Surveillance of stroke: a South-East Asia Region (SEAR) perspective

Yogeshwar V. Kalkonde,[a,*] Sukanya Rangamani,[b] Nijasri C. Suwanwela,[c] Prashant Mathur,[d] Ranjit J. Injety,[e] Ivy A. Sebastian,[f] Pranay J. Vijayanand,[g] Nistara S. Chawla,[h] P. N. Sylaja,[i] Meenakshi Sharma,[j] and Jeyaraj D. Pandian[k,**]

[a]Sangwari, Ambikapur, District Surguja, Chhattisgarh, India
[b]National Centre for Disease Informatics and Research, Indian Council of Medical Research, Bangalore, Karnataka, India
[c]Division of Neurology, Department of Medicine, King Chulalongkorn Memorial Hospital, Bangkok, Thailand
[d]National Centre for Disease Informatics and Research, Indian Council of Medical Research, Bangalore, Karnataka, India
[e]Department of Neurology, Christian Medical College and Hospital, Ludhiana, Punjab, India
[f]Consultant Neurologist, St. Stephen's Hospital, New Delhi, India
[g]Department of Neurology, Christian Medical College & Hospital, Ludhiana, Punjab, India
[h]Department of Neurology, Christian Medical College & Hospital, Ludhiana, Punjab, India
[i]Department of Neurology, Sree Chitra Tirunal Institute for Medical Sciences and Technology, Thiruvananthapuram, Kerala, India
[j]Division of Non-Communicable Diseases, Indian Council of Medical Research, New Delhi, India
[k]Department of Neurology, Christian Medical College, Ludhiana, India

The Lancet Regional Health - Southeast Asia 2023;17: 100286
https://doi.org/10.1016/j.lansea.2023.100286

Summary

Surveillance of stroke is critical to track its burden and assess progress in prevention and treatment. We reviewed the literature to evaluate stroke surveillance efforts in the South-East Asia Region (SEAR) countries, identify progress and assess gaps. Epidemiological data on all the major parameters such as the incidence, prevalence and mortality of stroke were available for India and Thailand but for none of the other SEAR countries. Most of the epidemiological data came from investigator-initiated studies. National stroke surveillance was present only in India in the form of a National Stroke Registry Programme and Thailand has a national database that was used to obtain epidemiological data for stroke. Research on novel methods for stroke registration, such as using information technology, was absent. This review identified serious gaps in the monitoring and surveillance of stroke in SEAR countries. Systematic efforts are needed to fill those gaps.

Keywords: Surveillance; Stroke; Epidemiology; Risk factors

Introduction

Stroke has emerged as a major global public health problem. Worldwide, it is the second leading cause of death and the third leading cause of death and disability combined.[1] Currently, nearly three-quarters of the global stroke burden falls in low- and middle-income countries (LMICs), where health services for stroke prevention and treatment are often inadequate. These inadequacies lead to excess morbidity and mortality.[2–4]

As defined by the World Health Organization (WHO), the South-East Asia Region (SEAR) consists of Bangladesh, Bhutan, India, Indonesia, Maldives, Myanmar, Nepal, the Democratic People's Republic (DPR) of Korea (North Korea), Sri Lanka, Thailand, and Timor-Leste.[5] These are low- or middle-income countries and harbour one-fourth of the world's population.[6] Premature mortality due to stroke weighs heavily on these societies,[4] where accessing and affording preventative and medical services for stroke are major challenges.[3] Because many of the SEAR countries do not have effective Universal Health Coverage, stroke care can lead to excessive health expenses and impoverishment.[7] It is therefore important that stroke surveillance be conducted in these countries to understand the burden of stroke, implement interventions systematically to reduce that burden and assess the impact of those interventions.

The WHO has developed a STEPwise approach to the surveillance of stroke and its risk factors.[8,9] This approach has standardized methods and tools for such surveillance, enabling within and between-country comparisons. However, the STEPwise approach has not been adopted by most SEAR countries. This is partly because of the low capacity of their health systems for such monitoring and because of an emphasis on the unfinished agenda of maternal and child health.

We conducted a systematic review of published literature over the last 25 years to understand stroke and risk-factor surveillance in SEAR countries. In the process, we identified both surveillance gaps and surveillance good practices.

DOIs of original articles: https://doi.org/10.1016/j.lansea.2023.100289, https://doi.org/10.1016/j.lansea.2023.100290, https://doi.org/10.1016/j.lansea.2023.100292, https://doi.org/10.1016/j.lansea.2023.100298
*Corresponding author.
**Corresponding author.
E-mail addresses: yvkalkonde@gmail.com (Y.V. Kalkonde), jeyaraj.pandian@cmcludhiana.in (J.D. Pandian).

Stroke surveillance system framework

Surveillance involves ongoing, systematic collection, analysis, and interpretation of health-related data essential to planning, implementation, and evaluation of public health practice.[10] Compared to other chronic diseases like ischemic heart disease or cancer, stroke lends itself especially well to surveillance because it is easily defined clinically. The WHO definition of stroke ("a focal (or at times global) neurological impairment of sudden onset, and lasting more than 24 h (or leading to death) and of presumed vascular origin") is commonly used in stroke surveillance studies in SEAR countries.[11]

The WHO advocates using the STEPwise approach to stroke surveillance. That approach tailor's surveillance to the resources available in each country and has sustainable surveillance as the goal. The first step of the STEPs surveillance involves capturing information on those who are hospitalised or admitted to other health facilities for stroke. The second step involves capturing information on those who have died outside hospitals, and the third step involves capturing information on the survivors who are managed outside hospitals.[12] The first group of patients is identified through hospital-based stroke registries, the second through population-based mortality surveillance, and the third through population-based stroke registries or surveys. The STEPwise approach has identified a core and an expanded set of data that needs to be collected for each of the above steps (Fig. 1). The core data can be collected easily while collecting the expanded data needs additional resources.

Hospital-based stroke registries

Hospital-based stroke registries (HBSRs) are relatively easy to establish for stroke surveillance. In their simplest form, these registries collect information about the age and sex of patients with stroke, whether it is a first time-ever or recurrent event, and the vital status during the hospital stay. The expanded data set includes brain imaging to determine whether the stroke was ischaemic or haemorrhagic. These registries are often investigator-initiated, relatively easy to implement, and often the first tools of stroke surveillance in the LMICs.

