

Chapter 3

Monitoring NCDs and their risk factors: a framework for surveillance

Noncommunicable disease surveillance is the ongoing systematic collection and analysis of data to provide appropriate information regarding a country's NCD disease burden, the population groups at risk, estimates of NCD mortality, morbidity, risk factors and determinants, coupled with the ability to track health outcomes and risk factor trends over time. Surveillance is critical to providing the information needed for policy and programme development and appropriate legislation for NCD prevention and control, and to support the monitoring and evaluation of the progress made in implementing policies and programmes.

Accurate data from countries are vital to reversing the global rise in death and disability from NCDs. Currently, many countries have little usable mortality data and weak NCD surveillance (1). Data on NCDs are often not integrated into national health information systems. Improving country-level surveillance and monitoring must be a top priority in the fight against NCDs.

The 2008–2013 Action Plan for the Global Strategy for the Prevention and Control of Noncommunicable Diseases (2) recommends critical actions for Member States to strengthen surveillance and standardize data collection on NCD risk factors, disease incidence and cause-specific mortality. The plan also calls on Member States to contribute, on a routine basis, data and information on trends related to NCDs and their risk factors stratified by age, sex and socioeconomic group, and to provide information on progress made in implementation of national strategies and plans.

NCD surveillance systems need to be integrated into existing national health information systems. This is all the more important where resources are limited. Table 1 provides a framework for a national NCD surveillance scheme. Three major components of NCD surveillance are: a) monitoring exposures (risk factors); b) monitoring outcomes (morbidity and disease-specific mortality); and c) assessing health system capacity and response, which also includes national capacity to prevent NCDs (in terms of policies and plans, infrastructure, human resources and access to essential health care including medicines). Monitoring NCDs in relation to this framework is discussed further in this chapter. A list of core indicators for consideration to be used with the framework above is provided in Annex 5.

Table 1. Framework for national NCD surveillance

Exposures	Behavioural risk factors: <i>tobacco use, physical inactivity, the harmful use of alcohol and unhealthy diet.</i>
	Physiological and metabolic risk factors: <i>raised blood pressure, overweight/obesity, raised blood glucose, and raised cholesterol.</i>
	Social determinants: <i>educational level, household income, and access to health care.</i>
Outcomes	Mortality: <i>NCD-specific mortality.</i>
	Morbidity: <i>Cancer incidence and type (as core).</i>
Health system capacity and response	Interventions and health system capacity: <i>infrastructure, policies and plans, access to key health-care interventions and treatments, and partnerships.</i>

Source: (3)

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Monitoring exposures: risk factor surveillance

Monitoring of risk factors at the population level (or in a subset of the population) has been the mainstay of national NCD surveillance in most countries. Taking an incremental approach, the first phase of surveillance in many low- and middle-income countries should be based on their priority information needs for policy and programme development, implementation and evaluation. Surveillance activities in low-resource settings should place the highest priority on national needs and the Global Strategy Action Plan's emphasis on population exposures to risk factors.

Data on behavioural and metabolic risk factors are typically obtained from national health interview or health examination surveys, either addressing a specific topic (e.g. tobacco) or multiple factors. Data on social determinants, which can then be used to further understand risk factor patterns, are also typically obtained from these sources.

In this context, the WHO STEPS approach (4) to NCD risk factor surveillance is a good example of an integrated and phased approach that has been used and tested by many countries. It allows countries to develop a comprehensive risk profile of their national populations. Information on sociodemographic factors and behavioural risk factors is collected through self-reporting. Physical measurements of height and weight for body mass index (BMI), waist circumference and blood pressure are made, and biochemical measurements are obtained for fasting blood glucose and total cholesterol levels.

The principles of STEPS risk factor surveillance are repeated in cross-sectional, population-based household surveys. STEPS promotes the concept that surveillance systems require standardized data collection but with sufficient flexibility to be appropriate in a variety of country situations and settings.

A good example of a topic-specific risk factor survey is the Global Adult Tobacco Survey (GATS) (5), which captures additional information on knowledge, attitudes and perceptions surrounding the health effects of tobacco use and exposure, advertising, promoting and economics of tobacco use, as well as information on cessation activities.

Any survey that includes the collection of blood samples can also be used to monitor trends in the prevalence of cancer-associated infections, notably HBV, HCV, and HIV.

In many countries, key surveillance activities related to exposures, such as surveys, only take place as one-time events that may be conducted by different agencies or external experts, and without adequate coordination with the national health information system. If this is the case, surveillance does not become institutionalized as a vital public health function and builds little or no sustained country capacity. A significant acceleration in financial and technical support is necessary for health information system development in low- and middle-income countries if global health priorities and goals are to be achieved.

Monitoring outcomes: mortality and morbidity

An accurate measure of adult mortality is one of the most informative ways to measure the extent of the NCD epidemic and to plan and target effective programmes for NCD control. All-cause and cause-specific death rates, particularly premature deaths before age 60 or 70, are key NCD indicators. High-quality mortality data can only be generated by long-term investment in civil registration systems (6).

