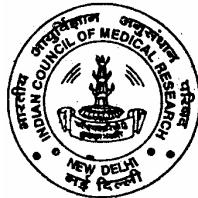


Stroke Surveillance in India

13-15th November 2006
New Delhi, INDIA

Workshop Report



Organized by

Division of Noncommunicable Diseases
Indian Council of Medical Research
Ansari Nagar, New Delhi

Workshop Report on Stroke Surveillance in India

Workshop Coordinated and Report Prepared by

Dr. Bela Shah

Senior Deputy Director General & Chief

Dr. Prashant Mathur

Assistant Director General

Division of Noncommunicable Diseases
Indian Council of Medical Research
Ansari Nagar, New Delhi-110029
INDIA

Supported by

The World Health Organization
(India Office and South East Asia Regional Office)
New Delhi

INDEX

S No.	Title	Page Nos
1.	Workshop report	1 - 19
2.	Conclusions	20 - 21
3.	Recommendations	22 - 23
4.	Annexures	24 - 33
	a. Agenda of the workshop	
	b. List of participants	

Stroke Surveillance in India

Stroke is a Non-communicable disease of increasing socioeconomic importance in ageing populations. According to WHO, stroke was the second commonest cause of worldwide mortality in 1990 and, the third commonest cause of mortality in more developed countries; it was responsible for about 4.4 million deaths worldwide. In the recent estimates made in 1999, the number of deaths due to stroke reached 5.54 million worldwide, with two-thirds of these deaths occurring in less developed countries. Stroke is also a major cause of long-term disability and, has potentially enormous emotional and socioeconomic consequences for patients, their families, and health services. The case-fatality rate due to stroke is reported to vary varies from 11.7% to 32.4%.

In 2005, estimates indicated that 58 million people died, and in them chronic diseases accounted for 35 million deaths (60%). Cardiovascular diseases, predominantly heart disease and stroke, were the cause of death in 17.5 million individuals. After heart disease, Stroke is the second leading single cause of death, with 5.8 million fatal cases per year, 40% of which are in people younger than 70 years. About 15 million new acute stroke events arise every year, and about 55 million people have had a stroke at some time in the past, either with or without residual disability; two-thirds of these individuals live in low income and middle-income countries. Demographic changes, urbanization, and increased exposure to major stroke risk factors will fuel the stroke burden in the future. By 2025, four out of five stroke events will occur in people living in these regions.

The prevalence of stroke in India varies in different regions of the country and, ranges from 40 to 270 per 100 000 population. Approximately 12% of all strokes occur in the population <40 years of age. Major risk factors identified in India are hypertension (blood pressure >95 mm Hg diastolic), hyperglycemia, tobacco use, and low hemoglobin levels (<10 gm %). Stroke accounts for 2 percent of hospital registrations, 1.5 percent of medical registrations and 9 to 30 percent of neurological admissions in major hospitals. The National Commission on Macroeconomics and Health has projected that cases of stroke would increase from 1,081,480 in 2000 to 1,667,372 in 2015. The ICMR study on Burden of Disease (2005) has

estimated that there has been an increase in the number of stroke cases in India during the last one and a half decades by 17.5 %. Mortality due to strokes has increased by 7.8% from 1998 to 2004.

- **Stroke Surveillance**

Surveillance is the ongoing systematic collection, analysis, interpretation and dissemination of health information. Lack of data on stroke hampers efficient coordination of stroke prevention, treatment, and rehabilitation. To tackle the future demographic changes, strategies to reduce stroke burden and ensure adequate health resources are urgently needed. Data are essential to plan the resource allocation needed to meet the increasing health-service needs created by a growing number of patients with chronic diseases, including stroke. Since the criteria for diagnosis of stroke is mainly based on a clinical definition, it is one of the few chronic diseases amenable to surveillance. Epidemiological data for stroke are useful not only for advocacy reasons but also for guiding and evaluating programmes aimed at reducing the future stroke burden. Currently, most stroke data are from high-income countries where rates of the disorder are relatively low compared with low-income and middle-income regions. Studies from geographically diverse populations might use different definitions and sampling methods to those applied in high-income areas, and local needs will affect the development of protocols for stroke data collection, thereby limiting comparisons between and within populations over time. Clinical trials and epidemiological studies have shown that stroke is largely preventable through preventive measures. A comprehensive public health action is required to bring about population level impact. The preventive strategy aims at primary, secondary and tertiary levels of action.

