

4 Surveillance of NCDs and their risk factors

Principles

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Noncommunicable disease surveillance is the ongoing systematic collection, analysis, interpretation and dissemination of data to provide appropriate information regarding a country's NCD disease burden, including the main causes of NCD mortality, the population groups at risk, morbidity, risk factors and determinants, coupled with the ability to track NCD-related health outcomes and risk factor trends over time. NCD surveillance is essential to support the planning, implementation and evaluation of NCD prevention and control efforts, particularly when it is closely integrated with the timely dissemination of these data to those who need to know and act.

Surveillance and monitoring of NCDs enables patterns of health and disease to be monitored in populations over time, which ensures the most relevant public health and healthcare interventions can be prioritized, and then the impact of these interventions to be measured. Surveillance therefore empowers decision-makers to act more effectively by providing timely and useful evidence ('data for action', 'what gets measured gets done') and to advocate for the necessary resource for action.

Despite the importance of surveillance and monitoring, these activities are often not prioritized and sufficiently resourced. Accurate data from countries is vital to reverse the global rise in death and disability from NCDs. Currently, many countries have little useable mortality data and weak NCD surveillance. Surveillance is a core component of the health system, and it needs to be prioritized as such. Data on NCDs need to be well integrated into national health information systems, including routine capture of patient health information status as part of patient management systems. Improving country-level surveillance and monitoring continues to be a top priority in the fight against NCDs.

A surveillance framework that comprehensively monitors exposures (risk factors and determinants), outcomes (morbidity and mortality) and health system responses (interventions and capacity) is essential. Ideally, surveillance should work towards capturing an agreed set of standardized indicators on these components, using methods that are as practical, uniform and simple to implement as possible, yet valid and accurate.

This chapter focuses on the principles of surveillance for NCDs, including mortality, morbidity and the prevalence of risk factors. Many of the principles

are also relevant for generating information on the public health response to NCDs over time (e.g. national policies, plans of action, guidelines, health system responses).

Surveillance enables policymakers to know the frequency and distribution of NCDs, risk factors and associated characteristics in their population in order to monitor and inform prevention and control programmes and policy. Information on current levels of NCD risk factors in the population also enables a prediction to be made on the NCD burden in the future and is important for planning services and interventions given the often long interval between current levels of risk factors and the occurrence of ill health (e.g. heart attack, stroke, cancer).

WHO recommends that their Member States have systems in place for generating reliable cause-specific mortality data on a routine basis, a comprehensive set of measures of NCD service quality and availability and for tracking clinical health outcomes for the facility-based patient and programme monitoring of NCDs and that a suitable survey to assess NCD risk factors is done every five years.¹ The results of these population-based surveys are essential for countries to report against the WHO Global NCD Accountability Framework (Chapter 35).

Key issues

Engage stakeholders. To ensure that the results from surveillance activities are used to support the development of policy and programming, it is important that key stakeholders (including community leaders) are involved in the full process, from design to the dissemination of results. It is better to collect small amounts of valid and useful data than collect larger amounts of information that may be less reliable or of limited use.

Ensure robust governance. It is imperative that when data are being collected, systems are in place to ensure participant confidentiality and information governance, with agreement on how aggregated and disaggregated data will be used.

Ensure enumerators (data collectors) are well-trained. Investing in the training of those conducting surveys or those recording patient status is critical to ensure that they understand the importance of collecting high-quality data.²

Collect only those data that will be used. Ensuring clarity on the purpose of each data item that is being collected is important in order not to waste resources associated with the collection, storage, analysis and dissemination. Data obtained must be properly summarized and aggregated, along with a description of the main findings and the implications for relevant authorities, in a timely manner.

Ensure a high level of participation. Nonresponse (both through the inability to make contact with survey participants or individuals that refuse to participate) has the effect of reducing the sample size from that required to draw

meaningful results and increases the risk of bias as nonrespondents (e.g. those with illness or marginalized groups) may differ from respondents in terms of characteristics measured.

Collect sufficient data to allow for disaggregation. Accurate prevalence surveys based on random sampling require a relatively small number of participants, often as little as a few thousands, even in large countries. Nevertheless, it is important that data obtained from such surveys can allow for disaggregation by socio-demographic variables when this is important for understanding the epidemiology and designing NCD prevention and control programmes and policy. These variables include age, gender, urban-rural divide, occupation and socioeconomic status.³

Disseminate findings. Publishing the results of population-based surveys and aggregated data from patient and facility-based monitoring and civil and vital registration systems in the peer-review literature is an important way of increasing access to the work and provides a further layer of quality control.

- *Total numbers* for overall incidence (including mortality) and overall prevalence (i.e. the total number of people with certain risk factors) inform on the needs in terms of use of health services (e.g. numbers needed to be treated and volume of services needed to treat them). The total numbers of people with NCDs or with risk factors inevitably (which are generally strongly associated with age) significantly increase over time in most populations as the mean age and the size of most populations increase over time (i.e. demographic transition), even if the risk of a NCD or the age-standardized prevalence of a risk factor is decreasing over time.
- *Rates* provide a measure of the frequency with which an event occurs in a defined population either over a specified period or at one point in time. Rates can be used to describe either new cases of (or deaths from) a particular NCD (incidence) or existing cases of a particular NCD or risk factor (prevalence). Given that NCDs and most risk factors are strongly associated with age: age-standardized rates (i.e. rates that have been weighted to a same standard age distribution)⁴ are particularly useful as they can be directly compared over time in the same population or between populations and inform about disease risk in the population irrespective of age and size of the population.

