

5 Surveillance of NCDs and their risk factors

Selected tools

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Chapter 4 describes the purpose of NCD surveillance and its underlying principles. This chapter describes examples of tools that are commonly used including those developed by WHO.¹

Assessing the prevalence of risk factors

These instruments require eligible participants to be scientifically selected from the population so that the results are generalizable. Data are obtained from standardized questionnaires and, in some cases, include a physical examination and/or biochemical measurements. Findings may be reported as crude or age-standardized estimates (see chapter 1 on the global burden of NCDs) and can be presented according to age, sex, income, education or other categories. There is a range of ethical considerations when collecting data through surveys² and they should be reviewed and approved by the relevant ethics committee/institutional review board, which will address, among other issues, that data management systems are in place to protect participants' privacy and that participation includes informed consent. It is imperative that those involved in surveys received adequate training and that support is on hand for those conducting the survey.

The WHO STEPwise Approach to NCD Risk Factor Surveillance (STEPS) has been developed to collect, analyze and disseminate responses to a set of questions on the key behavioural risk factors including alcohol and tobacco use, physical inactivity, unhealthy diet, along with the history of selected NCD conditions (Step 1); physical measures to assess the main biological risk factors such as overweight and obesity and raised blood pressure (Step 2); and biochemical measures of blood glucose, cholesterol and urinary sodium and creatinine (Step 3) among those aged 18–69 years. Where resources are available, an expanded set of measurements are available for each step. STEPS can be expanded to cover other public health priorities with additional add-on modules, including cervical cancer, objective measurement of physical activity, tobacco policy, oral health, mental health, sexual health, eye and ear health, and violence and injury. Countries can choose to add variables of local relevance. Scientific sampling of eligible participants is typically by clusters, e.g.

across regional, district and household levels. STEPS requires data collectors to visit the homes of participants for conducting Steps 1 and 2, and Step 3 (the latter being usually conducted in health centres or special study sites). All the tools required for STEPS are readily accessible, including those for electronic data entry on mobile devices, which allows rapid data analysis and generation of reports. Surveys should be repeated at regular intervals (e.g. every 5–10 years). While STEPS requires resources, the information it provides means it is important that these are seen as a priority. STEPS surveys have been conducted in many countries for more than 20 years, with many countries having undertaken repeat surveys to determine trends over time and to enable comparisons with other countries. Data from these surveys are included in the WHO NCD microdata repository.³ Results are often disseminated widely through WHO publications, peer-reviewed journals, and data are included in a range of global public health databases.

The Global School-based Student Health Survey (GSHS) is a collaborative surveillance approach led by WHO that allows countries to assess behavioural risk and protective factors in ten core areas (alcohol, drugs, dietary behaviour, hygiene, mental health, physical inactivity, sexual and reproductive health, tobacco, violence, bullying and injury) among school-going adolescents aged 13 to 17 years.⁴ Because the survey is based on a scientifically selected sample of schools and classes in the whole country or a country sub-region, the GSHS is a relatively low-cost survey, which uses a self-administered anonymous questionnaire. Physical measurements of height and weight are also included in calculating students' body mass index (BMI). Expanded sets of questions are available for each module, and additional country-specific questions about other topics of unique importance or interest can be added. Answer sheets can be rapidly scanned, with an automated analysis of results. GSHS can be conducted over a few days or weeks (after a preparation period). As with STEPS, GSHSs have been conducted once or several times in many countries, reports are widely available and data are included in a range of global public health databases. Data from these surveys are included in the WHO NCD microdata repository.

The Global Youth Tobacco Survey (GYTS), developed by WHO and the US Centers for Disease Control and Prevention, is a self-administered school-based survey of those aged 13 to 15 years. It is designed to monitor tobacco use among youth and to guide the implementation and evaluation of tobacco prevention and control programmes.⁵ GYTS is based on a scientifically selected sample of schools and classes. GYTS is an important tool to assist countries design, implement and evaluate tobacco control demand reduction measures.

The Health Behaviour in School-aged Children Survey (HBSC) is a cross-national study led by the WHO Regional Office for Europe. It is a collaborative cross-national study, initiated in 1982, which is conducted every four years in more than 40 (mostly European) countries. The study aims to gain insight into the well-being, health behaviours and social of 11–15-year-old

adolescents.⁶ Summary and raw data are available on NCD risk factors. Reports are widely available.