Among the SEAR countries, hospital-based stroke registries have reported data from India,[13–15] Indonesia,[16,17] Sri Lanka[18,19] and Thailand.[20] We did not come across such data from the other SEAR countries in the last 25 years. These registries have provided valuable information on the average age of the patients, female-male distribution, presence of risk factors, types of strokes and the aetiological subtypes of ischemic stroke among the admitted patients. For example, the Hyderabad stroke registry in India[14] and data from Thailand[21] showed that ischemic stroke was the commonest stroke type, accounting for close to 80% of total stroke cases. Haemorrhagic strokes accounted for the remaining 20%. In the Hyderabad stroke registry, large-artery atherosclerosis was the commonest aetiology for ischemic stroke, and in this group of patients, intracranial atherosclerosis was the commonest mechanism.[14] In the largest prospective ischemic stroke registry from India, large-artery atherosclerosis and cardioembolic strokes constituted 29.9 and 24.9% of all ischaemic strokes, respectively.[15] Hospital-based data from Thailand showed a different finding, as lacunar strokes were the most common subtype of ischemic stroke in this country.[22] In the SEAR countries currently, the tenth or the eleventh versions of the International Classification of Diseases (ICD-10 or 11) system are not routinely used to log stroke diagnoses for discharge or billing, and that limits the ability in these countries to use such hospital-based data for stroke surveillance.

Another limitation of these registries is that they are primarily located at tertiary care centres in cities. While many patients from rural areas may travel to cities to seek care, data from these registries might miss out on patients from rural areas who are unable to travel due to social or financial reasons. This might impact the stroke

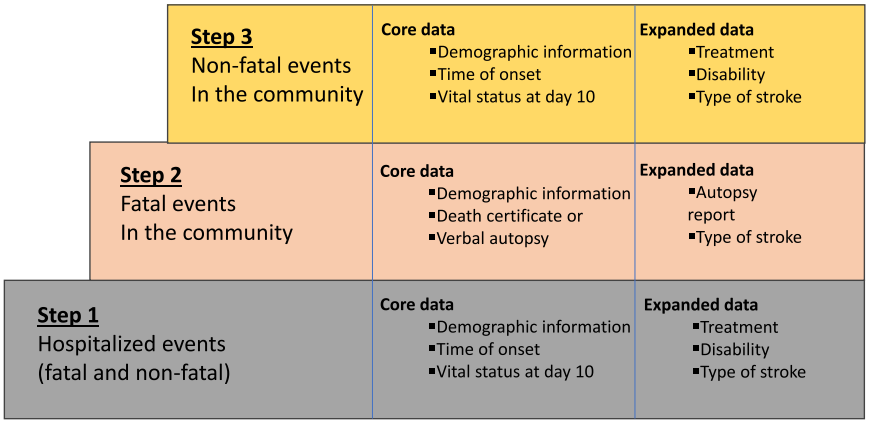

Fig. 1: **Steps and data requirements in the World Health Organization's STEPwise approach to stroke surveillance.**

subtypes and the risk-factor distribution reported by these registries. This potential limitation is illustrated by the data from the Ludhiana population-based stroke registry in northern India. In this registry, ischemic strokes were more common in urban areas, while risk factors such as high blood pressure and alcohol use were more common in rural areas.[23] Furthermore, investigations to determine the ischemic-stroke subtype may be incomplete in the registries due to resource limitations such as lack of Magnetic Resonance Imaging or echocardiography. This and other missing data in the hospital-based registries in resource-poor settings can limit the usefulness of the registries. Another limitation of the HBSRs is that they provide information on stroke subtypes and risk factors among patients admitted with stroke but do not provide information on the burden of stroke in the community.

Systems to monitor mortality due to stroke

After HBSRs, the next level of stroke surveillance is monitoring stroke mortality. It is estimated by counting total deaths due to stroke, those occurring in hospitals as well as at home, in a defined population. For deaths occurring in a hospital, medical certificates of cause of death can be used to ascertain deaths due to stroke. However, in many SEAR countries, a majority of sick patients die at home. For example, in a study from rural India, close to 90% of deaths from stroke occurred at home and thus were not medically certified.[24]

Civil Registration and Vital Statistics (CRVS) systems that compulsorily record all births and deaths, issue birth and death certificates, and provide information on the cause of death form the bedrock of population-wide mortality surveillance. However, CRVS systems often function sub-optimally in LMICs, including many SEAR countries, and that limits stroke-mortality surveillance in those countries. In settings where CVRS is not available and medical certification of cause of death is inadequate, a "verbal autopsy" surveillance system can be used to estimate causes of death.[4,24] A "verbal autopsy" is a narrative description of circumstances that led to death, plus answers to a series of questions seeking additional, specific information. While verbal autopsies perform well in identifying stroke deaths, some stroke deaths may get erroneously labelled as cardiac-arrest deaths, leading to an underestimation of stroke mortality.[25] Such a system of mortality surveillance using verbal autopsies reports on crude stroke mortality rates as well as age-standardized rates. This system also provides information on age- and sex-specific stroke mortality that can be compared to that of other countries in the region.

Estimates of the stroke mortality rate were reported in peer-reviewed studies from Bangladesh,[26] India[4,24,27] and Indonesia.[28,29] These were mostly based on investigator-initiated population-based studies. Additionally, the Global Health Observatory of the WHO reported stroke-mortality rates for all the SEAR countries based on a combination of sources, such as national vital-registration data, United Nations partners and inter-agency groups, technical programmes of the WHO, the Global Burden of Disease (GBD) and other scientific studies.[30] For some countries, deaths due to stroke were reported as the fraction of total deaths in the country and not as mortality rates. For example, in DPR Korea stroke accounted for 7% all of deaths,[31] while in Thailand stroke accounted for 12.2% of all deaths among women and 9.6% among men.[32] In India, the "Sample Registration System" under the Registrar General of India is a national system that monitors the cause of death using verbal autopsies,[4] and Thailand has a National Mortality Register.[33] We did not come across national systems to monitor deaths in the other SEAR countries. In a significant contribution to global stroke surveillance, the GBD study used mathematical models to provide estimates of stroke mortality. The estimates of mortality due to stroke in the SEAR countries are shown in Fig. 2. It shows a higher (100 or more per 100,000 population) stroke mortality rate in Bangladesh, Indonesia, Myanmar and DPR Korea compared to the other SEAR countries. However, we did not come across much primary data on stroke mortality in some SEAR countries, and it is likely that some of these estimates may be generated using mathematical models and could be skewed. Therefore, efforts are needed to capture and report more primary data on stroke mortality in these countries.