Assessing NCD mortality and morbidity in the population

Assessing NCD mortality requires accurate information on the number and distribution of deaths – including causes of death, usually obtained from well-functioning civil and vital registration systems where the entire population is covered and the system generates reliable, continuous and timely data on age-and-cause-specific mortality. Monitoring NCD mortality can only be achieved with reliable vital registration systems that count all deaths and reliably certify their causes. National initiatives to strengthen vital registration systems

and cause-specific mortality are a key priority for many countries. Physicians must be trained on the importance of completing death certificates. In settings where many deaths are not attended by a physician, alternate methods, such as verbal autopsy, may be used to complement data collected from death certificates. The global goal of high-quality mortality data will require long-term investment in civil registration.

Assessing NCD morbidity also requires robust health information systems capable of tracking the number and characteristics of those who are screened, diagnosed and treated for an NCD. Good systems should routinely collect, aggregate, analyze and report data on key NCDs including cancer, diabetes, cardiovascular disease and chronic respiratory diseases, among others. The use of a set of standardized indicators capable of tracking the cascade of screening, diagnosis, treatment and control is important for improving NCD programme responsiveness and effectiveness and for planning future service capacity. This helps health care providers, facility managers, Ministry of Health staff and their partners to better plan, target, tailor and scale interventions; assess whether programmes are being implemented with quality; respond effectively when they are not implemented as planned; and report on standardized global indicators. The challenges for completeness and accuracy of data from these systems include the need for the use of standardized criteria for diagnosis and standardized indicator aggregation and reporting, along with the inclusion of data from across all health facilities (including private sector providers). Such data may not be representative of the entire population – with bias against those not accessing health services, such as the poor, those in rural areas or those attending private health or other services that are not routinely included. Further, generating and using morbidity data requires strict robust governance procedures to be in place to protect the confidentiality and misuse of data.

Another source of morbidity metrics for the whole or part of the population may be from population-based registries for specific conditions and diseases, such as those for cancer and diabetes. Some morbidities will also need to be derived from population-based surveys, e.g. hypertension and diabetes prevalence, due to challenges in capturing these metrics completely from patient and program monitoring systems.

Assessing the levels of NCD risk factors in the population

Assessing levels of NCDs risk factors in the entire population is impractical, and therefore surveys that sample a scientifically selected sample of the population of interest are used. It is crucial that eligible participants are scientifically selected from the whole population in order to provide data that can be extrapolated to the whole population concerned. School-based surveys can provide population-based estimates among children and adolescents where there is a high level of school attendance. Assessing risk factors based on those accessing health care services is unlikely to provide accurate estimates across the whole population.

There are several types of surveys to assess risk factors in the population. They include:

Health examination surveys where eligible participants are requested to attend survey centres. Levels of participation are variable and can be as low as 30% in some settings (e.g. high-income countries). Low attendance can result in biased estimates, but this can be partly compensated (e.g. by weighing crude results to the expected distribution of the population in relation to some variables, such as education or income).

Household-based surveys require household visits and therefore need significant resources (e.g. travel to people's homes, availability of portable equipment, access to a secluded place to conduct the survey).

Phone- and internet-based surveys are increasingly used as they can require fewer resources. Challenges include obtaining contact details for eligible participants, bias towards those who have access to fixed and mobile phones and computers, and low response rates. Physical measurements (e.g. height, weight and blood pressure) rely on participants providing accurate information. In addition, participants may not respond to unsolicited calls, although participation can be substantially improved if incentives are provided.

Surveys based on electronic health records enable the rapid, up-to-date, inexpensive and ongoing collection of large amounts of information (risk factors, clinical and laboratory, etc.). If information is available at the entire (or nearly entire) population level ('whole of population surveillance'), prevalence estimates can be inferred to the entire population, e.g. national health systems in the UK, Spain, Denmark, Korea⁵ or from health care providers (e.g. health and medical insurance companies). As electronic health records are increasingly used in many countries, surveillance of NCD risk factors based on electronic records is likely to be used more widely in the future. Health data can also be linked with other electronic databases (e.g. medical prescriptions, social services, etc.), which can provide useful information on NCD control rates and health services use and efficiency and, possibly, assist with effective real-time prevention and control measures at the population and health care levels. Challenges include information only from those accessing health services, which may not be representative of the whole population.

Surveys of the capacity of health systems to perform NCD surveillance and of the health response to NCD prevention and control

A variety of surveys and/or tools exist for assessing issues that do not directly assess NCD outcomes in the population but are indirectly linked with surveillance. This includes surveys of the capacity of the health system to perform surveillance tasks, funding available for surveillance tasks, the existence of units/

sections for performing surveillance tasks, etc. Surveys of the public health response to NCDs assess governance, implementation of policies and strategies in a country to address NCDs and their risk factors in the population, the health care response for NCD service delivery and the management of NCDs.⁶

Notes

- 1 Noncommunicable Diseases Progress Monitor. WHO, 2020.
- 2 Croome A, Mager F. *Doing research with enumerators*. Nairobi: Oxfam, 2018.
- 3 GBD 2017 Causes of Death Collaborators. Global, regional, and national age-sex-specific mortality for 282 causes of death in 195 countries and territories, 1980–2017: a systematic analysis for the Global Burden of Disease Study 2017. *Lancet* 2018;392:1736–88.
- 4 Ahmad OB et al. Age standardization of rates: a new WHO standard. GPE Discussion Paper Series: No.31. WHO, 2001.
- 5 Carstensen B et al. Components of diabetes prevalence in Denmark 1996–2016 and future trends until 2030. *BMJ Open Diabetes Res Care* 2020;8:e001064.
- 6 Assessing national capacity for the prevention and control of NCDs: report of the 2019 global survey. WHO, 2020.