Position Paper:

Public Health Surveillance of Chronic Noncommunicable Diseases in the Americas

Pan American Health Organization / World Health Organization (PAHO/WHO) Chronic Disease Project
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Present the aim and thinking of the Secretariat, i.e. PAHO/WHO, regarding the implementation of a line of action on surveillance from the Regional Strategy and Plan of Action on an Integrated Approach for the Prevention and Control of Chronic Diseases through its main vehicle, the CARMEN (Collaborative Action for Risk Factor Prevention and Effective Management of CNCDs) Network.

1. Introduction

In the last half century, the public health community in the Americas has increasingly recognized the importance of understanding chronic diseases and risk factors associated with them, as well as their social, economic, and cultural roots. A plethora of data has been accumulated by economically advanced countries during these years. However, developing countries are still behind in terms of systematic and continuous data collection and in the use of quality and timely epidemiological data, and even more behind when it comes to gathering data on to provide evidence on the outcomes of interventions outcomes and on programs performance.

The epidemiological data show that the diseases with the largest burden in the Region are: cardiovascular diseases, cancer, diabetes, and chronic respiratory diseases; and the main risk factors associated to them are tobacco, low levels of physical activity, alcohol consumption, low intake of fruits and vegetables, obesity, hypertension, and elevated cholesterol and blood glucose. Risk factors are largely socially determined by government policies and private-sector forces, as well as by cultural and environmental factors.

Projections show that deaths due to chronic diseases will show a 17% increase by 2015. This includes a near tripling of mortality from ischemic heart disease and stroke over the next two decades, and over 833,800 deaths due to cancer in the Region. Yet 80% of cardiovascular diseases and 40% of cancers are preventable.

Part of these deaths will be due to a higher life expectancy and advanced ageing processes in the Region, as well as to fewer deaths from communicable diseases as a result of improved living standards. What concerns us here is the burden of premature death and disability-adjusted life years (DALYs), and the economic impact, as well as the need to have better information at our disposal on the relationship between premature deaths and underlying causes.
Research data published to date, mostly from developed countries, as well as gray literature from the developing world provides us with more and more information on “what works”\(^1\,\(^2\) when it comes to interventions aimed at preventing and controlling the risk factors (RFs) behind chronic noncommunicable diseases (CNCDs). The challenge is to have more data and evidence from developing countries in development and to support their comparability, exchange, and efforts to control the disease burden in their respective countries, including the underlying causes.

The Final Report of the Commission on Social Determinants states that

“Statistical data are essential to describe the extent of a public health problem but do little to explain the experience of that problem or its impact on people’s lives. Yet providing a sense of the lived experience is important for explanatory purposes, as well as for advocacy and to give politicians and others the rich story that can turn hearts and minds.”

The example of tobacco is one of these, with policy-makers often at a loss to explain why people smoke despite evidence of its negative impact on health and the addictive characteristics of tobacco as well as public awareness of the impact of highly refined marketing strategies on the part of the tobacco industry. Qualitative research showed that, for poor women, smoking can be a coping mechanism in response to the demands of living in poverty and being a mother.

### 2. Regional Strategy and Plan of Action: Line of Action for Surveillance

There has been renewed interest in health information systems at both the international and national levels. This has been driven by the increasing demand for evidence-based policy-making interventions. Given that CNCDs have the highest economic and social burden, countries in the Region are considering incorporating CNCDs, RFs, and program performance monitoring into the surveillance function of their health information systems. One of the most recent examples is the **Declaration of Port-of-Spain, Uniting to Stop the Epidemic of Chronic Disease**, endorsed by the heads of state of the English and Dutch Caribbean. The challenge regarding this particular function lies in the quality and timeliness of data coming from many different sources, the need to organize and aggregate that data, and to ensure the ongoing collection, analysis, dissemination, and use of data in the future.

Establishing a national or local CNCD surveillance system at the country or subregional level is still under development. Only a few countries in the Region are in a position to actually produce such a system. Such systems facilitate the production of comprehensive reports used to define public health priorities and monitor the long-term effectiveness of disease prevention programs (for example, in Chile, the National Health Objectives for the Decade (Objetivos Sanitarios para la década 2000–2010); in Brazil, the National Health Promotion Plan (Política Nacional de Promoção da Saúde); in Guatemala, the National Plan for the Prevention and Control of CNCDs (Plan de Acción 2008-2012 para la prevención y el control integral de las enfermedades crónicas y sus factores riesgos); in the USA, Healthy People 2010). They

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point out the need for strengthening public health capacity in the countries so that they can provide and manage data, as well as use the data for public health action to prevent chronic noncommunicable diseases.

Recognizing the need for an updated interprogrammatic chronic disease strategy, PAHO has facilitated a process including countries and partners in developing the *Regional Strategy and Plan of Action* (hereafter referred to as the Regional Strategy or Regional Action Plan) and subsequent Resolution CD47.17 by the PAHO Directing Council in 2006, endorsed by all countries. The Strategy relies on and is consistent with all previous WHO and PAHO resolutions on the subject.

The strategy notes that chronic diseases affect everyone without exception, particularly poor populations; and they are a growing threat to economic development. In Latin America and the Caribbean (LAC) over the next two decades alone, it is estimated that the incidence of ischemic heart disease and stroke will nearly triple if nothing is done to stop this upward trend. The social costs associated with chronic diseases are staggering. For example, the total annual cost for LAC associated with diabetes was estimated at US$ 65 billion in 2000.

The Regional Strategy has four lines of action, which

1. confirm that chronic diseases need to be prioritized in the political and public health agendas;
2. identify surveillance as a key component;
3. recognize that health systems must be reoriented to respond to the needs of people with chronic conditions; and
4. recognize the vital role of health promotion and disease prevention.

The four lines of action are vitally interdependent, and the one CNCD surveillance serves to fill in the information gap and provide evidence for policy, advocacy, promotion, and integrated disease management. It goes beyond epidemiological surveillance, encompassing a broader concept of public health surveillance with a support role in evaluating comprehensive CNCD programs, backing the necessary research, and achieving the goal of the Regional Strategy to prevent and reduce the burden of chronic diseases and their related risk factors in the Americas.