Early mortality due to stroke in the form of 28- or 30-day case-fatality rates have been reported in population-based studies from India and Thailand. One study from an urban city centre in eastern India has reported a high 30-day case-fatality rate of 41.1%.[34] A study from northern India has found a 28-day case-fatality rate of 22%,[35] and one from southern India found a rate of 24.5% in urban and 37.1% in rural populations.[36] Based on the National Health Security Office (NHSO) database, the 30-day case-fatality rate was 16.9% in Thailand.[37] It is important to note that the disparities in 30-day case-fatality rates depend upon various factors, including the severity of stroke, access to care and the quality of stroke care available.

Monitoring of stroke events in the community

Monitoring of all stroke events, fatal or non-fatal, in a defined community forms the third level of stroke surveillance. Such a system captures all strokes, including those not leading to hospitalization. Population-based stroke registries (PBSRs), and population-based cross-sectional or longitudinal studies in a well-defined population capture such data over a continuous time period and are the most important tools of stroke surveillance. They provide data on the prevalence of stroke (current status) and its incidence (risk of stroke) in the given population.

Population-based surveys or registries from Bangladesh,[38–40] India,[23,34,35,41–48] Indonesia,[49,50] Myanmar,[51]

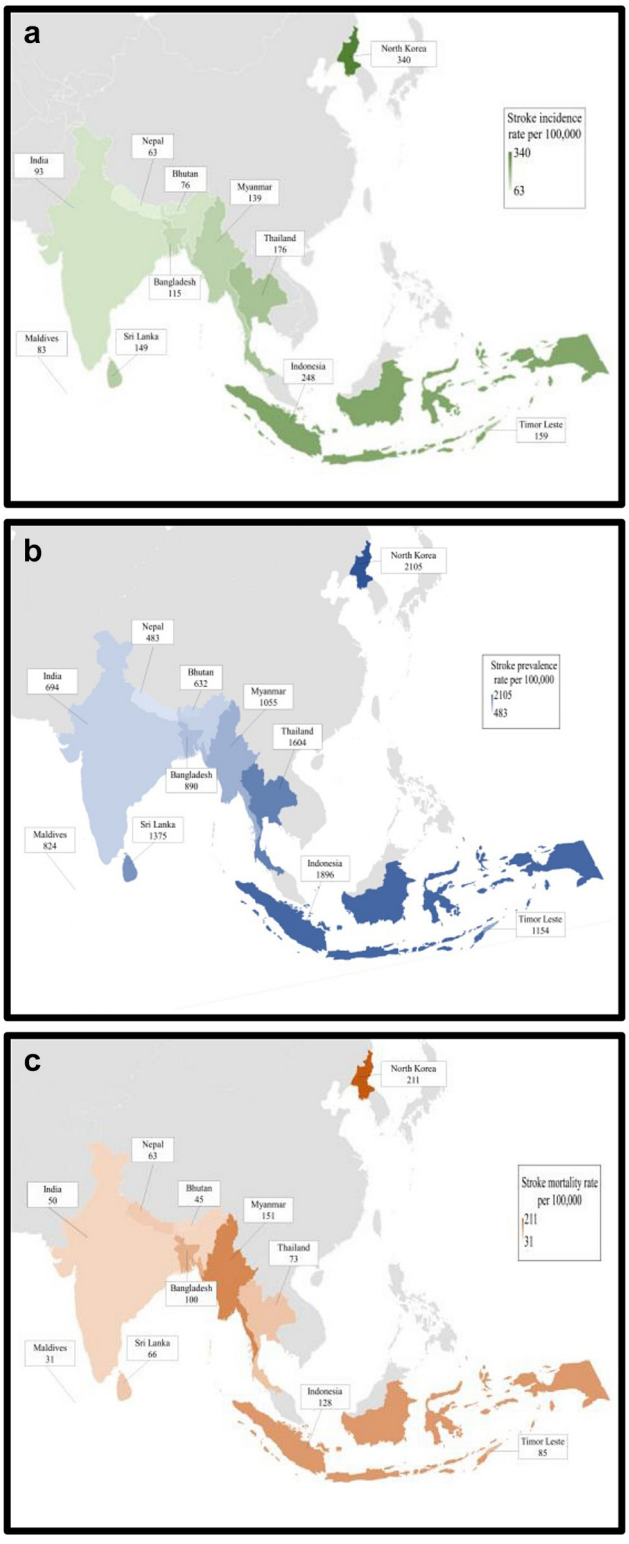

Fig. 2: Estimates of incidence (a), prevalence (b) and mortality (c) due to stroke in 2019 from the Global Burden of Disease study for the SEAR countries.

Nepal,[52] Sri Lanka,[53] DPR Korea,[31] and Thailand[54–56] have reported data on stroke prevalence (Table 1). Data on stroke incidence were extremely rare, as they need population-based longitudinal studies. Only India and Thailand had such studies.[34–37,57–61] As the majority of the population in the SEAR countries reside in rural areas, it is important that rural populations be represented in the PBSRs. Unfortunately, many SEARs countries do not have data on the epidemiological parameters of stroke in their rural areas (Table 2). The Trivandrum registry[36] in the state of Kerala in the southern part of India and the Ludhiana registry in northern India[41] are examples of PBSRs that have covered both the urban and the rural populations and have provided valuable information.

The estimates of stroke prevalence and incidence based on the GBD study are shown in Fig. 2 and show a higher prevalence and incidence in DPR Korea, Indonesia, Myanmar, Sri Lanka, Thailand, and Timor-Leste compared to the other SEAR countries.

National stroke registries

Most of the studies on stroke surveillance in the SEAR countries are investigator-initiated. Such studies might lack sustained funding, be conducted over a short duration, be restricted to smaller geographies, and have varying methodologies. These shortcomings underscore the need for government-initiated, long-term mechanisms for

Country	Mortality	Prevalence	Incidence
	Range	Range	Range
Bangladesh	140[26]	196–1139[38,39] 300 (above 40 years)[40]	NA
Bhutan	NA	NA	NA
India	52–122[4,24,27]	53–471[34,35,41–44] 382–3339 (above 45 years)[45–48]	108–171[34–36,57–61]
Indonesia	56–193[28,29]	830–1400[49,50]	NA
Maldives	NA	NA	NA
Myanmar	NA	6700 (above 40 years)[51]	NA
Nepal	NA	2368[52]	NA
DPR Korea	NA	178[31]	NA
Sri Lanka	NA	1004[53]	NA
Thailand	NA[a]	122[54] 1880 (45–80 years)[55] 3990 (among hypertensive patients)[56]	303[37]
Timor-Leste	NA	NA	NA

Data are crude rates per 100,000 population, where not indicated, rates are from studies or surveys that include all population or up to or more than 25 years of age, for other studies age groups are specified in the parentheses. [a]Thailand has mortality data reported as percentages of total deaths due to stroke. NA-data not available.