Registering every death is a key first step. Accurate reporting of the cause of death on the death certificate is a challenge, even in high-income countries. Death registration by cause is neither accurate nor complete in a large proportion of countries. From a global perspective, there has been only limited improvement in the registration of births and deaths over the past 50 years (7). Ascertaining all deaths and their cause on a country level is a critical requirement. Only about two thirds of countries have vital registration systems that capture the total number of deaths reasonably well (6). Although total all-cause mortality may be reported, significant accuracy problems exist in many countries with cause-specific certification and coding. National initiatives to strengthen vital registration systems, and cause-specific mortality statistics, are a key priority.

In the meantime, where cause-specific mortality data are not available or inadequate from a coverage and/or quality perspective, countries should establish interim measures such as verbal autopsy for cause of death, pending improvements in their vital registration systems (8).

As mentioned in Chapter 1, reliable data on NCD morbidity are scarce in many countries. Accurate information on morbidity is important for policy and programme development. This is particularly the case for cancer where data on the incidence and type of cancer are essential for planning cancer control programmes. The diversity of cancer types in different countries highlights the need for cancer control activities to fully consider cancer patterns and available resources, given that different cancers may be variably amenable to primary prevention, early detection, screening and treatment. In lower-resource settings, hospital-based registries can be an important step towards the establishment of population-based cancer registries (PBCR), but it is only the latter that provide an unbiased description of the cancer patterns and trends in defined catchment populations. A PBCR is therefore a core component of the national cancer control strategy and programme (9). PBCRs collect and classify information on all new cases of cancer in a defined population, providing incidence and survival statistics for the purposes of assessing and controlling the impact of cancer in the community (10, 11). Despite their overwhelming need, there remains a notable lack of high-quality PBCRs in Africa, Asia and Latin America, with approximately 1%, 4% and 6% of the populations of these respective regions being monitored (12).

Monitoring health system response and country capacity

Assessing individual country capacity and health-system responses to address NCD prevention and control in a comprehensive manner, and measuring their progress over time, are major components of the reporting requirements stated in Objective 6 of the Global Strategy Action Plan. To monitor country capacity to respond to NCDs, WHO has conducted periodic assessments of the major components of national capacity in all Member States. This was carried out in 2000–2001, following the endorsement of the *Global Strategy for the Prevention and Control of Noncommunicable Diseases* (13), and again in 2009–2010. A further assessment is planned for 2013.

The capacity assessments examined the public health infrastructure available to deal with NCDs; the status of NCD-relevant policies, strategies, action plans and programmes; the existence of health information systems, surveillance activities and surveys; access to essential health-care services including early detection, treatment and care for NCDs; and the existence of partnerships and collaborations related to NCD prevention and control.

A number of countries also monitor activities in tackling risk factors such as tobacco, harmful alcohol use and obesity. WHO supports this process, for example by conducting regular reviews of tobacco demand reduction policy measures (14), and the status of policies and programmes to address harmful use of alcohol (15).

Opportunities for enhancement

The dearth of reliable information and capacity, which includes important gaps in surveillance data, is a major challenge to NCD prevention and control in many countries. Tracking NCDs and their risk factors and determinants is one of the three key components of the *Global Strategy for the Prevention and Control of Noncommunicable Diseases*. Strengthening surveillance is a priority for every country. There is an urgent and pressing need for concerted efforts to improve the coverage and quality of mortality data, to conduct regular risk factors surveys at a national scale with standardized methods, and to regularly assess national capacity to prevent and control NCDs.

This chapter outlines a framework for monitoring of NCDs and reviewing the mortality burden, as well as the capacity of countries to respond to them. While technical, human, and fiscal resource constraints are major impediments in some countries, with judicious use of scarce resources and capacity building, the surveillance framework can be implemented in all countries. Such a framework is essential for policy development and assessment and for monitoring of trends in population behaviours and disease. The adoption and use of a standardized core set of indicators is of crucial importance for national and global monitoring of NCD trends.

Numerous recommendations have been made to improve country capacity for the development and maintenance of health information systems, and many are clearly applicable to NCDs. A permanent infrastructure for surveillance activities is required. Data collection can be organized in several ways, but an institution or a network with the relevant expertise is needed to guarantee the sustainability and quality of surveillance over time. However, knowing what to do is not the only obstacle; lack of experience in establishing health information systems, and obtaining the necessary resources, also remain key challenges.

Key messages

- Current capacities for NCD surveillance are inadequate in many countries and urgently require strengthening.
- High quality NCD risk factor surveillance is possible even in low-resource countries and settings.
- A surveillance framework that monitors exposures (risk factors and determinants), outcomes (morbidity and mortality) and health-system responses (interventions and capacity) is essential. A common set of core indicators is needed for each component of the framework.
- Cancer morbidity data are essential for planning and monitoring cancer control initiatives. Population-based cancer registries play a central role in cancer control programmes because they provide the means to plan, monitor and evaluate the impact of specific interventions in targeted populations.
- Sustainable NCD surveillance systems need to be integrated into national health information systems and supported with adequate resources.

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