values. Both qualitative and quantitative methods are used to determine completeness; qualitative methods can indicate the degree of completeness relative to other registries over time, and quantitative methods can provide a numerical evaluation of completeness.

Countries or regions with limited health infrastructure, financial resources and/or experience with cancer and health information systems are likely to encounter data quality challenges when setting up a cancer registry. For example, reliable population data is needed to estimate population size and rates of cancer, and a death notification system is needed to track diagnosed cases and estimate mortality. As well, completeness of the registry will be compromised and the burden of cancer will be underestimated if individuals with cancer never reach the healthcare system due to issues of access and availability of services. For a discussion of quality issues in cancer registries in low-resource settings, see *Cancer registration in developing countries: luxury or necessity?*[6]

3. DATA LINKAGES

The value and usefulness of a population-based cancer registry increases exponentially when it is linked with other sources of demographic, clinical and treatment-related data. Benefits of data linkages include the following:

- Clinical questions can be explored using fewer resources than prospective trials.
- Jurisdictions that have integrated delivery or single-payer systems can track an individual's encounters with the healthcare system using claims data, enabling researchers to follow cancer patients prospectively from their diagnosis to monitor long-term outcomes or retrospectively to examine the care received leading up to their diagnosis.[19]
- Rich information for etiological studies of the effect of income, urban-rural status and immigration on cancer incidence and survival is available where there are linkages between the cancer registry and neighbourhood-level demographic data.
- Research is supported when the registry is linked to national census data, cohort studies and financial information through tax filings.

In the United Kingdom, the Electronic Patient-reported Outcomes for Cancer Survivors (ePOCS) system collects data about the cancer experience following diagnosis. Research nurses recruit patients in hospital, who are invited to take part regularly in web-based surveys following their diagnosis. The survey information is subsequently linked to the cancer registry to study factors associated with improved outcomes from the patient's perspective.[20]

Biobanks – which store biological specimens, including tissue samples taken by a biopsy or during surgery and cytological samples collected during cervical screening – are increasingly being linked to cancer registries. Linking biological data stored in biobanks to registry information on disease, treatment and survival allows a vast number of questions to be explored about the biological mechanisms of, and predispositions to, cancer.[21]

In the United States, the SEER database has been linked to Medicare and Medicaid, and the Cancer Research Network has linked cancer registries to the enrollee populations of 14 integrated health systems.[22, 23,8] International examples of linkages between cancer registries and administrative health databases – particularly those capable of providing post-approval surveillance of anti-cancer drugs – can be found in.[24]

C. RISK FACTOR SURVEILLANCE SYSTEMS

Risk factor surveillance systems are a necessary component of a comprehensive cancer control program. These systems collect information on the type and level of cancer risks in the population. For example, lifestyle-related factors – such as diet, physical activity, alcohol consumption and tobacco use – contribute significantly to the risk of cancer. Since risk factors are similar for many non-communicable diseases, risk factor surveillance programs present an opportunity to collaborate with and share resources between several chronic disease programs and stakeholders. See the *Cancerpedia: Primary Prevention* chapter for more information.

Surveillance information is used to plan, implement and evaluate interventions to prevent cancer.[25] Although it may take several years for a prevention initiative to help reduce cancer incidence (i.e., because of the long latency of cancer), risk factor surveillance can monitor – in a relatively short period of time – the impact of the initiative on behavior.

4. POPULATION-BASED SURVEYS

Population-based surveys are the most common method for monitoring the prevalence of risk factors in the population.

The Behavioral Risk Factor Surveillance System (BRFSS) in the United States is the most widely known system in North America and Europe. The BRFSS is a system of telephone surveys that collects data from United States residents on their health-related risk behaviours, chronic health conditions and use of preventive services. The BRFSS completes more than 400,000 adult interviews each year, making it the largest continuously conducted health survey system in the world. Since it began in 1984, several countries have modelled their surveys on the BRFSS model.[26,27]

The World Health Organization's STEPwise approach to Surveillance (STEPS) provides standardized questions and protocols for risk factor surveillance in member countries. The system is targeted at lower- and middle-resource settings, encourages the collection of small amounts of useful information on a regular and continuing basis, and offers a simple and standardized method for collecting, analyzing and disseminating data related to the prevalence of chronic disease risk factors in adults.