Table 1: **Country-wise availability of surveillance data on stroke between 1997 and 2022.**

stroke surveillance. One example of such an initiative is the National Stroke Registry Programme (NSRP) implemented by the National Centre for Disease Informatics and Research of the Indian Council of Medical Research, which runs both hospital- and population-based registries.[62] This programme aims to estimate stroke incidence reliably and to assess stroke subtypes, treatment patterns, complications, disability, quality of care, case-fatality and survival rates. The stroke registries under this programme collect data in standard formats by reviewing medical records from all health facilities and imaging centres that cater to stroke patients in a defined geographical area. In addition, dedicated staff follow-up on patients to ascertain disability and survival at day 28 (PBSR and HBSR) and 3 months (HBSR) after the onset of symptoms. This system provides estimates of incidence and mortality due to stroke. Currently, there are five PBSRs under this programme, each of which covers a population of 1–2.5 million.

Although Thailand doesn't have a national stroke registry programme, it has Universal Health Coverage, and more than 80% of the population is covered by health insurance. The NHSO database has information on most stroke admissions in Thailand and the annual estimates of stroke incidence and case-fatality rates are reported using this database.[37] We did not come across any national programme for stroke registries in the other SEAR countries (Table 2). While such national programmes have distinct advantages listed above, the quality of data reported by them will depend upon the technical capacity available in such systems, including whether there is adequate coverage of the population and whether various population sub-groups are adequately represented.

Digital health systems and stroke surveillance

Currently, SEAR countries rely mostly on paper-based systems for stroke surveillance. Because of the extra time required for processing data collected on paper, the data are often reported several years after they are collected. Digital systems and electronic records for stroke surveillance can reduce some of the delays in data collection, analysis, and reporting. For example, the NSRP in India uses information-technology tools for data collection, management, and analysis. In Thailand, the national reimbursement database was successfully used to estimate the prevalence and incidence of stroke.[37,54] The use of electronic medical records in hospitals can lead to relatively easy pooling of data to calculate stroke admissions nationwide, as is currently done in high-income countries. Eventually, live data can be obtained at the country level using hospital records.

Monitoring the risk factors for stroke

Stroke is preventable. Ten major risk factors account for 90% of the risk of stroke,[63] and the control of risk factors can reduce stroke rates nationwide. Various hospital- and population-based stroke registries as well as population-based studies have provided information on the distribution of risk factors among stroke patients from the SEAR countries.[63–65] These investigations have shown that the risk factors for stroke in SEAR countries are largely similar among themselves and to high-income countries. There is an urgent need among the SEAR countries for sustained monitoring of stroke risk factors and their control. Available data on stroke risk factors from population-based studies are shown in Table 3.

Country	Hospital-based stroke registries	Population-based mortality surveys or systems to monitor stroke mortality	Population-based stroke surveys or registries		National stroke programme
			Rural	Urban	
Bangladesh	–	–	Yes[38,39]	Yes[38]	–
Bhutan	–	–	–	–	–
India	Yes[13–15]	Yes[4,24,27]	Yes[36,58,61]	Yes[34–36,57,59,60]	Yes[62]
Indonesia	Yes[16,17]	–	Yes[49,50]	Yes[49,50]	–
Maldives	–	–	–	–	–
Myanmar	–	–	–	Yes[51]	–
Nepal	–	–	Yes[52]	Yes[52]	–
DPR Korea	–	–	–	–	–
Sri Lanka	Yes[18,19]	–	–	–	–
Thailand	Yes[20]	Yes[33]	Yes[37,54]	Yes[37,54]	–
Timor-Leste	–	–	–	–	–

Table 2: **Registries, surveys and monitoring systems for stroke in the past 25 years in the SEAR countries.**

National non-communicable diseases (NCD) risk monitoring surveys

In the SEAR countries, studies on stroke risk factors are often done in the HBSRs and PBSRs and often in smaller geographies. While these studies provide

Country	Population-based studies on stroke risk factors		National NCDs monitoring surveys
	Rural	Urban	
Bangladesh	Yes[38]	Yes[38]	–
Bhutan	–	–	Yes[66]
India	Yes[36,58]	Yes[23,36]	Yes[67]
Indonesia	–	–	–
Maldives	–	–	–
Myanmar	–	–	Yes[68]
Nepal	Yes[52]	Yes[52]	–
DPR Korea	–	–	–
Sri Lanka	–	Yes[53]	–
Thailand	Yes[54]	Yes[54]	Yes[69]
Timor-Leste	–	–	–

Table 3: **Population-based data on the risk factors for stroke and national NCDs monitoring surveys.**

valuable information regarding the control of stroke risk factors, they may not be representative of the entire country. The WHO has therefore promoted national NCD risk-factor surveys for the surveillance of cardiovascular risk factors. These surveys can provide a comprehensive picture of risk factor control and spur action at the national level (Table 3). Results of such surveys are reported for Bhutan, India, Myanmar and Thailand.[66–70] For example, the survey conducted in Bhutan in 2014 revealed significant under-diagnosis and under-treatment of hypertension, the most important risk factor for stroke. Sixty-five per cent of those with hypertension were unaware of the diagnosis and only 5.7% of the hypertensive patients who were receiving treatment had their blood pressure adequately controlled.[66] The National NCD Monitoring Survey (NNMS) conducted in India in 2017–18 collected information on NCD risk factors, their control and the response of the health systems. It showed clustering of three or more cardiovascular risk factors among 40% of adults aged 18–69 years. Also, 13% of adults 40–69 years of age had a 10-year risk of cardiovascular disease that exceeded 30%.[67] Furthermore, among patients with diagnosed hypertension, only 13% had their blood pressure adequately controlled.[70] In Myanmar, the National STEPs survey in 2009 found that the prevalence of hypertension was 29.3% in women and 31% in men.[68] Thailand conducts National Health Examination Surveys (NHES) every five years. The NHES VI survey, conducted in Thailand in 2019, showed that the prevalence of hypertension in those aged 15 or more was 25.4%.[69] These surveys show a heavy burden of poorly controlled cardiovascular risk factors in the SEAR countries. To evaluate the progress made by the NCD control programmes and to take appropriate actions, all the SEAR countries should conduct such surveys every five years. Different survey methods used by the countries could limit comparisons amongst the countries. This problem could be overcome if all countries used the STEPs approach promoted by the WHO for NCD risk-factor monitoring.

