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AT THE HEART OF HEALTH

World Heart Day 2016 policy brief

How countries and regions collect data on cardiovascular disease with a focus on premature mortality caused by CVD

An executive summary





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Gaining insights into CVD data collection and tracking progress against 25by25

This World Heart Day, the World Heart Federation (WHF) is advancing the prevention and control of cardiovascular disease (CVD) by investigating gaps and opportunities in global monitoring and surveillance systems for health. This policy brief begins our research.

Findings and analysis have been drawn from a literature review to give insight into how countries and regions collect data on CVD and the CVD-related indicators (the Global Action Plan (GAP) Targets) provided by the World Health Organization (WHO). From this research, we can chart how close we are to reaching the “25by25” goal of reducing premature deaths from non-communicable diseases (NCDs) by 25 percent by the year 2025.

The World Heart Day 2016 campaign

This year on World Heart Day, WHF is launching a two-year campaign focusing on a topical theme: the power of information. As part of the campaign, in 2016 WHF is issuing a global policy call on governments:

“to implement reliable and fit for purpose surveillance and monitoring systems for CVD in order to better prevent, treat and control the world’s biggest killer.”

More specifically, WHF aims to secure commitments from governments to:

- Strengthen vital registration and cause of death registration systems
- Include coverage of CVD key interventions into existing health information systems
- Collect information on a representative subsample of the population on the prevalence and quality of care of patients with hypertension and CVD; and undertake periodic data collection on the behavioural and metabolic risk factors (harmful use of alcohol, physical inactivity, tobacco use, unhealthy diet, overweight and obesity, raised blood pressure, raised blood glucose, and hyperlipidemia), and determinants of risk exposure such as marketing of food, tobacco and alcohol in a sub sample of the population.

This policy brief supports and provides evidence for the WHF global policy call.

A focus on premature mortality due to CVD

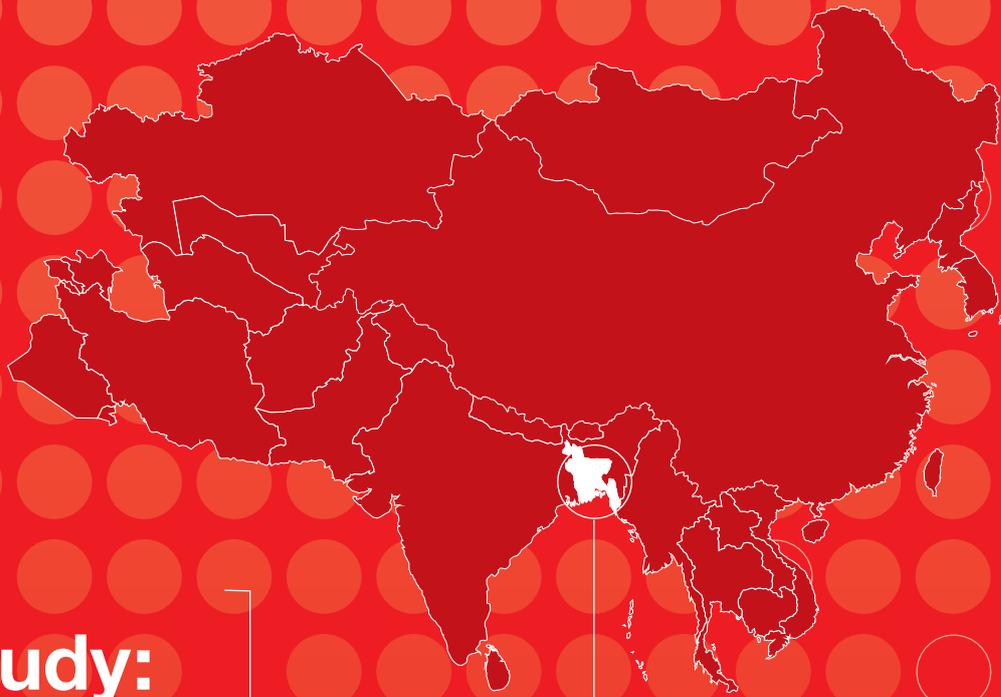
This policy brief focuses on how countries collect data on premature mortality due to CVD. It aims to provide snapshots of how CVD monitoring and surveillance is currently being carried out across the globe in a variety of settings, using the indicator of premature mortality as a point of reference. Based on a review of 23 studies, it presents a range of examples organized by region and country.