Many countries have developed national surveillance tools that focus on or include NCD risk factors. These surveys may include a physical examination (e.g. the US National Health and Nutrition Examination Survey [NHANES]),⁷ the Korea National Health and Nutrition Examination Survey), done by telephone (e.g. Switzerland Health Survey) or through the internet (e.g. Constance in France). As for all surveys, it is essential that samples of the eligible participants accurately represent the whole population. Population-based cohort studies are an alternative way to obtain information data, but the results can be difficult to extrapolate to the whole population for reasons that include selection and other biases. In some countries (e.g. Spain, Denmark), health and medical data (including on NCDs and their risk factors) are collated electronically from all healthcare providers, which provides a form of ‘whole population surveillance’, given that the majority of the population attend health care centres at some point in time.

Measuring NCD events

Tracking NCD events in the population is complex and resource-demanding and requires the ability to identify and report all (or nearly all) deaths and new events of NCDs. This requires access to deaths in public and private health services as well as those outside health centres across all parts of the country and that the causes of disease/death are assessed in a standardized manner (e.g. the WHO International Classification of Diseases) with a reliable knowledge of the main cause of illness/death among possibly several comorbidities (e.g. whether the death was due to a stroke or to a pulmonary infection). Clearly, there are some events that are likely to be described more accurately than others.

National civil registration and vital statistics. Data capable of reporting cause-specific mortality in the population rely on death certificates in which the primary, secondary and associated causes of death are systematically recorded and are, ideally, completed by healthcare professionals that either attended the death or knew the medical history of the deceased. Overall, less than half of all deaths in the world are registered with their cause and even when death certificates are available, the cause of death is often unreliable. It is important that those certifying deaths received training on completing meaningful returns.⁸ Calculating mortality rates also requires the size and age distribution of the entire population to be known.

Demographic surveys assess incidence (mortality and, to some extent, morbidity), typically in definite geographical areas populated by a few thousand or hundreds of thousands of people. Health officers visit each household at regular intervals (e.g. every six months), with the cause of death determined by *verbal autopsies* that enable the likely cause of death to be established.

Disease registries are available in some countries where resources are available. They can be either population-based or hospital-based. Population-based

cancer registries are used to determine cancer patterns among various populations or sub-populations, monitor trends and improve patient care. Registries also exist for other chronic diseases (e.g. stroke, heart diseases, kidney disease, hypertension, diabetes, inheritable conditions) and are generally established at hospital and/or primary health care levels: their main focus is to improve patient care.

Patient record systems are used to collect, store and report clinical information important to the delivery of NCD-related patient care and are an important source of data for those accessing health services regarding NCD diagnosis, management and care. A comprehensive set of reliable measures of service quality, service availability and clinical health outcomes for the facility-based patients and programme monitoring for NCDs, as well as practical and simple digital reporting tools, can address gaps in monitoring. WHO has developed a set of indicators to support standards-based data recording and reporting in health facilities at the primary care level in low-resource settings, and related tools to integrate these indicators are currently being piloted for inclusion, such as DHIS2 (District Health Information Software, developed by the Health Information Service Provider [HISP] global network, led by the University of Oslo)⁹ and other health information management system/electronic patient record platforms.¹⁰ A key challenge is that these data are often not fully representative of population health (as they only reflect people who access health services) and may be incomplete or of uneven quality.

Assessing services for NCDs

The Service Availability and Readiness Assessment (SARA) tool was developed by WHO and the US Agency for International Development (USAID).¹¹ It is designed to assess and monitor health services availability and readiness and provides information to support the planning and managing of a health system. Data collected include information on the availability of key human and infrastructure resources and the availability of basic equipment, basic amenities, essential medicines and diagnostic capacities (around NCDs and other health issues). Countries have also developed their service assessment instruments.¹²

Surveillance tools for measuring progress against the WHO Global NCD Action Plan indicators

Examples of tools that countries can use to measure indicators in the WHO Global NCD Action Plan are shown in Table 5.1.

Challenges when it comes to obtaining high-quality data from NCD risk factor surveillance include: (i) governments and their partners not prioritizing this area of work sufficiently with inadequate integration of NCD risk factor surveillance into national health information systems; (ii) the often high turnover of personnel involved in surveillance; (iii) the lack of resources available at the country level to support surveillance activities with weak infrastructure

Table 5.1 Surveillance tools to measure progress against the WHO Global NCD Action Plan indicators^a