Levels of stroke surveillance among SEAR countries

Our systematic review revealed that there are multiple gaps in stroke surveillance in the SEAR countries. We propose a framework to assess the level of stroke surveillance in a country (Table 4). In the framework, stroke surveillance levels range from zero (no HBSR in the country) to V [the presence of a national stroke registry programme covering a sizable population (>50%) of the country with real-time data]. There are several countries such as Bhutan, Maldives and Timor-Leste that do not have any published studies on stroke surveillance. Bangladesh, Bhutan, Maldives, Myanmar, Nepal, DPR Korea, and the Timor-Leste do not have published results from any stroke registry and thus have a surveillance level of zero (Table 4). The only data these countries have are on stroke mortality that are reported by the Global Health Repository.[30] India has published data on mortality, prevalence and incidence of stroke; and it has a national registry programme that covers less than 50% of the population. Thus, it has a stroke surveillance level of III. Thailand has reported annual national data on stroke incidence, percentage of total deaths due to stroke, and 30-day case-fatality rates for a majority of the population of the country based on a national database and thus has a stroke surveillance level of IV. This national database can potentially be used to obtain real-time stroke incidence and mortality data, and thus Thailand might readily be able to develop level V stroke surveillance.

Challenges and gaps in research

Stroke surveillance in SEAR countries suffers from insufficient country-level technical capacity, prioritization, and funds. A significant population of these

Level	Characteristics	SEAR countries
0	No hospital based stroke registries	Bangladesh, Bhutan, Maldives, Myanmar, Nepal, DPR Korea, Timor-Leste
I	Limited number of hospital-based stroke registries	India, Indonesia, Sri Lanka, Thailand
II	Limited number of population-based stroke surveys or registries	India, Thailand
III	National stroke registry programme covering non-sizable population of the country (<50%) without real time data	India
IV	National stroke registry programme covering a sizable population (>50%) of the country without real time data	Thailand[a]
V	National stroke registry programme covering sizable population (>50%) of the country with real time data	None

[a]Does not have a stroke registry programme as such but has a National Health Security Office database which has data on more than 80% of the insured population and can potentially be used to monitor annual stroke incidence and mortality at the national level.

Table 4: **Proposed levels of stroke monitoring and surveillance system.**

Challenges	Proposed solutions
Lack of prioritization of stroke surveillance within the health system in SEAR countries leading to paucity of primary data	Advocacy by the World Health Organization, World Stroke Organizations and country-level champions
Lack of country-level technical capacity and trained human resource to conduct surveillance	Technical capacity building of country-level human resource through training by the World Health Organization, it's collaborating centres or by other SEAR countries with such a capacity
Lack of sustained funding support for stroke surveillance	Funding support through the World Health Organizations or local governments Sustained and systematic stroke surveillance through national programmes
Poor representation of rural areas where a majority of the population lives in stroke surveillance efforts	Building capacity to develop population-based stroke registries where surveillance can be conducted over a defined time intervals and nesting stroke surveillance within non-communicable disease surveillance to reduce costs
Paper-based data collection methods which delays reporting	Use of digital tools and open access platforms for data collection using standardized methods
Lack of uniform stroke surveillance methodology including standardization and validation	Use of standardized tools such as those developed under the STEPs approach for the stroke surveillance by the World Health Organization
Need for active surveillance as hospital administrative data are not available	Strengthening civil registration and vital statistics systems Use of ICD-10 or -11 codes for discharge diagnosis and in death certificates in hospitals to make stroke surveillance easy Universal health coverage so that insurance claims data can be used for stroke surveillance
Lack of research on novel methods of stroke surveillance which can be used in resource limited settings	Research on the use of mobile phone and other digital technologies to simplify stroke surveillance

Table 5: **Current challenges and proposed solutions to improve stroke surveillance in the SEAR countries.**

countries lives scattered in rural areas, where people do not have easy access to health care, including brain imaging. They may not seek modern medical care, making surveillance more challenging. Additionally, the lack of uniform stroke surveillance methodology with appropriate standardization and validation hinders inter-country comparisons. The use of comprehensive health insurance data could improve stroke surveillance, but of the SEAR countries, only Thailand has comprehensive health insurance. Also generally lacking in the SEAR countries is research on novel methods for stroke surveillance, such as the use of information technology, that can be deployed easily in resource-poor settings. However, these obstacles are not insurmountable and can be addressed systematically (Table 5).

The way forward

There is an urgent need to build capacity in SEAR countries for sustained stroke surveillance. This can be done through a WHO collaborating centre for improving stroke surveillance, initially at the regional level and then at the country level. We propose a stepwise roadmap to improve stroke surveillance in the SEAR countries (Fig. 3).

To begin with, one or two academic centres in the country can be identified to start HBSRs and their capacity can be built through the collaborating centre. These centres can then become the training centres to set up more HBSRs in that country.

Strengthening CRVS systems to monitor the causes of deaths is crucial to improving stroke surveillance in the SEAR countries. In countries where deaths commonly occur at home, verbal autopsy-based monitoring of deaths could be deployed. The unavailability of physicians to code the cause of death hinders the reporting of the causes of death, but recent developments in computer technology are helping to automate the coding process.[71] Such technological advances can be leveraged to improve CRVS systems.

In the countries with no PBSRs, one or two registries could be started that cover both the rural and urban populations. These can be spearheaded through academic institutions initially and then extended through the national government. A National HBSR program can link multiple HBSRs to provide dynamic and live data. This should be followed by setting up a national PBSR programme to ensure representative data from all parts of the country. To reduce operational costs, these PBSRs can also include surveillance for other NCDs, and the surveillance can be done every 5–7 years. National NCD stroke risk-factors surveys need to be conducted to monitor the control of those risk factors. Finally, all these national data on stroke can be collated under a national stroke surveillance programme.