STEPS Stroke surveillance strategy highlights three components of case finding that differentiate three major subsets of patients within a defined geographical area, which are necessary for building an ideal incidence study. The three steps represent the possible sources of notification for stroke patients: events in hospital (step 1); episodes that are fatal before admission is arranged (step 2); and non-fatal strokes cared for entirely in the community (step 3). The stroke-surveillance system begins with patients admitted to hospital, because this group is the one most easily identified. All individuals are followed up

until either discharge or death, and status at 28 days is recorded when feasible. The addition of stroke events identified outside hospital, either fatal (step 2) or non-fatal (step 3), linked to the defined geographical population from which the stroke patients come, is necessary for establishing mortality or incidence. With limited resources and capacity, this option is not always feasible, and a step 1 study (hospital-based register) is a reasonable place to start registration of stroke patients.

- **Stroke Prevention and Control**

As in other developing countries, public health advocacy has been mostly devoted to communicable diseases, nutritional deficiencies, population stabilization and recently to HIV/AIDS. Clinical health care providers on the other hand are more focused on developing advanced health-care facilities for treatment of established chronic diseases. Policy makers have been impeded by the inadequacy of data on the burdens of chronic diseases. Recently, the Ministry of Health and Family Welfare, Govt. of India proposes to launch a integrated National Program for Prevention and Control of Cardiovascular diseases, Diabetes and Stroke. Some State governments, such as Tamil Nadu and Kerala, have identified chronic disease prevention and control as a high priority. Tamil Nadu has incorporated this component into its recently launched state wide health systems project, which is supported by the World Bank. The need for multi component interventions, affecting several behaviors would be necessary for designing programs related to chronic diseases.

Establishment of surveillance systems for non-communicable diseases and their risk factors is essential for developing prevention strategies and monitoring the impact of control programs. In response to the need for stroke collection, prevention and treatment, ICMR organized a Workshop on Stroke Surveillance in India to bring together key cerebro-vascular disease experts (clinicians, public health professionals, biostatisticians) from India and the International arena to discuss datasets on stroke epidemiology of India and suggest mechanisms for setting up stroke surveillance.

➤ **Objectives** of the workshop:

1. To describe the current knowledge base on the incidence/prevalence of cerebrovascular events in India.
2. To review the National experience in conducting hospital and population based stroke surveys in India
3. To identify the scope of Stroke surveillance in India

❖ **Dr. Bela Shah** emphasized the need for public health approach along with setting up data base and evolving better management strategies for stroke. India has been witnessing increasing morbidity and mortality due to chronic diseases especially those related to stroke, diabetes and cardiovascular diseases. Over the last few decades, increase in life expectancy and better diagnostic facilities has highlighted the need to focus on newer health problems. The problem of stroke was recognized long back in India and some study results appeared in since 1960s. Some studies have looked at the stroke data from hospitals retrospectively, while other studies from Bangalore have described the rural-urban differences in stroke. They have shown its high prevalence in young population below 40 years. Its links with major risk factors has also been established. Though very few risk factors were studied, but the types of stroke were identified in these studies. It was seen that the prevalence of ischaemic stroke was comparable with studies done in the Western population. Several investigators from India have undertaken field based studies, and some are involved in the multi-centric STEPS stroke surveillance activity. WHO has been working on stroke prevention and control, and is partnering with ICMR and other Indian researchers. The Ministry of Health and Family Welfare, Govt. of India has initiated Integrated Disease Surveillance Programme (IDSP) with the support of World Bank in November 2005, which would be interested in stroke surveillance modules. The NCD surveillance component of IDSP has been assigned to ICMR. It is expected that the experiences learnt and tools & methodologies prepared in this programme would ultimately be used in Government of India's programmes. We expect that the participants in this workshop, which include the public health specialists, statisticians, neurologists,

cardiologists, physicians and epidemiologists, would evolve guidelines for stroke surveillance.

- ❖ **Dr. Ruth Bonita** stressed on the need for stroke surveillance so as to update the global burden of stroke. The Global goal set for stroke control by 2015 which would require imminent steps to improve the stroke data on prevention and on measuring the impact of the intervention taken. There were 5.7 million stroke deaths in 2005 world wide and 1.2 million of these occurred in South East Asia. Two million new strokes occur every year and 6 million live with disability. In response to the need for stroke data collection, WHO has developed an international stroke surveillance system, the STEPwise approach to stroke surveillance (STEPS-stroke) which forms a framework for surveillance and data collection and aims to provide data for all WHO member states. It also helps countries to get started into using common tools and protocols, track changes over time on incidence and case fatality, measure impact on health services in acute and long term, help in understanding the impact of interventions, and provide local data for advocacy.

The workshop members were informed about the recent WHO report “Preventing Chronic Diseases: A Vital Investment” which has highlighted the importance of prevention. There are variations between countries in stroke death rates, and thus each country needs to profile its own characteristics and trends for intervention programs. Better prevention and treatment will lead to a decline in the stroke related death rates. Several agencies and organizations are working for stroke prevention and control and there is need for global collaborations.