The Regional Action Plan indicates the roles and responsibilities of governments as well as PAHO’s role as secretariat, in promoting a stepwise approach to success.

To be able to plan, monitor, and assess the effects of CNCDs on population health, the countries need to build the necessary capacity for the ongoing collection, monitoring, and analysis of data related to chronic disease risk factors, morbidity, and mortality, as well as related polices and program performance.

The line of action for CNCD surveillance in the Regional Strategy and Plan of Action emphasizes the need to strengthen a system for monitoring CNCDs and their risk factors at the Regional, subregional, and national levels, and to build consensus on standards for its development and functional structure. This plays a facilitating role in country capacity in terms of obtaining reliable
and timely information and ensuring intra- and intercountry comparability over time, sustainability in terms of continuous data collection and analysis, and ever stronger partnerships.

Throughout the Region, there exist inadequacies and varying levels of capacity for chronic disease surveillance. Most of the countries have limited resources for conducting epidemiological chronic disease surveillance. In response to this paucity, the objective set within the Regional Action Plan is aimed at strengthening and/or expanding established surveillance systems for chronic disease risk factors in PAHO Member States.

The focus will be on strengthening:

1. a system for ongoing, systematic collection of high-quality data;
2. the capacity to adopt an analytical approach and carry out advanced data analysis using other sources, e.g. from the finance or education sectors or on minority groups, etc.; and
3. the capacity to use the data collected for national policy-making and planning, as well as for Regional and subregional decision-making related to health.

Therefore, discussion and agreement among countries and leading public health institutions working in CNCD surveillance in the Region requires health promotion activities aimed at accomplishing the following:

a. endorsement of CNCD surveillance as part of national, subregional, and Regional health surveillance, with minimal, optimal, and appropriate set of indicators covering mortality, morbidity, risk factors, coverage, quality of care, and context indicators;

b. standardized and validated methodologies and tools for data collection and analysis, with the goal of ensuring intra- and intercountry comparability and the sustainability of collection and analysis, and which will foster the adoption of a complex analytic approach and stronger partnerships.

c. repository of quality information that can be accessed and analyzed by interested parties; and

d. use of information for policy development, orientation, social marketing, and quality assurance.

All the above will make it easier for countries, subregions and the Region as a whole to follow up on progress made in meeting the objectives of the international agenda, as Millennium Development Goals, Global and regional strategies for prevention and control of CNCDs, Tobacco Framework Convention and Global strategy for diet, physical activity and health, Global Plan of Action for CNCDs and other related strategies and resolutions.

3. WHO and PAHO InfoBase for Strengthening Chronic Disease Surveillance

Based on the World Health Assembly Resolution [WHA 53.17](http://www.who.int), passed in 2000, the World Health Organization (WHO) has developed a global surveillance approach for CNCDs. Its overall goal is to enable countries to build and strengthen their capacity to conduct surveillance on chronic disease
risk factors and on the diseases themselves within the framework of an integrated, systematic approach aimed at each country’s achieving sustainability in collecting its own data.


To support its global surveillance approach, WHO has developed a standard methodology for risk factor surveillance that can be adapted to different socioeconomic and cultural settings: the STEPwise approach to RF surveillance, or more commonly, STEPS, which supports country capacity-building. It focuses on eight leading risk factors that predict CNCDs. PAHO has adapted this methodology for the Americas with Pan American (PanAm) STEPS, tailored to the needs of the Region and including several additional modules. The PanAm STEPs methodology is being promoted as the standardized methodology for the Region in that it will enable intercountry comparisons.

Regarding RF detection among youth, WHO has introduced its Global School-Based Student Health Survey (GSHS) as well as its Global Youth Tobacco Survey (GYTS). PAHO has developed a PanAm GSHS and PanAm GYTS, using the same principles as in the STEPS methodology.

The idea behind both methodologies is to establish circles of studies on RF prevalence among adults and youth that will serve the purpose of CNCD surveillance.

In 2002, WHO established a Global InfoBase, the purpose of which was to have a global repository of RF data to help researchers and governments know what the current situation is and thus be better prepared to predict their future burden of chronic diseases. The CNCD InfoBase collects all country-level data on important CNCD risk factors for all WHO Member States. It acts as a repository of all survey information relevant to the eight major risk factors:

1. tobacco use, 5. high blood pressure,
2. alcohol consumption, 6. high cholesterol,
3. fruit and vegetable intake, 7. physical inactivity, and
4. overweight and obesity, 8. diabetes.

It periodically provides a SuRF report on Surveillance of Risk Factors.

For stroke (cerebrovascular disease), the WHO initiative on stroke surveillance promotes the STEPS-Stroke approach to data collection and analysis. It has been implemented by researchers in several countries in the Region, supported by scientific societies, and offered by PAHO to its Member States.

The International Agency in Research on Cancer (IARC) has been providing support for training on cancer registries to the individual countries of the Region. A joint PAHO-IARC workplan for 2009–2013 has been developed, with first-year activities already proposed.
The 28 Member States of the CARMEN network have participated in a broad discussion on strengthening surveillance capacity and have taken on a leadership role in implementing the surveillance line of action.

Several subregional initiatives have obtained comparable data on CNCD risk factors at the subregional level:

- One instance is the Central American Diabetes Initiative (CAMDI). One tangible product along these lines is the *Survey of Diabetes, Hypertension and Chronic Disease Risk Factors: Villa Nueva, Guatemala 2007*.

- Yet another is the English-speaking Caribbean, which is in the process of implementing the PanAm STEPS methodology, with support from the Caribbean Epidemiology Centre (CAREC). Both serve as examples of building a comparable subregional dataset.

- The Southern Cone countries, which already have conducted several RF studies at the national level, are participating in the process of data harmonization with PanAm STEPS, with the end goal of facilitating subregional analysis. The Southern Cone Common Market (MERCOSUR) is serving as the platform for the political integration process. In 2008, it set up an official task force on CNCD surveillance, working under the MERCOSUR Task Force on Health (*Salud, Grupo de Trabajo / SGT* 11).