To improve stroke surveillance, technology can be used innovatively. Digital tools could be used to collate data, link records, remove duplicity, and facilitate patient opt-in consent for data sharing. Given that some of the SEAR countries have limited resources, such tools can be developed by the WHO, or the few SEAR countries with such capabilities can share their tools. For example, the digital tools for stroke surveillance used in the NSRP and NNMS of India can simplify analysis and reduce reporting time. Gradually, the technical capacity

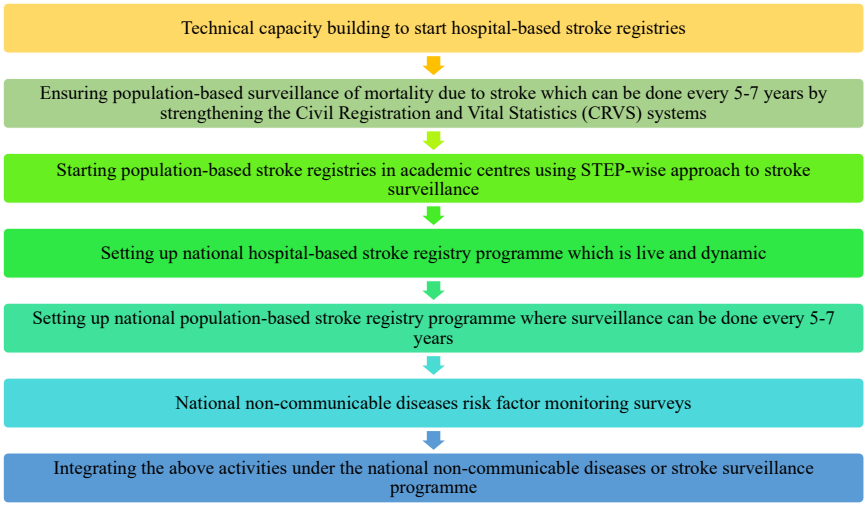

Fig. 3: The proposed steps for systematic development of stroke monitoring and surveillance capabilities in the SEAR countries.

to handle these tools can be built in the SEAR countries with low resources. Now a significant proportion of households in the SEAR countries have access to mobile phones. Mobile phones can potentially be used to notify stroke events. An open-source digital platform can also be developed for stroke registration in SEAR countries that lack technical capacity.

Needless to say, developing stroke surveillance needs to go hand in hand with developing stroke care and preventive services. Controlling key risk factors for stroke will be important. The National Programme for Prevention and Control of NCDs in India, the India Hypertension Control Initiative and the 5-Year National NCDs Prevention and Control Plan (2017–2021) in Thailand are examples of the national initiatives to control NCD risk factors.[72–74] Primary health care services can promote risk-factor control and make such care easily accessible.

To summarize, our review found that systematic and sustained stroke surveillance was lacking in most SEAR countries. It also identified specific deficiencies that can be overcome by planned capacity-building in SEAR countries, ultimately improving stroke care and outcomes.

Search strategy and selection criteria

We searched PubMed, Web of Science and SCOPUS databases for articles describing surveillance of stroke and its risk factors in SEAR countries published over the last 25 years between December 1, 1997, and December 31, 2022. We used search terms Stroke OR "Cerebrovascular accident" OR CVA OR "stroke risk factor" OR "stroke incidence" OR "stroke prevalence" OR "stroke mortality" OR "stroke disability" OR" stroke survey" OR "stroke case-fatality" OR "stroke epidemiology" OR "stroke risk factors" OR "cardiovascular risk factors" AND Monitoring OR surveillance OR registry OR "WHO STEPS" OR "hospital-based stroke registry" OR "population-based stroke registry" OR "models" AND SEAR OR "south-east Asia region" OR India OR Nepal OR Bangladesh OR "Sri Lanka" OR Bhutan OR Maldives OR Indonesia OR Thailand OR "Timor-Leste" OR "North Korea" OR Myanmar. Additional searches were also conducted with the term "Democratic People's Republic of Korea". We limited the search to original articles, reviews or government documents and excluded articles on stroke care or treatment pathway models, animal models, radiology or other experimental models or simulation or other predictive models. Also, articles from countries other than SEAR and languages other than English were excluded. Additionally, we identified other studies through search engines such as Google and through experts working in these countries. This review was conducted using the Preferred Reporting Items for Systematic reviews and Meta-Analysis (PRISMA) guidelines. We identified 5010 articles, out which 4454 articles were screened, 266 were assessed for eligibility, and 57 articles were included in this review.

Contributors

YVK, JDP conceptualized the review; YVK, RJI, PJV, and NSC conducted literature search, data collection and analysis; YVK supervised data collection and wrote the first draft of the manuscript; SR, NCS, PM, IAS, PNS, MS, JDP revised the draft critically for important intellectual content. All authors have read and approved the final version of the manuscript.

Editor note

The Lancet Group takes a neutral position with respect to territorial claims in published maps and institutional affiliations.

Declaration of interests

We declare no competing interests.

References

1 GBD 2019 Stroke Collaborators. Global, regional, and national burden of stroke and its risk factors, 1990-2019: a systematic analysis for the Global Burden of Disease Study 2019. *Lancet Neurol*. 2021;20:795–820.

2 Feigin VL, Norrving B, George MG, Foltz JL, Roth GA, Mensah GA. Prevention of stroke: a strategic global imperative. *Nat Rev Neurol*. 2016;12:501–512.

3 Pandian JD, Kalkonde Y, Sebastian IA, Felix C, Urimubenshi G, Bosch J. Stroke systems of care in low-income and middle-income