- ❖ **Dr. Cherian Varghese** informed that WHO has given high priority to NCDs and has prepared a regional strategy for their control. Tobacco, sugar, salt and fat are four major risk factors which need to be tackled. Due to changing habits, the use of these risk factors has increased. The average consumption of salt in India is 15-16 grams per person per day. If we are able to reduce the salt intake by 2-3 grams per person per day, it would be a great achievement. Sugar and fats are very high in manufactured and packed foods. The people, medical colleges and medical personnel, should create pressure groups and should force the policy makers to look at this problem.

- ❖ **Dr. RK Srivastava** mentioned that worldwide 3 million women and 2.5 million men die from stroke every year, and it is the third most common cause of death in developed countries. Stroke is most common in China and that it is the leading cause of long term disability since about two-thirds of patients require rehabilitation. Almost 10% of stroke patients recover completely, 25% recover with minor impairment, 40% experience moderate to severe impairments that require special care. Strategies for stroke rehabilitation include assessment, realistic goal setting, interventions and evaluation. He stressed on the strategies for rehabilitation of stroke disability and proposed that surveillance must also incorporate the “disability” angle in patients living with stroke, in the National Program on Cardiovascular diseases, Diabetes and Stroke. Surveillance data will be useful to policy makers for identifying intervention strategies.

- ❖ **Dr. AK Tiwary** presented the proposed National Program on Prevention and Control of Cardiovascular diseases, Diabetes and Stroke. He outlined the program objectives, delivery strategy, components of service, and integration of activities. He said that the pilot project for the year 2006-2007 has already been cleared. The operational aspects would include a phased implementation. There would be a NCD cell in each state and there would be 20 resource centers in the country. In phase I, 100 medical colleges covering 100 districts will be covered. The emphasis will be on control of risk factors, capacity building for prevention and early detection and management of risk factors through life style modifications. In the National Rural Health Mission, indigenous systems of medicine would be a part of preventive aspect. The health system will use existing health workers/ASHAs (local guides) to carry out basic awareness programs.

- ❖ **Dr. D Nagaraj** deliberated on the burgeoning stroke burden due to changing population with increasing life expectancy. There is a wide variation in the figures reported for the incidence (13-105/100,000), prevalence (52-842/100,000) of stroke across the country and across past decades. Case fatality ranges from 11.7%-32%. The figures on Stroke in Young have also varied from 7.9%-32% depending on whether they were community based or hospital based surveys. Mostly the ischemic strokes have been quoted to account for 70% to 80%. The studies from Kolkata and Guwahati however, have recorded a higher

percentage of hemorrhagic strokes. Hypertension is the single most important risk factor and is reported to be especially high in Kolkata, Assam and Kashmir and is proposed to be due to high salt consumption. The prevalence of smoking tobacco varies from 28% to 50% in different studies and alcohol use in hospital based studies ranged from 1.5% to 47%. Hypercoagulopathies accounted for 6% of stroke in Young in the study from Bangalore, PGI, Chandigarh and from SGPGI, Lucknow. Hyperhomocysteinemia was recorded to be as high as 40% in some studies. Studies on genetics in stroke have been conducted from Lucknow and Bangalore. Moderate to severe disability (57%) have been recorded in most studies. Bangalore stroke registry recorded that one-third of all stroke patients were disabled.

- ❖ **Dr. PM Dalal** presented the STEPS stroke pilot data from India as part of the Global Stroke Initiative. In the STEP 1 study, CT confirmed stroke cases from major university hospitals across India were included. The analysis showed that 34% could present to the hospital with in 6 hours of onset and that Stroke in Young accounted for 12%. Infarcts included 77% of the total strokes. Hypertension was the most common risk factor. Stroke severity as assessed by the NIHSS at admission was correlated with the disability scores as assessed by Barthel Index (BI) at the end of 12 weeks. Patients with mild stroke severity (NIHSS < 7) fared better with higher BI scores > 75% as compared to patients with greater stroke severity at admission. He opined that the single most important parameter for improved stroke surveillance is “commitment”. TIA/RIND cases (with stroke symptoms/signs which recover within 24-hours) should be identified and suitably advised for measures to prevent a future stroke (30% are at risk of developing a major stroke).

There were presentations from Hospital based stroke registries and Community based stroke surveys done in India. Their experiences were discussed.

1. Mumbai Stroke Registry which is a population based stroke registry. The data presented was from a preliminary feasibility survey done from January to December 2005. A defined geographical area was identified and the entire medical, para medical facilities and death registries were documented. A total of one lakh and eighty six thousand people were covered

under the survey. CME programs were conducted in the defined area at periodic intervals for increasing the participation of the medical personnel in the project. The WHO manual version 2.0 was converted into a postcard size information card. STEPS I to III were administered and data transferred to WHO for analysis. On account of floods in July, some retrospective data had to be included. A total of 232 index cases of stroke in one year were recorded. This gave a Crude Incidence Rate (CIR) of 148/100,000 (CI 1.2-1.7). Of these 77% were ischemic strokes. TOAST classification was used to subtype ischemic strokes. Hypertension was seen in 25.3%. Most of the data was obtained by means of “hot pursuit” of information. In future, urban and rural areas are proposed to be covered.