In 1997, Resolution *CD40.R10* of the PAHO Directing Council established the PAHO Regional Core Data initiative, calling for a database of basic indicators with an online table generator that includes several indicators for CNCDs (morbidity, mortality, and the prevalence of certain risk factors). As the amount of data received to date from the countries has been limited, the morbidity and RF indicators have not been published yet.

The newly established PAHO Program for the Improvement of Vital and Health Statistics (p. 18 of link) will be one more component to work towards strengthening data quality for the epidemiological surveillance of CNCDs.

**PATIOS**, the Pan American Tobacco Information System, is PAHO’s main database for the surveillance of tobacco as one the main CNCD risk factors. PATIOS provides information on: the health impact of tobacco use, policy and legislation aimed at curbing tobacco use, the economic factors involved, smoking cessation, and country planning and programming. The data included in the PATIOS database comes from different sources, e.g. the

- PATIOS country survey,
- Global Youth Tobacco Survey (GYTS),
- WHO Global InfoBase,
- United Nations (UN),
- UN Food and Agriculture Organization (FAO),
- UN Commodity Trade Statistics Database (UN Comtrade),
- UN Industrial Development Organization (UNIDO), and
- WHO Global Burden of Disease Estimates.
Country Capacity for CNCD Surveillance

To be better able to respond to the proposed activities of the surveillance line of action, and subsequently to implement and evaluate the Regional Strategy at both national and subregional level, a certain level of capacity is required. Also required is a commitment to continuous improvement.

The 2005 PAHO/WHO study on country capacity to respond to CNCDs shows the following results in the area of CNCD surveillance and information-gathering and use.

### National Health Report Systems, Surveys, and Surveillance

<table>
<thead>
<tr>
<th>National health reporting systems, surveys and surveillance</th>
<th>Yes (No. of countries that have them)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health information system covering chronic diseases and major risk factors</td>
<td>21</td>
</tr>
<tr>
<td>Inclusion of chronic diseases in the annual health report system</td>
<td>26</td>
</tr>
<tr>
<td><strong>Surveys including CNCD risk factors (00-05)</strong></td>
<td></td>
</tr>
<tr>
<td>➔ Alcohol consumption</td>
<td>20</td>
</tr>
<tr>
<td>➔ Cancer</td>
<td>13</td>
</tr>
<tr>
<td>➔ Chronic respiratory diseases</td>
<td>7</td>
</tr>
<tr>
<td>➔ Diabetes</td>
<td>20</td>
</tr>
<tr>
<td>➔ Dyslipidaemia</td>
<td>21</td>
</tr>
<tr>
<td>➔ Heart diseases</td>
<td>14</td>
</tr>
<tr>
<td>➔ Hypertension</td>
<td>20</td>
</tr>
<tr>
<td>➔ Overweight and obesity</td>
<td>17</td>
</tr>
<tr>
<td>➔ Physical inactivity</td>
<td>18</td>
</tr>
<tr>
<td>➔ Stroke</td>
<td>12</td>
</tr>
<tr>
<td>➔ Tobacco use</td>
<td>5</td>
</tr>
<tr>
<td>➔ Unhealthy diet</td>
<td>19</td>
</tr>
<tr>
<td>Has the STEPS methodology been implemented?</td>
<td>6</td>
</tr>
<tr>
<td>Regular surveillance system for RFs</td>
<td>10</td>
</tr>
</tbody>
</table>

In the Region of the Americas, 28 of the 36 countries have presented results, although these only show a wide-angle perspective, providing information on chronic disease and its inclusion in the Annual National Health Reporting System (AHRS) of the Ministry of Health. The majority of the countries include mortality data in their report. Morbidity information is less frequently available, though population studies include data on incidence or prevalence, as well as data from disease registries and hospital admission or discharge. The inclusion data on risk factors and on the outcomes of interventions and programs was reported as being low. Information on data quality (from the registries), completeness, timeliness, or any other aspects was not explored by the 2005 study.
Even from these results, however, it is evident that a large proportion of the responding countries do not have established systems for the comprehensive surveillance or monitoring of the major CNCDs. Very few surveillance system registries were population based or based on primary health care. In reality, most were based at health facilities and seldom covered the whole population.

There was little evidence of policy- or program-driven systematic collection of health information of any type. Consequently, the infrastructure and capacity for data collection, management, and analysis in many of the countries interviewed was judged by the respondents to be entirely inadequate (WHO/MNC/01.2). Within the framework of monitoring country capacity, PAHO recently developed a section on CNCD surveillance that should serve as a guide for the countries to follow when assessing their capacity for CNCD surveillance and the adequate functioning of their systems.

In 2005, the PAHO Health Analysis and Statistics Project (HA) carried out an analysis of country capacity in relation to information systems, surveillance capacity as a public health function, and the availability of data from vital statistics. The goal was to be able to prioritize technical cooperation (TC) for the next planning period. For the national public health information systems, the criteria used for surveillance were vital statistics from subregistries, with the participation of non-defined cases; organizational structure; the relationship between subsystems; and PAHO core data.

This led to the development of a program proposal, its presentation and subsequent endorsement by the Regional Program for Strengthening Vital and Health Statistics (proposal CSP27/13 and subsequent Resolution CSP27.R12, Strategy for Strengthening Vital and Health Statistics in the Countries of the Americas, by the Pan American Sanitary Conference in 2007, and later to the proposal for its workplan (passed by the PAHO Directing Council in 2008 with Resolution CD48.R6, Regional Plan of Action for Strengthening Vital and Health Statistics.

CNCD and RF surveillance largely depends on the capacity of the overall health information system, such that collaboration with the program to improve vital and health statistics is part of process to strengthen this capacity.