Identifying gaps in CVD monitoring and surveillance

The literature review, complemented by interviews with global experts in the field, indicates that countries face the following challenges:

- **Lack of resources:** Many countries lack adequate resources, including a dedicated budget, for CVD monitoring and surveillance. Other countries fail to allocate available resources. Experts note that underinvestment in health information systems often leads to gaps in data collection and analysis.
- **Limited workforce capacity:** Lack of funding for training within the health workforce exacerbates already limited technical expertise and impedes reliable and robust data collection. When surveillance systems fail to designate dedicated staff to maintaining vital registration, disease registries and hospital records, surveillance capacity suffers.
- **Lack of political will:** National surveillance programmes are hampered by a lack of commitment of both politicians and health policy makers, and a subsequent lack of priority accorded to NCDs, including CVD, and their surveillance.
- **Limited data collection mechanisms:** Many countries, particularly low-to-middle-income countries (LMICs), lack the capacity to collect basic data through vital registration, which is essential for accurate CVD mortality data among other uses. They also have insufficient capacity to collect data on risk factors, service statistics and health management, or to maintain disease-specific registries. Their limited capacities in data collection inhibit the generation of financial information, assessments of health equity, and explorations into the social and economic determinants of health.
- **Failure to use CVD data for policy making and planning:** In some cases, countries may collect valuable surveillance data, but fail to use it as a tool for policy making and planning. This can occur when countries lack established mechanisms for data dissemination to the appropriate decision-makers, or for a variety of other reasons, including lack of political will.
- **Absence of harmonization of data:** When countries fail to harmonize different national surveys and to streamline data collection through various sources they often face costly duplications instead of building greater efficiency through synergy. Failure to harmonize data collection results in a limited capacity to generate national CVD health information.

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Case study: Bangladesh

Bangladesh represents an interesting case of an LMIC that has begun to recognize NCDs as a major health threat and has made strides in policy development to address the epidemic, but where unfortunately implementation has not kept apace.

The country has adopted a national NCD plan, the Strategic Plan for Surveillance and Prevention of Non-communicable Diseases in Bangladesh, (2007– 2010; 2011-2015). The Health, Population and Nutrition Sector Development Program (2011-2016) identifies CVDs, diabetes and cancer as major public health problems, and includes an operational plan to reduce NCD morbidity and premature mortality. Bangladesh has begun to collect NCD data through the Bangladesh Network for Noncommunicable Disease Surveillance and Prevention (BanNet), and the National Survey on NCD Risk Factors (using the WHO STEPwise approach). The Alliance for Community Based Surveillance (ACSNet) promotes periodic population-based surveys of NCDs and their risk factors, and the Matlab Health Research Center collects selected NCD-related risk factors, morbidity and mortality data.

While these steps signal a growing commitment to addressing NCDs, the country currently lacks national surveillance of NCD-related morbidity and mortality, and there are no national CVD surveillance mechanisms in place. The relative success that Bangladesh has experienced in maternal and child health indicates that the country has the capacity to bring about real change in its health sector, and lessons learned from these achievements could potentially be applied to the control of NCDs.

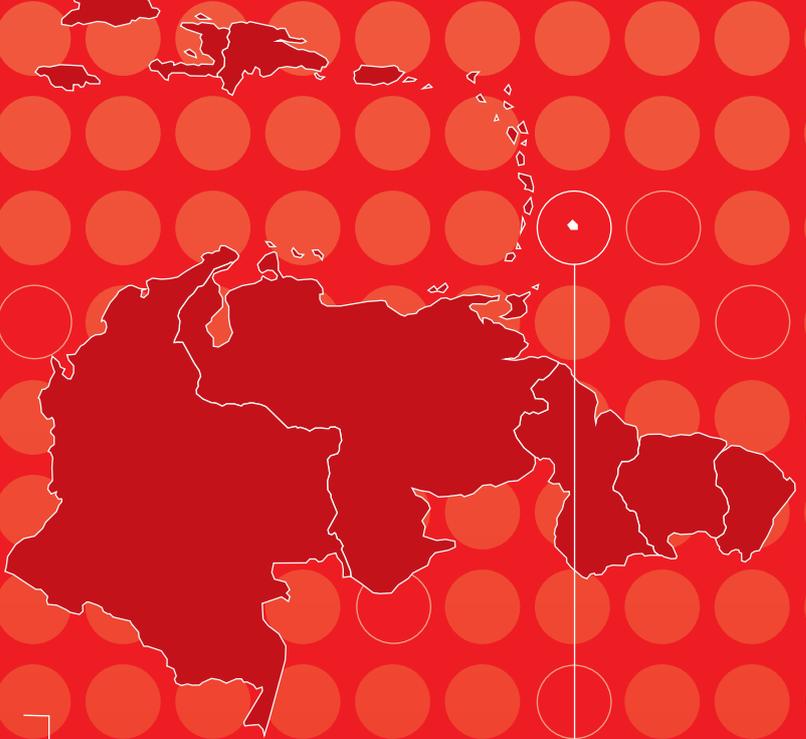
To address knowledge gaps that hamper NCD surveillance capability, it is recommended that the country:

- expand surveillance activities to include the measurement of NCD-related morbidity and mortality;
- improve the monitoring and evaluation of existing and planned NCD programmes; and
- identify remedial risk factors specific to the population.