countries: challenges and opportunities. *Lancet*. 2020;396:1443–1451.
4 Ke C, Gupta R, Xavier D, et al. Divergent trends in ischaemic heart disease and stroke mortality in India from 2000 to 2015: a nationally representative mortality study. *Lancet Glob Health*. 2018;6:e914–e923.
5 World health organization South-East Asia | world health organization. https://www.who.int/southeastasia. Accessed February 19, 2023.
6 World bank country and lending groups – world bank data help desk. https://datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups. Accessed February 19, 2023.
7 World Health Organization. *Regional office for South-East Asia. Strengthening frontline services for universal health coverage by 2030*. Regional Office for South-East Asia. World Health Organization; 2019. https://apps.who.int/iris/handle/10665/329858. Accessed February 19, 2023.
8 World Health Organization. *Noncommunicable Diseases and Mental Health Cluster. WHO STEPS stroke manual: the WHO STEPwise approach to stroke surveillance*. World Health Organization; 2005. https://apps.who.int/iris/handle/10665/43420. Accessed February 19, 2023.
9 STEPwise approach to NCD risk factor surveillance (STEPS). https://www.who.int/teams/noncommunicable-diseases/surveillance/systems-tools/steps. Accessed February 19, 2023.
10 Gregg MB. *Field epidemiology*. 3rd ed. Oxford, New York: Oxford University Press; 2008.
11 Hatano S. Experience from a multicentre stroke register: a preliminary report. *Bull World Health Organ*. 1976;54:541–553.
12 Truelsen T, Bonita R, Jamrozik K. Surveillance of stroke: a global perspective. *Int J Epidemiol*. 2001;30(Suppl 1):S11–S16.
13 Banerjee TK, Choudhury D, Das A, Sekhar A, Roy D, Sen S. Analysis of hospital-based stroke registry in a neurological centre in Kolkata. *J Indian Med Assoc*. 2005;103:665–668.
14 Kaul S, Alladi S, Jabeen SA, et al. Intracranial atherosclerosis is the most common stroke subtype: ten-year data from Hyderabad stroke registry (India). *Ann Indian Acad Neurol*. 2018;21:209–213.
15 Sylaja PN, Pandian JD, Kaul S, et al. Ischemic stroke profile, risk factors, and outcomes in India: the indo-US collaborative stroke project. *Stroke*. 2018;49:219–222.
16 Wijaya VO, Pinzon R. Complications as poor prognostic factors in patients with hemorrhagic stroke: a hospital-based stroke registry in Indonesia. *J Neurol Sci*. 2019;405:106–107.
17 Harris S, Kurniawan M, Rasyid A, Mesiano T, Hidayat R. Cerebral small vessel disease in Indonesia: lacunar infarction study from Indonesian stroke registry 2012-2014. *SAGE Open Med*. 2018;6:2050312118784312.
18 Differences in ischaemic and haemorrhagic strokes in Sri Lanka: 7-year data from the ragama stroke registry (P1.092) | Neurology. https://n.neurology.org/content/84/14_Supplement/P1.092. Accessed April 30, 2023.
19 Perera ND, Bandara KM, Ranasinghe IR, Gunatilake SB. Comparison of risk factors, severity and outcome between lacunar and non-lacunar stroke in a tertiary care center in Sri Lanka: a descriptive study. *Ceylon Med J*. 2015;60:103–106.
20 Nilanont Y, Nidhinandana S, Suwanwela NC, et al. Quality of acute ischemic stroke care in Thailand: a prospective multicenter countrywide cohort study. *J Stroke Cerebrovasc Dis*. 2014;23:213–219.
21 Suwanwela NC. Stroke epidemiology in Thailand. *J Stroke*. 2014;16:1–7.
22 Jedsadayanmata A. Patterns and adherence to guidelines of antithrombotic therapy in Thai patients with nonvalvular atrial fibrillation. *J Med Assoc Thai*. 2013;96:91–98.
23 Kaur P, Verma SJ, Singh G, et al. Stroke profile and outcome between urban and rural regions of Northwest India: data from Ludhiana population-based stroke registry. *Eur Stroke J*. 2017;2:377–384.
24 Kalkonde YV, Deshmukh MD, Sahane V, et al. Stroke is the leading cause of death in rural gadchiroli, India: a prospective community-based study. *Stroke*. 2015;46:1764–1768.
25 Kumar R, Thakur JS, Rao BT, Singh MMC, Bhatia SPS. Validity of verbal autopsy in determining causes of adult deaths. *Indian J Public Health*. 2006;50:90–94.
26 Mateen FJ, Carone M, Alam N, Streatfield PK, Black RE. A population-based case-control study of 1250 stroke deaths in rural Bangladesh. *Eur J Neurol*. 2012;19:999–1006.
27 Joshi R, Cardona M, Iyengar S, et al. Chronic diseases now a leading cause of death in rural India–mortality data from the Andhra Pradesh Rural Health Initiative. *Int J Epidemiol*. 2006;35:1522–1529.
28 Kusuma Y, Venketasubramanian N, Kiemas LS, Misbach J. Burden of stroke in Indonesia. *Int J Stroke*. 2009;4:379–380.
29 Global stroke belt. https://www.ahajournals.org/doi/full/10.1161/STROKEAHA.115.008226. Accessed May 7, 2023.
30 The World Health Organization. Global health estimates: leading causes of death. https://www.who.int/data/gho/data/themes/mortality-and-global-health-estimates/ghe-leading-causes-of-death. Accessed May 7, 2023.
31 WHO country cooperation strategy Democratic People's Republic of Korea, 2009-2013. https://apps.who.int/iris/bitstream/handle/10665/161137/B4501.pdf.
32 Porapakkham Y, Rao C, Pattaraarchachai J, et al. Estimated causes of death in Thailand, 2005: implications for health policy. *Popul Health Metr*. 2010;8:14.
33 Butsing N, Mawn B, Suwannapong N, Tipayamongkholgul M. Long-term survival of ischemic and hemorrhagic stroke patients: an analysis of national Thai data. *Southeast Asian J Trop Med Public Health*. 2018;49. https://www.tm.mahidol.ac.th/seameo/2018-49-2/16-7353-9-322.pdf.
34 Das SK, Banerjee TK, Biswas A, et al. A prospective community-based study of stroke in Kolkata, India. *Stroke*. 2007;38:906–910.
35 Pandian JD, Singh G, Kaur P, et al. Incidence, short-term outcome, and spatial distribution of stroke patients in Ludhiana, India. *Neurology*. 2016;86:425–433.
36 Sridharan SE, Unnikrishnan JP, Sukumaran S, et al. Incidence, types, risk factors, and outcome of stroke in a developing country: the Trivandrum Stroke Registry. *Stroke*. 2009;40:1212–1218.
37 Stroke incidence, rate of thrombolytic therapy, mortality in Thailand from 2009 to 2021. *Open Access Macedonian J Med Sci*. 2022;9:110–115.
38 Mondal MBA, Hasan ATMH, Khan N, Mohammad QD. Prevalence and risk factors of stroke in Bangladesh: a nationwide population-based survey. *eNeurologicalSci*. 2022;28:100414.
39 Zaman MM, Choudhury SR, Ahmed J, Hussain SMA, Sobhan SMM, Turin TC. Prevalence of stroke in a rural population of Bangladesh. *Glob Heart*. 2015;10:333–334.
40 Mohammad QD, Habib M, Hoque A, et al. Prevalence of stroke above forty years. *Mymensingh Med J*. 2011;20:640–644.
41 Pandian JD, Singh G, Bansal R, et al. Establishment of population-based stroke registry in Ludhiana city, northwest India: feasibility and methodology. *Neuroepidemiology*. 2015;44:69–77.
42 Kalkonde YV, Sahane V, Deshmukh MD, Nila S, Mandava P, Bang A. High prevalence of stroke in rural gadchiroli, India: a community-based study. *Neuroepidemiology*. 2016;46:235–239.
43 Banerjee TK, Mukherjee CS, Sarkhel A. Stroke in the urban population of Calcutta–an epidemiological study. *Neuroepidemiology*. 2001;20:201–207.
44 Saha SP, Bhattacharya S, Das SK, Maity B, Roy T, Raut DK. Epidemiological study of neurological disorders in a rural population of Eastern India. *J Indian Med Assoc*. 2003;101:299–300, 302–304.
45 Kodali NK, Bhat LD. Prevalence and associated factors of stroke among older adults in India: analysis of the longitudinal aging study in India-wave 1, 2017-2018. *Indian J Public Health*. 2022;66:128–135.
46 Mukhopadhyay A, Sundar U, Adwani S, Pandit D. Prevalence of stroke and post-stroke cognitive impairment in the elderly in Dharavi, Mumbai. *J Assoc Physicians India*. 2012;60:29–32.
47 Ferri CP, Schoenborn C, Kalra L, et al. Prevalence of stroke and related burden among older people living in Latin America, India and China. *J Neurol Neurosurg Psychiatry*. 2011;82:1074–1082.
48 Das SK, Biswas A, Roy J, et al. Prevalence of major neurological disorders among geriatric population in the metropolitan city of Kolkata. *J Assoc Physicians India*. 2008;56:175–181.
49 *Report on result of national basic health research (RISKESDAS)*; 2007. https://biofarmaka.ipb.ac.id/biofarmaka/2014/Riskesdas2007%20-%20Report%20on%20Result%20of%20National%20Basic%20Health%20Research.pdf. Accessed May 7, 2023.
50 Setyopranoto I, Bayuangga HF, Panggabean AS, et al. Prevalence of stroke and associated risk factors in sleman district of yogyakarta special region, Indonesia. *Stroke Res Treat*. 2019;2019:2642458.
51 Zaw KK, Nwe N, Hlaing SS. Prevalence of cardiovascular morbidities in Myanmar. *BMC Res Notes*. 2017;10:99.