Revision of Data Availability to Be Used for Surveillance Purposes

**Mortality**

- Since 1960, cause-specific mortality data has been compiled (C18-C38)
- Mortality data from 10 countries with fairly accurate longitudinal data are being built into a strong database by the PAHO Health Analysis and Statistics Project to facilitate trend analyses.
- PAHO also uses an algorithm to compensate under registration and ill-defined mortality for countries with those problems.
- For approximately five countries in the Region, mortality data time series are not available.
- PAHO is incorporating multiple cause approach in the analysis of mortality to facilitate information on ‘hidden’ causes and RF.
Morbidity

- Data on prevalence of diabetes and hypertension are part of the Basic Data country reports (D23-26).
- Data on diabetes prevalence, incidence through Diabetes registries (DIAMOND project, p. 1).
- Cancer registries at subnational level (in conjunction with IARC). Available from Argentina (Bahia Blanca, Concordia), Brazil (Campinas, Goiânia), Colombia (Cali), Cuba (Villa Clara), Ecuador (Quito), Uruguay (Montevideo); and at national level, from Puerto Rico, Martinique, Costa Rica, and Trinidad and Tobago.
- Stroke registries using the STEPS-Stroke methodology (with PAHO support) in Brazil (São Paulo), Mexico (Querétaro), Chile (Talca), and Barbados, with a national stroke registry.

Risk Factors

- Some CNCD risk factor data (on obesity and tobacco) are included in the list of Core Indicators (D29-30); but since information obtained from countries is scarce, the data are not published.
- A literature review carried out in 2005 by the PAHO Chronic Disease Project on surveys conducted in Latin America and the Caribbean showed that both the countries and international agencies tended to focus their work on health surveys to assess the prevalence of CNCD risk factors. Many surveys are conducted by clinical and academic groups and reflect their interests. Most of these studies have been one-time cross-sectional surveys and have not been systematically repeated over time, so that any assessment of current trends has not been possible.
- Some countries—Brazil, Chile, Colombia, and Cuba—have conducted national risk factor surveys, and Brazil and Chile have conducted two or more subsequent studies.
- Since 2005, several ministries of health (MoHs) have been taking on the responsibility for collecting and analyzing population-based epidemiological data to guide them in resource mobilization and decision-making. The WHO Stepwise approach, in the form of PAHO’s PanAm STEPS, has been accepted and carried, with data being collected or analyzed in 22 countries of the Americas. This will facilitate subregional comparability and data analysis for the Caribbean as well as for MERCOSUR Member Countries.
- Prevalence data on biological and behavioral risk factors, as well as data on health service utilization, are available for six of the national capitals in Central America as a part of the CAMDI study, which in its next stage will moves on to national studies applying the PanAm STEPS methodology.

Policies, Programs and Contextual Factors

- Data from 2005 on CNCD-related polices and programs are available for the Region as a whole and for the Caribbean subregion through the CNCD Capacity Study (carried out in 2007), which provides a bird’s-eye view of health information.
- The joint project between PAHO and the Public Health Agency of Canada (PHAC) created a Policy Observatory for CNCDs, which is currently in the process of tailoring...
existing capacity instruments to include both qualitative and quantitative information on CNCDs to provide decision-making support in the form of additional information available for use in 2008–2009.

➔ The PAHO Core Data Initiative for CNCDs provides information that goes beyond epidemiological data, encompassing CNCD prevention, the performance of specific programs, and contextual factors, thus serving as guide for secondary data collection for further study and analysis.

Examples from the Region on Progress Made in Developing Indicators for Surveillance Systems

Brazil is one of the few countries that has succeeded in developing a framework for collecting epidemiological data, thanks to the re-organization of its healthcare system, which combines various sources of information from its different parts.

Components of a CNCD Surveillance System: The Case of Brazil

Canada, due to its decentralization, shows different levels of development regarding CNCD surveillance and related indicators, depending on the province. British Colombia has focused their work on developing a framework for wellbeing indicators that encompass health status, determinants, and health system performance and characteristics.
Wellbeing Indicator Framework in British Colombia, Canada: Working Model

<table>
<thead>
<tr>
<th>Health Status</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Health status can be assessed in a variety of ways, including wellbeing, health conditions, disability, and death.</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Wellbeing</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Human Function</td>
<td>Health Conditions</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Determinants of Health</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Determinants of health are known to affect our health, and in some cases, when and how we use health care.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Environmental Factors</th>
<th>Personal Resources</th>
<th>Living and Working Conditions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Behaviors</td>
<td>Community Vitality</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Health System Performance</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>These indicators measure various aspects of the quality of healthcare services.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Accessibility</th>
<th>Appropriateness</th>
<th>Competence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Effectiveness</td>
<td>Safety</td>
<td>Acceptability</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Health System Characteristics</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>These measures provide useful contextual information but are not direct measures of the quality of health care.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Health System Resources</th>
<th></th>
</tr>
</thead>
</table>
The United States has several well-established epidemiological surveillance systems that are collecting, processing, and using data on CNCDs and RFs. The US initiative *Healthy People 2010* has included in its framework a set of leading health indicators where some of them address determinants, some RF and some the context.

**Health Determinants and Health Outcomes: Set of Leading Health Indicators, USA**

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Measure</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Physical environment</td>
<td>Percentage of population living in areas where air quality meets or exceeds all National Ambient Air Quality Standards and whose community water systems receive a supply of drinking water that meets the safe drinking water act regulations.</td>
</tr>
<tr>
<td>2. Poverty</td>
<td>Percentage of population with household incomes less than 100% of the federal poverty limit</td>
</tr>
<tr>
<td>3. High school graduation</td>
<td>Percentage of population ages 18-24 who have completed high school</td>
</tr>
<tr>
<td>4. Tobacco use</td>
<td>Prevalence of any use of tobacco products among youth up to age 17</td>
</tr>
<tr>
<td>5. Weight</td>
<td>Percentage of population whose body mass index is no more than 20% lower and no more than 20% higher than that recommended for their age and gender</td>
</tr>
<tr>
<td>6. Physical activity</td>
<td>Percentage of population whose participation in physical activity with significant cardiovascular benefits meets or exceeds recommended levels with respect to the number of times per week and the number of minutes per time</td>
</tr>
<tr>
<td>7. Health insurance</td>
<td>Percentage of population under age 65 who report that they currently have health insurance coverage</td>
</tr>
<tr>
<td>8. Early detection of cancer</td>
<td>Percentage of uterine/cervical, colorectal, and breast cancers detected at an early stage</td>
</tr>
<tr>
<td>9. Preventable deaths from injury</td>
<td>Percentage of preventable deaths attributed to intentional and unintentional injury</td>
</tr>
<tr>
<td>10. Disability</td>
<td>Average number of days per year lost to school, work, homemaking and other social roles (e.g. volunteering) for a defined population</td>
</tr>
</tbody>
</table>