When beginning to plan a population-based health survey, it is advisable to use the BRFSS or STEPS model for efficiencies, and to ensure comparability between surveys for international benchmarking. Both models have extensive publicly-available resources on their websites.[26,28]

5. SURVEY CONSIDERATIONS

This section uses the BRFSS and STEPS as examples to illustrate survey considerations that include: governance and scale; content; methodological challenges; and the accessibility and timeliness of data collection.

Governance and Scale

The governance and scale (i.e., sample size) of a population health survey should reflect the structure of healthcare and public health service delivery in the population.

A geographic unit for the survey must first be determined. Aligning the level of information production to the level of information use increases the likelihood of buy-in from public health units and other potential data users, and the likelihood that the content will be relevant to the needs of the population.[29]

The sample size of the survey must be sufficiently representative to estimate prevalence on the same scale that health services are planned and delivered; for example, if health services are provided at a subnational level, a national surveillance survey may only be as useful as its ability to provide regional/state/provincial-specific data. To illustrate, Statistics Canada centrally administers the Canadian Community Health Survey, which is designed to have sufficient sample sizes to tabulate the prevalence of any given factor in each of the 115 health regions of Canada.[30]

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Resources are available to guide survey development efforts at the subnational level and increase efficiencies and comparability. For example:

- In the United States, the BRFSS has a centralized office at the Centers for Disease Control and Prevention, responsible for determining the core content of surveys and providing training and support for smaller jurisdictions (i.e., state health departments) that administer the survey to their constituents.[26,27]
- Italy recently adopted the BRFSS model, and a national co-ordinating group provides leadership to health regions collecting data within their respective areas.[29]

Content

The content of population health surveys varies, based on available resources and the needs of the jurisdiction conducting the survey. Most surveys include a combination of core and optional modules. *Core modules* are constant across time and geography (i.e., asked in every jurisdiction conducting the survey), and include data elements deemed to be most important. Core content in the BRFSS includes the following.[26]

- Health status
- Health-related quality of life
- Healthcare access
- Hypertension awareness
- Cholesterol awareness
- Chronic health conditions
- Tobacco use
- Fruits and vegetables
- Exercise
- Disability
- Arthritis burden
- Seatbelt use
- Immunization
- Alcohol consumption
- HIV/AIDS
- Demographics

Core content in the STEPS system includes basic demographic information, tobacco use, alcohol consumption, fruit and vegetable consumption and physical activity.[28]

Optional modules are identified, supported and developed by the central agency responsible for the survey, but can also be adopted by a jurisdiction at its discretion based on available resources and needs. The BRFSS offers more than 30 optional modules, including the following:[26]

- Pre-diabetes
- Diabetes
- Sugar-sweetened beverages and menu labelling
- Preconception health and family planning
- Visual impairment and access to eye care
- Inadequate sleep
- High-risk/healthcare worker
- Cardiovascular health
- Actions to control high blood pressure
- Heart attack and stroke
- Cancer screening
- Smoking cessation

Optional modules in the STEPS system include mental health, violence, intentional and unintentional injury, and oral health.[28]

The content of core and optional modules can be fixed (i.e., unchanged and asked every year) or rotating (i.e., asked at regular intervals). For example, the Canadian Community Health Survey rotates some content by conducting focused surveys on specific topics every three years.[30] This supports comparability and enables trends to be monitored over time.

Structures are needed to introduce new questions that reflect emerging health issues. In the BRFSS, an expert panel meets biannually to identify new survey questions and to assess the usefulness of previously added questions, to decide if they should be fixed or rotating.[27]

Methodological Challenges

Typical challenges related to survey methodologies include minimizing non-response, achieving sufficient coverage of the target population, maintaining data quality and attaining a sufficient sample size.[29,31] Well-established population-based surveys, such as the BRFSS, have adapted their design over time to address new challenges, including demographic, cultural and technological shifts.