52 Thapa L, Shrestha S, Kandu R, et al. Prevalence of stroke and stroke risk factors in a south-western community of Nepal. *J Stroke Cerebrovasc Dis*. 2021;30:105716.
53 Chang T, Gajasinghe S, Arambepola C. Prevalence of stroke and its risk factors in urban Sri Lanka: population-based study. *Stroke*. 2015;46:2965–2968.
54 Kongbunkiat K, Kasemsap N, Thepsuthammarat K, Tiamkao S, Sawanyawisuth K. National data on stroke outcomes in Thailand. *J Clin Neurosci*. 2015;22:493–497.
55 Hanchaiphiboolkul S, Poungvarin N, Nidhinandana S, et al. Prevalence of stroke and stroke risk factors in Thailand: Thai Epidemiologic Stroke (TES) Study. *J Med Assoc Thai*. 2011;94:427–436.
56 Chantkran W, Chaisakul J, Rangsin R, Mungthin M, Sakboonyarat B. Prevalence of and factors associated with stroke in hypertensive patients in Thailand from 2014 to 2018: a nationwide cross-sectional study. *Sci Rep*. 2021;11:17614.
57 Ray BK, Hazra A, Ghosal M, et al. Early and delayed fatality of stroke in Kolkata, India: results from a 7-year longitudinal population-based study. *J Stroke Cerebrovasc Dis*. 2013;22:281–289.
58 Singh S, Kate M, Samuel C, et al. Rural stroke surveillance and establishment of acute stroke care pathway using frontline health workers in rural northwest India: the Ludhiana experience. *Neuroepidemiology*. 2021;55:297–305.
59 Dalal PM, Bhattacharjee MA, Vairale JY. WHO-global stroke initiative-Mumbai stroke registry: a report on incidence of first-ever-stroke during re-survey 2009. *Int J Stroke*. 2012;7:E3.
60 Dalal PM, Malik S, Bhattacharjee M, et al. Population-based stroke survey in Mumbai, India: incidence and 28-day case fatality. *Neuroepidemiology*. 2008;31:254–261.
61 Bhattacharya S, Saha SP, Basu A, Das SK. A 5 years prospective study of incidence, morbidity and mortality profile of stroke in a rural community of eastern India. *J Indian Med Assoc*. 2005;103:655–659.
62 Mathur P, Rangamani S, Kulothungan V, Huliyappa D, Bhalla BB, Urs V. National stroke registry programme in India for surveillance and research: design and methodology. *Neuroepidemiology*. 2020;54:454–461.
63 O'Donnell MJ, Chin SL, Rangarajan S, et al. Global and regional effects of potentially modifiable risk factors associated with acute stroke in 32 countries (INTERSTROKE): a case-control study. *Lancet*. 2016;388:761–775.
64 Venketasubramanian N, Yoon BW, Pandian J, Navarro JC. Stroke epidemiology in South, East, and South-East Asia: a review. *J Stroke*. 2017;19:286–294.
65 Turin TC, Shahana N, Wangchuk LZ, et al. Burden of cardio- and cerebro-vascular diseases and the conventional risk factors in South asian population. *Glob Heart*. 2013;8:121–130.
66 *Non-communicable diseases risk factors: Bhutan STEPs survey report*; 2019. https://cdn.who.int/media/docs/default-source/searo/ncd/noncommunicable-disease-risk-factors-bhutan-steps-survey-report-2019.pdf.
67 Mathur P, Kulothungan V, Leburu S, et al. National non-communicable disease monitoring survey (NNMS) in India: estimating risk factor prevalence in adult population. *PLoS One*. 2021;16:e0246712.
68 Ministry of Health. *Health in Myanmar*; 2014. https://mohs.gov.mm/Main/content/publication/health-in-myanmar-2014. Accessed April 29, 2023.
69 Aekplakorn W. Thai national health examination survey VI (2019–2020). https://online.fliphtml5.com/bcbgj/znee/#p=187. Accessed June 11, 2023.
70 Amarchand R, Kulothungan V, Krishnan A, Mathur P. Hypertension treatment cascade in India: results from national non-communicable disease monitoring survey. *J Hum Hypertens*. 2022;37(5):394–404. https://doi.org/10.1038/s41371-022-00692-y.
71 Hazard RH, Buddhika MPK, Hart JD, et al. Automated verbal autopsy: from research to routine use in civil registration and vital statistics systems. *BMC Med*. 2020;18:60.
72 *5-Year national NCDs prevention and control plan (2017-2021)*; 2017. https://www.who.int/docs/default-source/thailand/ncds/national-ncd-prevention-and-control-plan-2017-2021-eng.pdf.
73 National NCD programme: ministry of health and family welfare, government of India. https://ncd.nhp.gov.in/. Accessed June 11, 2023.
74 Kaur P, Kunwar A, Sharma M, et al. The India Hypertension Control Initiative-early outcomes in 26 districts across five states of India, 2018-2020. *J Hum Hypertens*. 2022;37(7):560–567. https://doi.org/10.1038/s41371-022-00742-5.