2. JIPMER stroke registry is a hospital based registry and has been sponsored by the ICMR. The uniqueness of this registry pertains to the catchment area of the hospital which caters to extremely poor people who only visit this hospital and thus ensure a remarkably uniform population. A total of 105 stroke patients in a 6 months period were analyzed along with age matched controls. Stroke in Young accounted for 36.2% of all strokes. In the 40-60 years age group stroke occurred in 39%. Intracranial atherosclerosis was the commonest pattern of disease seen in 79%. Stroke fatality rate was 14%. Amongst the risk factors, syncope was recorded as significant which needed further clarification. Surprisingly, and probably on account of small numbers in analysis, hypertension, diabetes mellitus and smoking did not reach statistical significance. In 27.6% subjects there was previous history of TIAs/ stroke and, 8/11 persons screened for hyperhomocysteinemia recorded high homocysteine levels.

3. Bangalore Stroke Registry is a population based registry. The existing lacnae in the epidemiological studies conducted so far in India were also summarized. The prevalence rates vary from 44-842/100,000 population. The pooled analysis reveals 115-203/100,000. The incidence varies from 105-124/100,000. Mortality varies from 29-73/100,000. Case fatality varies from 11.7%-32.4%.

The variations in rates could be due to:

- 1). Researchers focus.
- 2). Bias/errors.
- 3). Sampling variations.

- 4). Definitions.
- 5). Identification of cases.
- 6). Diagnostic evaluation.
- 7). Types of studies.
- 8). Statistics.
- 9). Variations in pooled data.

The need of the hour is therefore, an integrated approach and comprehensive information. The study period of the registry was from March to October 2005. The objective was to assess the feasibility of establishing a stroke registry in a defined population and identify a data collection instrument for uniform collection. WHO STEPS Stroke Manual Version 2.0 was used for data collection. NIMHANS and two other hospitals in Bangalore and the Municipal Corporation were involved. A population of 4.7 million was surveyed. STEP I was administered in NIMHANS and St. Johns Hospital. Daily visits by trained staff till discharge or death was carried out. Follow-up was by hospital visits/telephone/home visits. Monitoring was done weekly/monthly and every 3 months. However, the limitation of the study was poor definition of the geographical limits in urban studies. There were concerns regarding the authenticity and completeness of the death certification. Approximately 70% could be obtained from the death records. There was also concern regarding missing out on TIAs in the collection of data for Step III.

4. Trivandrum Stroke Registry is a population based stroke registry. The defined geographical areas consisted of both urban (141 sq Km with a population of 7,41,307) and rural (Athiyanoor Panchayat, 60 sq Km and a population of 1,84,560) areas. Medical Social Workers (MSWs) and medical investigators pre-ascertained the medical facilities. The priming was in the form of first gathering information on how many strokes present to these facilities; education of the concerned medical personnel and convincing them for participation. The health care institutions were also categorized into government, private, allopathic and indigenous medical facilities and the periodic medical visits for recording the relevant information was based on the “load” of strokes which present on an average to the at medical facility per week. There is a designed WHO proforma for the collection of data and the means for obtaining the follow up data is by physicians or neurologists or by

telephonic interviews by MSWs. The project was labor intensive as it required a well trained team of project officers including the MSWs. This reiterates the contention that for a population based surveillance program you need field workers who are dedicated and honest, authentic in recording and proficient in what they record. As regards the data collected from April to September, the crude incidence rates for stroke were estimated as 97.9 in urban and 81.3 in rural areas/100,000 population. There have not been too many variations as regards the demographics of stroke, the risk factors or the stroke subtypes. However, the rate of stroke in Young was recorded as 4.3% which is in accordance with the community based surveys which have uniformly recorded low rates as compared to the hospital based registries which have recorded high rates. One of the factors could be that a young patient is more likely to be taken to the hospital and some of the elderly may be neglected and not reported where as in the community all the events may have been collected. Stroke awareness was phenomenally better with a literacy rate of 96%. Nearly 55% knew the risk factors for stroke; 60% reported that brain is involved in stroke and 40% realized that stroke is an emergency.

5. Kolkata stroke registry, an ICMR funded project, was a random selection of heterogeneous population from a metropolitan city of Kolkata. A total of 52,377 persons were surveyed (Male- 27,626, Female- 24,751). The survey team had field workers and the period was from 2003 to 2005. The information gathering instrument was prepared on the lines of the WHO proforma. This was validated to have good sensitivity and specificity. The literacy rate was 81%. Stroke in young was recorded to be 8%. Nearly 57% of stroke patients became independent. The Crude Prevalence Rate was 471/100,000 and the weighted prevalence rate was 624.32/100,000. Hypertension was recorded in 79%. Crude incidence rate was 145/100,000. Strokes were more common in women, probably due to uncontrolled hypertension in women. The 30 day case fatality rate was 41% and was again higher in women. Nearly 51% had obtained a CT scan of the brain with in the first month of stroke. There was no difference in the rates recorded between the slum and non-slum dwellers.