Countries as well as subregions need an established, reliable, and ongoing CNCD surveillance system as a part of their overall national or subregional health information system. Such a system will enable them to contribute to monitor progress made towards the United Nations Millennium Development Goals (MDGs). Having such a system in place is also crucial for following up on progress made in terms of response to the objectives of the Regional Strategy and Plan of Action, and those parts of PAHO’s Strategic Plan 2008-2012 that relate to CNCDs as well as more broadly to global mandates of the 2000 WHO Global Strategy on Prevention and Control of NCDs (noncommunicable diseases, used simultaneously here with chronic noncommunicable diseases) and its implementation, and responding to WHO policy documents supporting the fight against CNCDs:

- The Framework Convention on Tobacco Control (FCTC, 2003)
- Global Strategy on Diet, Physical Activity and Health (DPAS, 2004)
- World Health Assembly Resolution on Cancer (2005)
- Resolution of the Harmful Effects of Alcohol (2008, p. 7)

The definite solution is to coordinate efforts and investments so that they strengthen the surveillance component within each country’s existing health information system.

The development of a surveillance component in a health information system should be based on the principles of the PAHO Strategic Plan 2008-2012 and support all the lines of action in the Regional Action plan for CNCD Prevention and Control:

- Prioritizing CNCDs on the health agenda
- Policy and advocacy
- Health promotion and disease prevention
- Integrated management of chronic disease and risk factors

Such a system should be:

- **Comprehensive**, covering population and individual measures monitoring; integrated – mortality, morbidity, RF determinates e.g. contextual factors and policies and programs
- **Stepwise**, with core, expanded, and optional actions.

**Principles for Work in CNCD Surveillance**

The PAHO/WHO perspective on surveillance of CNCDs from a public health surveillance perspective is based on the premise that CNCD surveillance goes beyond health outcomes and exposures, e.g. risk factors. The proposal includes monitoring the health situation (mortality and morbidity data plus data on the prevalence and incidence of RFs), socioeconomic determinants, and...
data on program and policy performance, all for the purpose of analyzing this information from different perspectives. This will in turn help to select priorities, allocate resources, and strengthen comprehensive policies and programs. The proposal is first and foremost guided by the expressed interests and needs of the countries:

- Countries have expressed the opinion that developing a CNCD surveillance component needs to be included in their agenda for developing information technology and strengthening of public health information systems.
- To avoid duplication of efforts as much as possible, data and indicators for the CNCD and RF surveillance need to be a part of existing WHO, PAHO, and broader UN initiatives on health information and statistics (PAHO Core Data, Global InfoBase, Health Metrics).
- Any future work needs to be coherent with previous work done by PAHO, WHO, and the international community—and it needs to continue doing it.
- Work needs to be based on the WHO strategic directions for global surveillance and the existing PAHO priority agenda, using a stepwise framework.

**Challenges**

- There is a lack of the necessary country capacity and infrastructure for developing effective surveillance systems.
- The concept of surveillance is still related to a response of infectious disease outbreaks: this challenge needs to be overcome and the concepts adjusted for CNCDs.
- There is a limited availability of population-based, cause-specific mortality data, or data with respect to the major risk factors and CNCD program performance.
- The multifactorial origin of CNCDs makes it difficult for countries to collect and analyze data from multiple sources.
- The globalization process and/or subregional organization of countries calls for data-sharing, comparison among countries, and joint analysis.
- There is a need for research using appropriate methodologies to collect, analyze, and disseminate data.

**Opportunities**

- The existing CARMEN network of Member Countries has already made a commitment to work on CNCD prevention and control.
- There is an increasing demand for technical cooperation in the development of quality surveillance systems, particularly with regard to the acquisition of mortality and risk factor data to support program development and monitoring.
- Countries have sought to incorporate the CNCD surveillance component into their public health information system.
- PAHO’s strategic orientation for intra-organizational cooperation facilitates establishing surveillance as a cross-cutting issue.
- WHO’s strategic orientation for monitoring-training-planning (MTP) establishes surveillance and information for policy-making as priority areas until 2003.
- Many countries collect PAHO Core Data and publish them annually. Some CNCD data and indicators are already included. This model can be used for setting the criteria and methodology for data collection so that additional CNCD indicators can be included and reported as a part of the same process.
- PAHO is perceived as partner in the area of CNCDs by such important actors as the US Centers for Disease Control and Prevention (CDC); the National Heart, Lung and Blood
Institute of the US National Institutes of Health (NIH/NHLBI), the International Agency for Research on Cancer (IARC), and the Institute of National Cancer Institute of the Brazilian Ministry of Health (MS/INCA).

Other partners interested in strengthening surveillance are St. Louis University (SLU), CDC, the Americas' Network for Chronic Disease Surveillance (AMNET), the Public Health Agency of Canada (PHAC), the World Bank, etc.

Subregional technical centers like the Caribbean Epidemiology Centre (CAREC: the first one to have a mandate especially for surveillance and response), the Caribbean Food and Nutrition Institute (CFNI), the Institute of Nutrition of Central America and Panama (INCAP).

Technological Development: Cell phones, palm devices (PDAs), and computer-assisted interviewing all create new opportunities for the use of MultiMod methodology in CNCD surveillance.

There has been a revitalization of primary healthcare (PHC) and renewed interest in electronic patient records to support patient information through PHC and the referral system.

Workplaces/companies are showing interest in workplace wellness programs and support to monitoring the progress of these programs.

A Regional strategy for CNCD and risk factor surveillance has been developed based on the concept of a stepwise approach. This approach is required primarily to address the needs of the countries with the most basic surveillance structure using minimal resources. Second, there will be work with the countries to increase existing surveillance capacity and ensure adequate resources. Finally, there will be work with the countries with more resources and more sophisticated surveillance systems.

STEPS will be progressively applied, with ever greater complexity. Core data are the most critical, followed by expanded and optional, to produce an optimal dataset for surveillance purposes.