<i>Element</i>	<i>Target</i>	<i>Indicator</i>	<i>Examples of surveillance tools</i>
Mortality and morbidity			
Premature mortality from NCDs.	1. A 25% relative reduction in mortality from CVD, cancer, diabetes or chronic respiratory diseases.	1. Unconditional probability of dying between the ages of 30 and 70 from CVD, cancer, diabetes or chronic respiratory diseases. 2. Cancer incidence, by type of cancer, per 100,000 population.	National civil registration and vital statistics capable of reporting cause of death, verbal autopsy tools, DHS, etc. Population censuses are also needed.
Behavioural risk factors			
Harmful use of alcohol.	2. At least a 10% relative reduction in the harmful use of alcohol, as appropriate within the national context.	3. Total alcohol per capita (aged 15+ years old) per year (litres of pure alcohol). 4. Prevalence* of heavy episodic drinking in adolescents and adults. 5. Alcohol-related morbidity and mortality in adolescents and adults.	STEPS, NHS, GSHS, DHS and similar surveys (with or without examination).
Physical inactivity.	3. A 10% relative reduction in the prevalence of insufficient physical activity.	6. Prevalence of insufficiently physically active adolescents (<60 minutes of moderate to vigorous intensity activity daily). 7. Prevalence* of insufficiently physically active adults (<150 minutes of moderate-intensity activity per week, or equivalent).	Idem (as for alcohol). Surveys must include physical activity at work, at home, for transport and during leisure time.
Salt/sodium intake.	4. A 30% relative reduction in mean population intake of salt/sodium.	8. Mean* population intake of salt per day in adults.	Idem. Biological samples are needed if spot or 24-hour urine samples are taken.

(Continued)

Table 5.1 (Continued)

<i>Element</i>	<i>Target</i>	<i>Indicator</i>	<i>Examples of surveillance tools</i>
National systems response			
Drug therapy to prevent heart attacks and strokes.	8. At least 50% of eligible people receive drug therapy and counselling to prevent heart attacks and strokes.	18. Proportion of persons aged ≥ 40 years with 10-year CVD risk $\geq 30\%$ receiving drug therapy and counselling for hypertension or diabetes.	Idem. Patient record systems.
Essential NCD medicines and basic technologies to treat major NCDs.	9. An 80% availability of affordable basic technologies and essential medicines to treat major NCDs in both public and private facilities.	19. Availability and affordability of quality, safe and efficacious essential NCD medicines, including generics, and basic technologies in both public and private facilities.	SARA, other facility-based surveys.

*Age-standardized.

CVD: cardiovascular disease; BP: blood pressure, BMI: body mass index, adults: persons aged 18+ years. DHS: demographic health survey.

a Noncommunicable diseases global monitoring framework: indicator definitions and specifications. WHO, 2014.

(e.g. travel and transport systems) that make household surveys difficult, weak country capacity in data management, analysis and report writing; and (iv) out-of-date sampling frames and lack of geographical accessibility of some areas in some countries.¹³

Notes

- 1 Surveillance systems & tools. www.who.int/teams/noncommunicable-diseases/surveillance/systems-tools/.
- 2 Hammer MJ. Ethical considerations for data collection using surveys. *Oncol Nurs Forum* 2017;44:157–59.
- 3 WHO NCD microdata repository. <https://extranet.who.int/ncdsmicrodata/>.
- 4 Global school-based student health survey. WHO. www.who.int/teams/noncommunicable-diseases/surveillance/systems-tools/global-school-based-student-health-survey.
- 5 Global youth tobacco survey. WHO. www.who.int/teams/noncommunicable-diseases/surveillance/systems-tools/global-youth-tobacco-survey.
- 6 Health behaviour in school-aged children. WHO collaborative cross-national survey. www.hbsc.org/about/index.html.
- 7 National Health and Nutrition Examination Survey. US Centre for Disease Control and Prevention. <https://www.cdc.gov/nchs/nhanes/index.htm>.

- 8 Brooks EG, Reed KD. Principles and pitfalls: a guide to death certification. *Clin Med Res* 2015;13:74–84.
- 9 What is DHIS2? <https://docs.dhis2.org/en/use/what-is-dhis2.html>.
- 10 Webster P. The rise of open-source electronic health records. *Lancet* 2011;377:1641–42.
- 11 Service availability and readiness assessment (SARA). WHO. [www.who.int/data/data-collection-tools/service-availability-and-readiness-assessment-\(sara\)?ua=1](http://www.who.int/data/data-collection-tools/service-availability-and-readiness-assessment-(sara)?ua=1).
- 12 Hoa NT et al. Development and validation of the Vietnamese primary care assessment tool – provider version. *Prim Health Care Res Dev* 2019;20:e86.
- 13 Riley L et al. The World Health Organization STEPwise approach to noncommunicable disease risk-factor surveillance: methods, challenges, and opportunities. *Am J Public Health* 2016;106:74–78.



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