6. Guwahati stroke registry was sponsored by the ICMR and the WHO. The data is entirely from the North-East. Due to a very poor literacy rate, the awareness regarding stroke is poor in this region; 46% were aware about stroke, 35% knew that brain is involved,

26% knew about the risk factors and only 20% could recognize the symptoms of stroke. There was a significant difference recorded in the rates of incidence etc between the hospital (GNRC) and the community. The age adjusted prevalence of stroke was 922/100,000 population, one of the highest recorded in the country. The incidence of stroke was recorded as 163/100,000. The mortality was 45%, in the community and 17% in the hospital (6% in ischemic and 23% in hemorrhagic). 60% were independent at 5 years in the community. In the community there were more strokes in the elderly and in the hospital strokes were seen in much younger population. The M:F ratio was 45:55 in the community and 72:28 in the hospital! 50% were ischemic and 47% were hemorrhagic again, the rate of hemorrhagic strokes was much higher than reported from the rest of the country. As regards the risk factors, smoking was seen in 46% of cases. High levels of homocysteine were seen in 54.6%. Anemia was not a significant factor for stroke. Thickened carotid artery was seen in 39.1% in the community and 79% of ischemic strokes in the hospital.

7. Nizam's Institute of Medical Sciences stroke registry, Hyderabad is a hospital based registry. This was done in a prospective and conservative manner and was part of the ICASS study from 2001 to 2005. The WHO STEP I form was used. 80% were ischemic strokes, and the most common ischemic stroke subtype was large artery intracranial atherosclerotic. The other etiologies determined were hyperhomocysteinemia, Moya Moya disease and aPLA syndromes. Snake bite was also recorded as one of the etiologies. Only 4.7% reported within 3 hours of the onset of stroke. 39% were independent after stroke. Lacunar strokes had the best outcome. Mortality was 7% in ischemic and 22% in hemorrhagic strokes.

8. Lucknow stroke registry was a hospital based registry. Only a limited number of entries were made in the registry which were presumed to be "relevant". Family history was included in the stroke proforma and used for subsequent genetic studies. MTHFR gene related to hyperhomocysteinemia and gene polymorphism was studied. The pattern of atherosclerosis was also studied in consecutive ischemic stroke patients with MRA studies. Extracranial disease was seen in 64.9% and intracranial disease in 75.5%. Severe extracranial disease was seen in only 24.4%. The registry also documented recurrent hemorrhages in 13 patients. So far 280 stroke patients have been recorded of whom 17.8% occurred in the young. Hypertension was seen in 55.7%. They also recorded data on venous sinus

thrombosis and documented that nearly 40% of strokes have the “metabolic syndrome”. Maintaining the stroke registry helped in better patient care and also gave research questions to be answered.

Some of the concerns that were raised during discussion on these presentations were:

- 1). How good is our case ascertainment? Proper attention to methodology is of paramount importance.
- 2). Interpolation of data from part of the country to the other in a wide complex country with a mosaic of genetic, lifestyle, educational and socioeconomic profiles cannot be pertinent.
- 3). Dispassionate discussion of data collected and its validation is again very important.
- 4). Samples from different parts of the country may be used to derive figures with a degree of precision to give for policy making.
- 5). Lack of comparability amongst different studies which have used different definitions and parameters has lead to widely variable figures. Mention of confidence intervals while mentioning rates is a must.
- 6). Duplication of data and non-agreement in findings must be avoided in further community surveys.

The members agreed that the stroke surveillance system should be able to some important changes such as:

- 1). Cardiovascular diseases risk factors
- 2). Stroke deaths
- 3). Stroke morbidity
- 4). Hospitalization rates
- 5). Stroke treatment improving

The data collected must be:

- 1). Useful
- 2). Simple, flexible.
- 3). Oriented to action.
- 4). Capable of integration into common activities.
- 5). Used for capacity building.