The use of data dissemination to the general public, in different ways and using different communication channels and formats will help stimulate public opinion and influence the decision-making processes.

**The Stepwise Approach to CNCD Surveillance**

**Step 1: Core Data**

The first step will use existing resources and include the collection and analysis of core or existing information and the assurance of its reliability.

This step will include activities to be developed in collaboration with the countries and with other PAHO team, such as Health Information and Statistics (HA), Health Systems and Services (HSS), and Human Resource Development (HR). It is vital in order to use exiting country capacity, which will enable countries to carry out the collection of selected data, produce reliable indicators, analyze data to establish priority groups or areas for CNCD control, and enter this data into the subregional and global CNCD InfoBase.

Countries will be stimulated to use routine statistical data for surveillance purposes, and implement at least simple surveillance systems in sentinel sites. Initially this can be for the mayor chronic diseases events, some modifiable RF, and then for program performance.
Example of dataset to be obtained in the First step

- Core Data (socio-demographic, economic data, specific mortality of CNCDs)
- Expanded data (Hospital discharge)
- Desirable (optional) data (service coverage)

Example of analysis: life expectancy and years of life expectancy lost, which are measures derived from mortality data, by which it is possible to demonstrate the impact that a particular disease will have on the premature mortality of their population. These simple forms of analysis are not sufficiently used as tools for situational analysis and for decision-making in public health, when information is based only on mortality data.

**Step 2: Expanded Data**

The second step concerns expanded data and is focused on obtaining and analyzing the information collected, with realistic forecasting of trends to help increase resource allocation.

Within this agenda, priority will be given to countries that are already using routine statistical data for surveillance purposes and to strengthening national capacity for RF surveillance and data analysis. Collaboration with other PAHO teams is needed to include this aspect of surveillance in the country’s work. Technical cooperation will be emphasized in order to provide support to the countries so that they can establish regular, periodic data collection of behavioral and, if possible, biological RFs using PAHO/WHO instrument(s) to complement routine data collection—as well as data on program performance. Emphasis will be placed on the analysis of these data to track RF prevalence and incidence and the impact of preventive programs. Country data will be part of the subregional and global InfoBase.

Countries that have already collected and analyzed specific morbidity and mortality data on CNCDs and have performed at least one study on RFs will be encouraged to establish the periodic collection of this type of data using the PAHO/WHO methodology and instruments. This will help achieve standardization and comparability when including the data in global and Regional CNCD InfoBase.

Examples of the dataset to be obtained in the second step

- Core data (First step + behavioral RF prevalence)
- Expanded data (Incidence and prevalence of CNCD, preventive services utilization)
- Optional data (biological RF, program evaluation)

**Step 3: Optional Data**

The third step concerns optional data and will focus on obtaining and analyzing the desired optional information that remains beyond the reach of most countries and their available resources.

The challenge in the field of collecting CNCD and RF epidemiological surveillance data will be to strengthen population registries for cancer and stroke, which will provide an opportunity for fine-tuning intervention programs (some LAC counties have already started such registries) and to include follow-up for policy and program implementation. The challenge in the area of data analysis will be to achieve greater detail to support national policy changes.

Examples of the dataset to be obtained in the third step

- Core data (First +Second step + cancer and stroke hospital registers prevalence, incidence and Mt)
- Expanded data (population registers data)
- Optional data (studies, evaluation reports, laws, policies etc)
A stepwise approach will allow countries to see the entire framework, envisions themselves as a part of it, and move ahead from one step to another, as their capacities permit.

**Subregional Capacity-Building**

Strengthening of subregional capacity is seen as important to the overall development agenda, given the growing evidence of the relationship between CNCDs and RFs, besides concerning such sectors health as agriculture, trade, education etc. Development will depend of the leadership shown by the countries in the respective subregions, as well as by the existence or potential of adequate resources and infrastructure within their political integration platforms, as well as their capacity for advanced analysis at the subregional level.

Existing subregional centers should be strengthened, e.g. CAREC for the English- and Dutch-speaking Caribbean, and new ones for Central America and the Spanish-speaking Caribbean, in addition to a Brazilian information platform for the MERCOSUR countries and SGT-11. These centers will receive support in capacity-building in data collection and analysis and in subregional planning and evaluation in the area of health, as well as in providing training on the recommended methodology and tools.

The development of a subregional InfoBase will then follow. The establishment of infrastructure is seen as a responsibility of the subregional platforms or center, and PAHO/WHO will provide methodological support in its development in accordance with WHO Global InfoBase. The development of the InfoBase will facilitate subregional comparability and the sustainability of data collection and analysis, foster a complex analytic approach, and strengthen partnerships. Its objective is to produce a standard way of describing and comparing data all over the entire subregion. It should facilitate evidence-based advocacy for a public health approach to chronic disease prevention and control, thus assisting policy-makers, researchers, analysts, and data managers.

The InfoBase concept is about CNCDs, RFs and context factor data-gathering and analysis. It help in summarizing and reporting country or subregional profiles that will then be made available to public health agencies, health advocacy groups, and researchers. These enhanced data allow for the generation of subregional and Regional data reports, as well as disease-specific profiles on the current situation, for continuous quality improvement. The information from these assessments will identify areas (for the individual Member States, PAHO, and other partners) for education, targeted technical assistance, and training.

In addition, disease-specific sections can be developed in the InfoBase— e.g. for cancer, diabetes, and stroke, diabetes—to provide additional information through the following:

1. Greater access to disease-specific data for the general public, the scientific community, and policy-makers (with public use of national data files on disease incidence).
2. More accurate and stable estimates of disease incidence for specific population groups, including racial and ethnic minorities, medically underserved populations, and other subpopulations.
3. Information for Regional and national analyses to more accurately identify geographic variability in disease treatment practices, as a means to assess the use of state-of-the-art prevention and treatment.
Overall Goal

- Integrated information system for CNCD surveillance established in collaboration with countries and partners; implemented at subregional and national level, and facilitating public policy formulation, implementation, and evaluation in relation to chronic noncommunicable diseases.