Recommendations for addressing gaps in CVD surveillance and monitoring

We recommend the following interventions to build effective CVD monitoring and surveillance as part of an overall strategy to: enhance quality of care for CVD patients; strengthen health systems; and support the delivery of the WHO NCD goal of “25 by 25”:

- **Align national targets with global targets and use WHO NCD Global Monitoring Framework (GMF) indicators to monitor progress towards 2025 targets:** When national targets are aligned with global targets as specified in the GMF, and indicators are defined in a standardized way, comparability of data between countries will be enhanced.
- **Build capability to track trends in risk factors as part of a surveillance strategy:** Experts call for investments in developing and institutionalizing surveillance, monitoring and health information systems, including the enhancement of capacity to track trends in risk factors.
- **Strengthen national civil registration systems (births, deaths, causes of deaths):** Some experts recommend that countries strengthen vital registration systems by passing and enforcing legislation to make recording of deaths mandatory by law. Other strategies include building capacity of physicians and other health care providers (in both curricula during training and through in-service training) to record deaths appropriately, thus standardizing cause-of-death reporting. In settings where physician certification of deaths is not possible, experts recommend the implementation of verbal-autopsy-based assessment. Ideally, countries would develop the capabilities to leverage unique citizen identifications (IDs) to create national mortality databases.
- **Invest in capacity building for technical expertise:** An investment in technical expertise will ultimately build capacity for reliable and robust data collection systems that are timely, acceptable and representative.
- **Expand the range of existing national surveys, include coverage of CVD key interventions in national health information systems, and harmonize data sources:** Some experts recommend incorporating CVD and NCD indicators into existing national surveys and data collection systems, where possible, and harmonizing national surveys and data sources to avoid duplication and wasteful expenditure. In settings where incorporating additional indicators into existing data collection systems is not feasible, experts suggest piloting new CVD/NCD surveillance systems and scaling up to national coverage based on results and lessons learned.
- **Strengthen existing data collection systems in the health sector and non-health sector:** Some experts see the potential in both strengthening health sector data collection (e.g., hospital administrative data) and relevant non-health sector data collection (e.g., tracking sales of oil, sugar, salt and alcohol to estimate per capita consumption, etc.). They recommend strengthening data collection systems in hospitals, including those in the private sector, by, for example, developing and implementing transferable electronic health records for patients based on unique citizen IDs.
- **Learn from the experience of countries that have strong surveillance capabilities and from successful surveillance strategies for communicable diseases:** Experts point to the experience of countries such as Finland, the US and the UK in tracking CVD-related risk factors and disease, as well as health service delivery and outcomes. Other experts concur that monitoring strategies used in communicable disease surveillance (e.g., tuberculosis) can be leveraged with suitable adaptations.
- **Enhance global mechanisms to monitor country capacity in CVD surveillance:** Efforts to strengthen the monitoring of country capacity in CVD surveillance will ultimately yield more reliable data as the publication of these data will be a “stimulus for countries to examine and improve their data.” In addition, experts recommend that future assessments of country CVD surveillance efforts include details of NCD funding as a percentage of total health budget and staffing.
- **Overcome political inertia and draw attention to the importance of CVD surveillance:** Experts recommend advocacy and the dissemination of data in easy to read formats to encourage utilization of data for action, and building community partnerships with a range of stakeholders (i.e., government, local authorities, public health workers, academics, researchers, etc.) to enhance the acceptability and accountability of surveillance data.



Case study: Barbados

Barbados illustrates an interesting trajectory in its development of NCD surveillance and monitoring capacity with its development of the first national, population-based, multiple disease NCD registry in the Caribbean – the Barbados National Registry for Chronic NCDs (BNR).

The architects of the new system combined the different components (BNR-Stroke, BNR-Heart and BNR-Cancer) into a shared registry to maximize efficiency and cut costs through sharing of staff and office space. Basing their development of datasets on international guidelines and other countries' models, they launched the system through a phased introduction. The CVD components (BNR-Heart/Stroke) identify incident cases prospectively and follow the WHO STEPwise approach to stroke surveillance, collecting data from hospital, national death register and community sources. Sustainability remains a challenge for the BNR and finding qualified personnel presents difficulties for a country with a small population.

It is anticipated that future surveillance costs will be lower due to the introduction of electronic health information systems throughout the country. An initial challenge of launching the BNR was a lack of understanding of it by the general population and health care providers, including concerns about confidentiality. As a successful model of a multi-NCD registry that has recorded baseline incidence and post-event mortality for CVD patients, the story of the launch of the BNR can be instructive to other limited resource settings.



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