The highlights of discussions on these issues were:

- 1). The implementation of mass screening surveys to identify “hypertensives” and “stroke-prone” subjects should be undertaken to prescribe simple, practical and cost-effective remedies.
- 2). The patient’s compliance to clinic referral is usually unsatisfactory. Therefore, medical social or multipurpose workers should endeavor to remain in constant contact with “stroke prone” individuals. This situation needs to be established to ensure regular intake of medicines and control of risk factors.
- 3). It is also vital that National Councils liaison cohesively with various agencies (health\ industry\ finance) etc. and provide essential co-ordination at all levels.
- 4). The political effort to legislate National Health Policy in support of the above objectives is highly recommended.
- 5). There is need for simple screening instruments, adequately trained field investigators in eliciting proper response and providing the necessary supervision. Asking questions, and eliciting appropriate responses often depends upon the adequacy of training and communication skills of interviewers and should be in local languages.
- 7). The specific relationship between stroke, occupation and socioeconomic status needs to be examined with particular reference to aetiopathogenesis, utilization of services and provision of care for neurological disorders.
- 8). In terms of methodological issues, the present studies have clearly demonstrated that it is possible to conduct population-based neuro-epidemiological studies in situations of scarce resources. Utilizing adequately trained field investigators for enumeration and screening is a

crucial component of this study, since in many developing countries specialist manpower limitations often hinder researchers from undertaking such studies.

9). It is more appropriate to establish rational neurological services according to such scientific and valid population based epidemiological data rather than on educated estimates.

10). The results of these studies have also identified the need for continuously evolving mechanisms of developing epidemiological data through surveillance, and conducting further analytical studies based on a risk factor approach that aims towards prevention.

11). One important aspect which was highlighted during the proceedings was that any extrapolation of the data obtained from the hospital registry to the community will be unjustified and unwarranted since these two registries are entirely different from several angles and must not be combined for policy making.

The representatives from Indonesia, Thailand and Bangladesh also presented their country stroke surveillance scenario. Bangladesh has done a pilot study on stroke survey in a selected rural population, while Thailand and Indonesia are collecting ongoing morbidity and mortality data on stroke through hospital and community based approaches. At all places existing health related data capture mechanisms are being utilized. These efforts have been linked to their NCD risk factor surveillance strategies. No formal national program on stroke is in place in these countries.

- **National Requirements for Stroke Surveillance**

This discussion was aimed at identifying the workable methods for surveillance which could ultimately be used & systematized for implementation in the National Programmes. They should be cost effective, sustainable and should not require any special funds separately for this activity.

Some salient issues for stroke surveillance suggested are as following:

1. Sensitization of masses should be the first and foremost step before undertaking a National level survey for Stroke Registration through generation of awareness in the masses regarding stroke as a disease entity

2. Proper training of staff/individuals that would collect data and ascertain proper recording & maintenance of data. Develop appropriate modules for this purpose.
3. Regular monitoring and follow up at regular intervals.
4. Public-Private partnership should be explored and facilitated.
5. Other systems of medicines should also be involved for collection of data for stroke surveillance.
6. There was stress on the need for a uniform operational definition of stroke for collecting stroke data. Proper clinical guidelines should be chalked out for identifying and including stroke patients for ensuring proper surveillance.
7. Stroke registry should combine with mortality data base (Causes by death) for finding out incidence and prevalence. It was suggested that a stroke atlas on the similar lines as Cancer Atlas will be useful.

The ICMRs Rheumatic fever/heart disease registry program was referred to for its experience and it was suggested that hospitals would be right place to maintain all records. The stroke surveillance program should focus on;

1. Utilizing available linkages.
2. Involving the existing health system
3. Building stakeholdership and ownership

In order to strengthen national surveillance systems:

- 1). Emphasize on simple and practical tools.
- 2). Adaptation to local contexts.
- 3). Focus on capacity building.
- 4). Feedback and regular monitoring.

Limitations identified which could weaken the surveillance systems:

- 1). Absence of a legal framework.
- 2). Weak co-ordination.
- 3). Shortage of critical resources
- 4). Undefined expectations

The group was informed that many developed countries broadly follow two approaches for gathering data for stroke surveillance viz., Mortality database and Incidence through long term cohort study. Keeping in view the data coverage of Sample Registration System (SRS) in India it would be useful utilize the SRS system for stroke deaths. It was also suggested that stroke mortality estimates could be obtained from SRS data and Integrated Disease Surveillance Program (IDSP) NCD surveillance could be used for finding out burden of disease due to stroke. For morbidity data a population based Registry may be ideal. This could be either linked to National Cancer Registry Program (NCRP) or through the Regional Resource centres identified under the other National Programmes like CVD, Diabetes and stroke programme which is due to be initiated shortly.

Recommendations:

1. The Group noted that there is adequate information on prevalence of stroke. However, a need for cohort studies was felt so as to provide incidence data.
2. Region specific stroke registries should be initiated.
3. Cost effective sustainable data collection method may be used to ensure sustainability of the program possibly through SRS.
4. All the members recommended that the data should be obtained from all available sources viz. GP's, private medical institutions, and nursing homes besides govt. hospitals. They also suggested that alternate systems of medicines should also be involved.

- **Methodological Issues for Stroke Surveillance: Tools, techniques and quality**

The discussions in this section focused on the constraints in the methodology, tools used to collect data and how to improve its quality. The invited speakers provided their experiences and highlighted issues related to the Medical Certification of Causes of Deaths, Verbal autopsy tool and challenges on valid data collection.