General Objective

- Encourage and support the development and the strengthening of country capacity for better surveillance of chronic diseases and their consequences and risk factors, as well as the impact of public health interventions as part of an integrated strategy for CNCD prevention and control.

Specific Objectives

1. Encourage the development and strengthening of chronic disease surveillance systems that are ongoing, systematic, and linked to public health actions, in order to assess the burden of chronic disease (e.g. morbidity, mortality, disability, economic costs), trends, related risk factors (e.g. tobacco use, unhealthy diet, physical inactivity, alcohol abuse), social determinants (e.g. social, economic, and political conditions), and public health interventions (e.g. health service utilization).

2. Improve multipartner collaboration to mobilize community, national, subregional, and regional partnerships to stimulate the effective development of surveillance systems and optimize the use of information.

3. Support quality improvement for CNCD surveillance data (accuracy, completeness, and comprehensiveness), increase its availability, and ensure its comparability when used for policy and program development purposes.

4. Develop indicators in the surveillance system for evaluating the effectiveness, accessibility, and quality of population-based health services and interventions, as well as the operations of the surveillance system itself.

5. Support the timely and effective communication of information on chronic diseases and their risk factors to the appropriate target audiences.

6. Encourage the development of national surveillance strategies to define the best framework to exchange the necessary surveillance information with decision-makers for the development and evaluation of public health policies and programs.

7. Foster continuous education and training in order to improve the capacity, human resources, expertise, and technical competency of the surveillance workforce.

8. Encourage innovative ideas in chronic disease surveillance to meet new challenges and needs.

PAHO’s mandate is to

1. Provide technical assistance and training to Member States in the establishment and operation of surveillance and monitoring systems, by supporting the development of recommendations for monitoring compliance with program standards for data completeness, timeliness, and quality.

2. Report on the epidemiological situation and response to CNCDs.
Considering the Regional Action Plan and PAHO’s Strategic Plan 2008-2012 for CNCDs, this mandate should support following activities:

**Activities**

1. Conduct a detailed situation analysis of the infrastructure for surveillance; the availability and quality of data on the epidemiological situation; health outcomes; coverage; local, national, subregional, and Regional interventions; and country capacity. Carry out an analysis that summarizes the challenges and information gaps to be addressed in view of the global epidemic of chronic diseases and their risk factors and the surveillance infrastructure (Specific Objective 1). Examples of some of existing tools include the following:
   - NCD country profile assessment tool (section on surveillance).
   - WHO Framework for country action (chapter on getting started and situation analysis).
   - WHO Cancer Situation Analysis Guide.

2. Convene a stakeholders’ analysis to identify the main actors in the international arena, with the purpose of presenting the surveillance line of action and ongoing activities and discussing how to improve information-sharing and organize joint activities for CNCD surveillance in the Region (Specific Objective 2).

3. Convene a PAHO interprogrammatic working group with representatives Health Analysis and Statistics (HSD/HA), Risk Assessment (SDE/RA), Health Systems based on Primary Health Care (HSS), and Sustainable Development and Environmental Health (SDE), with the task of developing and finalizing a Core/Minimum/Basic dataset for CNCD surveillance, with a protocol and tools (list of indicators, sources of information, methodology for data collection, elements for the InfoBase) (Specific Objective 3).

4. Facilitate discussion forums at subregional level, using CARMEN and other networks and country representatives to reach consensus on framework, indicators, methodologies, and analysis, as proposed by the working group (Specific Objective 3).

5. Provide technical assistance and training to Member States in the establishment and operation of RF, stroke, and cancer monitoring, as well as in developing a set of recommendations for monitoring compliance with international (WHO, PAHO, IARC) standards for data completeness, timeliness, and quality (Specific Objective 4).

6. Provide methodological support for the establishment of subregional data management centers to link to the subregional integration movement, using information platforms from existing centers (e.g. CAREC in the Caribbean, INCAP in central America, ORAS in the Andean subregion, and MERCOSUR in the Southern Cone) to lead subregional monitoring and continuous training in CNCD and RF surveillance, thus ensuring countries’ support for and participation in the CNCD subregional InfoBase (Specific Objectives 6, 7).

7. Develop a ‘business case’ for subregional InfoBases (in the Caribbean, Central American, and MERCOSUR countries) to serve as vehicle for disseminating information on trends and distribution of the burden of disease posed by CNCD and on RF prevalence over time and in association with other factors related to chronic disease (Specific Objective 5).

8. Produce a capacity-building plan in collaboration with training institutions and public health agencies to assure training for countries in RF surveillance systems, international protocols, and tool application. Include it in CARMEN School framework (Specific Objective 7).

9. Conduct research into new methodologies/options for CNCD and risk factor surveillance.

10. Publish regular reports on patterns and trends in CNCDs and RFs, with ample dissemination.
## Regional Expected Results (RER) and Indicators

### RER S0.03.03

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<th>RER Indicator Reference</th>
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<tr>
<td><strong>RER Indicator Title</strong></td>
<td>Number of countries with a national health reporting system and annual reports that include indicators of chronic noncommunicable conditions and their risk factors</td>
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<tr>
<td><strong>Baseline Countries</strong></td>
<td>ANI, BLZ, BOL, COL, DOR, ECU, GUY, HAI, JAM, MEX, PAN, SUR, URU, VEN (Antigua &amp; Barbuda, Belize, Bolivia, Colombia, Dominican Republic, Ecuador, Guyana, Haiti, Jamaica, Mexico, Panama, Suriname, Uruguay, Venezuela)</td>
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Office-Specific Expected Results (OSER): HDM.02.02 Surveillance Systems for Chronic Diseases

Indicator: Support given to the subregions and countries for the development of subregional and national systems of presentation of annual reports that include the indicators for chronic diseases, noncommunicable and its risk factors.