Increasing population diversity usually presents language issues and barriers, and challenges related to ensuring the presence of relevant and valid survey content for all cultural groups; for example, food frequency questionnaires may not include foods frequently consumed by certain cultural groups.[26] Cultural shifts have changed societal behaviours and attitudes toward privacy, resulting in declining survey response rates. As for technological shifts, population-based surveys have traditionally been administered by telephone. The increasing move from landlines to mobile phones means that telephone numbers are no longer linked to a specific geographic area. As well, there may be several phone numbers per household, which poses challenges for surveys that rely on random digit dialing.

The method of data collection (e.g., telephone, face-to-face, web-based, mail) affects the extent to which a survey can successfully adapt to challenges. Pilot studies conducted by BRFSS indicate that sending letters before calling to conduct a survey increases response rates, whereas leaving scripted voicemail messages does not.[27] In fact, mailing out letters prior to calling was cost-efficient, since the costs to achieve a targeted number of surveys was lower with mailing than the cost without advanced letters.[27] In Italy, a mailed letter followed by up to six phone attempts achieved a response rate of 82 per cent.[29] In the United States, mailed surveys, rather than telephone surveys, increased response rates, but only in states that initially had a response rate of less than 40 per cent.[27]

The STEPS survey system uses in-person interviewing. This method may be preferable when telephone numbers or addresses are not available or do not provide an adequate sampling frame for the population (e.g., where mobile phones predominate). Face-to-face interviewing also provides an opportunity to collect physical measurements from respondents.[28] The STEPS program includes physical measurements. As well, the United States National Health and Nutrition Examination Survey (NHANES) surveys 7,000 people annually in their homes and invites them for more intensive physical examinations in mobile vans.[31] The advantages of collecting physical measurement data in-person must be weighed against the additional resources required to collect this information.

The difference in response rates due to different methods of data collection in different settings highlights the fact that there is no one-size-fits-all approach to population-based surveys. The appropriateness of the method depends on its suitability and feasibility within each unique setting.

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Accessibility and Timeliness of Data Collection

Collected data is only useful if it is accessible in a timely fashion to those who want and need to use it. Survey design must consider the optimal frequency and schedule of data collection and release to researchers and/or the public. The Canadian Community Health Survey, for example, collects data continually and produces a combined data file every two years, which includes data collected over the previous two years.[30] Italy's program, which is modelled after the BRFSS, collects from health units and uploads anonymized data to a central database monthly.[29]

A user-friendly and accessible data set is more likely to be used to the benefit of the public. The BRFSS website provides easy access to documentation and data for its surveys dating back to 1984. Their online Web-Enabled Analysis Tool allows users to generate frequencies, cross-tabulations, stratified analyses and simple logistic regression models without exporting data or using complex statistical analysis software.[27] The openness of the data adds value to the survey by allowing outside researchers to ask questions of interest and determine the answers.

D. INFRASTRUCTURE

An effective infrastructure is needed to support population-based cancer registries and risk factor surveillance systems at all levels. This infrastructure includes human resources, information systems and physical facilities.

In terms of *human resources*, population-based cancer registries and risk factor surveillance systems require oversight and support by professionals with simple statistical skills, at a minimum. Many jurisdictions benefit from additional expertise in: longitudinal population studies; etiological factors; disease progression and modelling; the risk and protective factors spanning the environmental, nutritional, behavioral, occupational, metabolic and genetic correlates of disease; and big data management and harmonization.

In terms of *information systems*, systems are needed to both capture data direct from source (e.g., for risk factor surveys) and to integrate data from multiple sources (e.g., national census data, cohort studies, biobanks). Information systems are also needed to make data accessible to researchers and/or the public. A secure physical network and operations architecture must be developed to control secure access. In addition, a secure and highly-regulated interface (i.e., firewall) between internal systems and external internet systems is imperative.

Information systems must be supported by *physical facilities and equipment* that enable the collection and safe storage of data, such as secure offices, computers and servers.

E. THE FUTURE

The popularity of wearable technology has brought new possibilities for population-based information collection and surveillance. Products such as cellular phones, digital watches and other wearable devices now support the tracking of many health-related behaviours and other factors at an individual level, such as diet, activity, sleep, heart rate and other physiological measures.

Moving forward, the integration of this data into population-based health registries and risk factor surveillance systems may be beneficial; however, data quality will be a significant consideration.

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