There are multiple diseases coded under circulatory system. The medical certificate of cause of death should narrow down to identify exact cause of death. The education status of

interviewer and interviewed, socioeconomic status of the interviewed, and time gap between the death and Verbal Autopsy (VA) tool administered should have effect on the sensitivity and specificity of the VA tool. Medical Insurance systems in urban areas may have impact on quality of data collected by VA tool. In few states like Assam, immigration has affected adversely and creates lots of problem for data collection. Under Medical Certification of Causes of Death (MCCD), there should be matching between the non medical team that collects the information and other the medical team which ascertains the cause of death on that information. There has been change from ICD-IX to ICD X system of classification. There has been a change in the data capturing mechanisms in the states of Chennai and Kolkatta. There are existing systems in our country like RGI, SRS, MIS, population based registry, and hospital based information, CRDS that collect morbidity and mortality data. We need to identify standard guidelines for them and can learn from different registries undertaken in our country.

- **Strategies for Sustaining Stroke Surveillance**

This session was aimed at identifying strategies and issues involved in sustaining stroke surveillance activities at a national level. Dr Bela Shah presented the results of the NCD Risk factor surveillance studies done at six sites across the country and its usefulness in developing the national strategy for undertaking NCD risk factor surveillance under IDSP. These efforts were useful in adopting and adapting the STEPS model to suit the local circumstances in spite of the complexities and huge amount of time, manpower and resources involved in it. Through these studies, non-communicable diseases have carved a niche for itself in the policy makers mind and created a space for itself in the health care. This workshop has been able to bring together a wide range of experts and the policy makers on a common platform to deliberate on issues related to stroke surveillance. The dialogue has further raised the need of building surveillance in the health infrastructure. It has also brought for the platform for building a network of the experts. It was felt that the stage has now been set for the establishment of a chronic diseases institute in India and its time to begin a process of chronic disease surveillance rather than just risk factor surveillance.

Dr J Leowski said that the top challenges of NCDs in general and stroke in particular are to improve availability and validity of information, improve accessibility of information and promoting utilization of data which most often does not reach the stakeholders. He elaborated on the efforts of WHO SEARO in dissemination of the Regional Strategy for NCD surveillance in different countries. The strategy has set 10 targets for implementation that includes collection of standardization of data on NCD risk factors, incorporation of NCD surveillance into the existing HIS, capacity building, strengthening the morbidity and mortality database. He applauded the efforts of ICMR in sensitizing the Ministry of Health for inclusion of NCD component in IDSP. SEARO has developed capacity building modules for policy makers and plans to implement it in due course.

On the argument on the need for establishing stroke surveillance he felt that the following points need consideration:

- Huge disease burden
- Risk factor burden
- Common Determinants
- Interventions are available
- Specific information required needs to be collected
- Use of the information beyond health service and research in terms of development and implementation.

On establishment of stroke surveillance the following points were discussed:

- WHO STEPS method needs to be validated
- Population coverage
- Ownership by the Ministry of Health

The sustenance of the program would largely depend on the support of national policy strategy and integration with HIS along with human and financial resource allocations. While expanding on the 'data collection processes' it is important to develop a plan for prevention and control of stroke in India, based on the leads generated from the data that is already

made available. Clear cut interventions for reducing exposure to risk factor, risk reduction for those already exposed, clinical care and rehabilitation has to be developed as appropriate for the various settings. The interventions and services at different levels of health facilities have to be arrived at. Surveillance should be modified/adapted to capture the indicators of these interventions (at population level and hospital level, depending on the intervention that is being evaluated). A draft action plan for this can be generated and will strengthen the advocacy for stroke surveillance so that it moves beyond data collection.

It was felt that stroke surveillance would sustain only if it identifies and involves all the key stakeholders. On the very issue of the need for stroke surveillance it was felt that among NCDs stroke is the diseases which has very obvious conditions, and does not need a lab support. It has already been demonstrated that non-medical educated youths can be trained to identify stroke cases in the community. All the panelists felt that India has the capacity and resources for doing disease surveillance and stroke surveillance could be a good entry point. Stroke can be taken as a marker for a number of risk factors that constitute almost 70% of all NCDs. It was also felt that to sustain interest among policy makers and the public it is essential to have a program in place.

Conclusions

Based on the presentations and discussions held by the participants and experts of the workshop, the following were concluded.