Indicator RER linked 03.03.4

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<td>Semester 1</td>
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<td>Semester 4</td>
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<td>Preparation of a subregional plan for chronic diseases reporting to the system, and including two subregional groups</td>
<td>Subregional plans sent to political entities such as the CARICOM and MERCOSUR</td>
<td>Two reports of the subregional plans available</td>
<td>Information systems for chronic diseases established in three subregions</td>
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## RER SO.06.02

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<td>RER Indicator Title</td>
<td>Number of countries that have developed a functioning national surveillance system using the PanAm STEPs (Pan American Stepwise Approach to Chronic Disease Risk Factor Surveillance) methodology for regular reports on major health risk factors in adults</td>
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List of countries where link is recommended
**OSR 1: HDM.02.08 Monitoring of Risk Factors and InfoBase**

Indicator: Number of countries that have established a national surveillance system that uses the methodology PanAm STEPS (Pan American Stepwise Approach to Chronic Disease Risk Factor Surveillance) to submit periodic reports on the main risk factors.

Indicator: Indicator RER linked to 06.02.1

Baseline: 6/40 (ARG, BAH, BRA, CHI, NEA, URU: Argentina, Bahamas, Brazil, Chile, Netherlands Antilles [inc. Aruba and Curaçao], Uruguay)

Milestone 2009 10/40 (ARG, BAH, BRA, CHI, NEA, URU, BLZ, COR, DOR, ELS, FEP, GUT, GUY, JAM, PAN, PAR, TCA, TRT, VEN: Argentina, Bahamas, Brazil, Chile, Netherlands Antilles [including Aruba and Curaçao], Uruguay, Belize, Costa Rica, Dominican Republic, Field Office El Paso on the US-Mexico Border, Guatemala, Guyana, Jamaica, Panama, Paraguay, Turks & Caicos Islands, Trinidad & Tobago, Venezuela)

Milestone 2013: 20/40

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**Status**

List of Countries where link is recommended

Need more countries
OSER 2: HDM.02.08 Monitoring of Risk Factors and InfoBase

Indicator: Number of countries that generate information on risk factors through registries and population studies in order to include it in the Regional Database on Chronic Noncommunicable Diseases and Risk factors (CNCD InfoBase)

**Indicator:** Indicator RER linked to 06.02.3

Baseline: 0/40 (ARG, BAH, BRA, CHI, NEA, URU: Argentina, Bahamas, Brazil, Chile, Netherlands Antilles [inc. Aruba and Curaçao], Uruguay)

Milestone 2009: 15/40 (ARG, BLZ, BOL, BRA, CHI, ELS, FEP, GUT, GUY, MEX, PAR, TRT, URU, VEN: Argentina, Belize, Bolivia, Brazil, Chile, El Salvador, Field Office El Paso on the US-Mexico Border, Guatemala, Guyana, Mexico, Paraguay, Trinidad & Tobago, Uruguay, Venezuela)

Milestone 2013: 30/40
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<td>Number of countries that have implemented (that use and analyze) the standardized Core Health Indicators for Chronic Noncommunicable Diseases and Risk Factors together with other statistical information.</td>
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Minimum number of countries that need to be linked: 0
Status: OK
List of countries where link is recommended: 27
## OSER 3: HDM.02.08 Monitoring of Risk Factors and InfoBase

**Indicator:** Number of Countries that have applied (used and analyzed) the standardized basic health indicators for chronic diseases and risk factors in combination with other statistical information

**Indicator:** Indicator RER linked to 06.02.04

**Baseline:** 3/40 (BRA, CAN, USA: Brazil, Canada, United States)

Milestone 2009 8/40 (BRA, CAN, USA, DOR, ELS, FEP, GUY, HON, PAN, VEN: Brazil, Canada, United States, Dominican Republic, El Salvador, Field Office El Paso on the US-Mexico Border, Guyana, Honduras, Panama, Venezuela)

Milestone 2013: 12/40

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</table>
Mandate, Roles and Responsibilities:

WHO-PAHO has a mandate to deliver technical cooperation to Member Countries and contribute to strengthening country capacity by responding to the level of each country’s needs. There is an area of work on CNCD surveillance in WHO, with human resources dedicated to the InfoBase, RF surveillance, and the stroke registry. The PAHO Chronic Disease Project has established CNCD surveillance as a cross-cutting area of work. Also at PAHO, the Chronic Disease Project of the Health Surveillance and Disease Prevention and Control Area (HSD/NC) and the Health Analysis and Statistics Project (HSD/HA), the Health Systems based on Primary Health Care (HSS), and the Sustainable Development and Environmental Health Area (SDE) are all involved in and incorporated into CNCD surveillance.

It is known that effective interventions for strengthening systems include training, organization, and funding; hence, responsibilities for these interventions will be shared with existing centers (the Caribbean Epidemiology Centre / CAREC, the Institute of Nutrition of Central America and Panama / INCAP, and the Andean Health Authority / ORAS for Organismo Andino de la Salud) or newly established ones.

PAHO’s role will be to facilitate the development of a standardized CNCD surveillance protocol, guarantee training for both its application and in data analysis for policy purposes, and will also ensure country participation in the InfoBase.

PAHO’s Responsibilities

- Form a working group to carry out a baseline assessment and present a proposal.
- Provide leadership in discussions and in building consensus regarding the protocol.
- Facilitate the organization of workshops.
- Provide requirements for the subregional and Regional infrastructure of the InfoBase as well as methodological support for the production of subregional and Regional CNCD profiles.
- Facilitate dissemination channels for the subregional and Regional situation analysis. Countries, through their governments, have both a mandate and a responsibility to develop surveillance as an essential public health function. As such, the role of the countries will be to facilitate the process of incorporating CNCD surveillance into their respective public health systems.

Countries’ Responsibilities

- Provide information for basic assessment.
- Actively participate in discussions and workshops.
- Assure adequate infrastructure and facilitate training.
- Send information to the Regional InfoBase on a regular basis.
Partners and Potential Partners

One of the added values of this initiative lies in building partnerships within both the Organization (i.e., PAHO) and the overall UN system, as well as with other relevant actors. Existing and potential partners consist of several areas within PAHO; WHO Headquarters; PAHO/WHO Representations, i.e., country offices; ministries of health; leading scientific institutions in the countries; nongovernmental organizations (NGOs) active in issues related to chronic disease prevention and control; and existing initiatives and networks on CNCD risk factor surveillance, e.g., the Health Metrics Network and America’s Network for Chronic Disease Surveillance (AMNET).

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