1. The available information on stroke and its risk factors suggests that it poses a significant public health burden in India. Data indicates that stroke is one among the top five causes of mortality in the Indian region, requiring measures for prevention along with better management and adequate rehabilitation
2. The existing survey data on stroke mortality and morbidity has limitations of representativeness, validity and coverage but still provides sufficient information to initiate action. For this, it should be adequately disseminated and utilized.
3. Data presented by various sites demonstrates feasibility, strengths and weaknesses of health facility based and population based stroke registries.
4. Prospective studies on risk factor of stroke from India are limited.
5. The WHO STEPS framework has been successfully used after suitable adaptation to the Indian requirements at select sites.
6. The proposed National program on CVD, Diabetes and Stroke is a welcome step. It has the potential to reduce the large burden due to stroke and other diseases in a concerted manner.
7. Mortality surveillance being done under the SRS and MCCD program of RGI Office provides useful information on stroke mortality.
8. The NCD risk factor surveillance by IDSP will provide wide coverage to several risk factors connected with chronic diseases.
9. The chronic disease morbidity surveys are often weak and are inadequately placed in the health systems.

10. Stroke is a good example of an NCD for demonstrating disease surveillance as it is a marker and tools are available. (Easy to do in the field settings).
11. Stroke surveillance provides a good entry point for NCD Surveillance
12. The existing information is adequate to initiate Risk factor intervention.

Recommendations

1. Stroke needs to be addressed as a public health problem through the health system.
2. To establish stroke registries across various regions of the country so as to obtain nationally representative data on stroke incidence.
3. The available information needs to be disseminated further to policy makers and program managers.
4. Both public and private health sector involvements along with other sectors and disciplines are needed.
5. Appropriate mechanisms for stroke surveillance in selected centers across the country (as sentinel sites) need to be initiated in the country.
6. Mortality coverage for stroke by MCCD and SRS is largely adequate and needs to be strengthened in terms of validity. Data analysis needs to be promoted and encouraged at state and regional levels
7. Hospital based surveillance should be done, despite its limitations. They can be complimented by the population based studies around them.
8. Include rural population in surveillance program since it forms a large population base
9. Morbidity surveillance should be strengthened by including it in the routine reporting systems of health facilities.
10. Population based registries should be started in urban and rural areas with some criteria so as to obtain mortality, morbidity and risk factor data from the same population eg.
 - a. Multiple and regional representativeness
 - b. Sufficiently large population coverage (of more than 100,000)
11. Explore the integration of Stroke surveillance with other NCD related activities, eg;
 - a. Using existing mechanisms or opportunities eg.

- i. National program on CVD, DM and stroke
 - ii. Integrated Disease Surveillance Program
12. Undertake the identification and strengthening capacity of Regional resource centers identified who would be undertaking;
 - a. Training, monitoring and supervision, validation, data analysis and report preparation
 - b. Addressing regional/local research needs / issues
13. Use of Information Technology for reporting format, development of an atlas etc.
14. To develop linkages with stroke activities around the world and with relevant agencies
15. Risk Factor Intervention starting at school, college and work places needs to be launched
16. Some of the important research issues identified were;
 - Risk factors for stroke and monitoring their trends over a period of time
 - Identify and adapt early intervention strategies
 - Support and strengthen ongoing NCD surveillance activities

ICMR-WHO Workshop on Stroke Surveillance in India

13-15th November 2006

Venue: Conference Room, Indian Council of Medical Research, Ansari Nagar, New Delhi

Day 1 (13th November 2006, Monday)

09.30-10.00am Registration of participants

Inaugural Program

10.00-10.15am	Welcome	Dr Bela Shah
10.15-10.25am	Global scenario on Stroke Prevention and Control	Dr. Ruth Bonita
10.25-10.35am	WHO's perspective on Stroke Surveillance	Dr. Cherian Varghese
10.35-10.45am	National program on CVD, Diabetes and Stroke	Dr. AK Tiwary
10.45-11.00am	Inaugural address	Dr. RK Srivastava
11.00am	Vote of thanks	Dr. Prashant Mathur

Refreshments

Day 1 (13th November 2006)

Session I: Stroke: Burden and Surveillance

Chairpersons: Dr. LM Nath, Dr. AK Tiwary
Rapporteur: Dr. Tanvir Kaur

11.30-12.00pm	Burden of Stroke and its Risk Factors in India	Dr. D Nagaraj
12.00-12.30pm	WHO STEPS Stroke surveillance strategy	Dr. R Bonita
12.30-1.00pm	Challenges and Opportunities for Stroke surveillance in India	Dr. PM Dalal

1.00-2.00pm LUNCH BREAK

Session II: Key methods and findings of Stroke Surveillance/Registry in India

Chairpersons: Dr. Gourie Devi, Dr. Cherian Varghese
Rapporteur: Dr. Meenakshi Sharma

2.00- 4.00pm	(10 mins each)	
	Mumbai	Dr. M Bhattacharjee
	Pondicherry	Dr Sunil K Narayan
	Bangalore	Dr. G Gururaj
	Trivandrum	Dr. S Dinesh Nayak
	Kolkatta	Dr. SK Das
	Guwahati	Dr. NC Borah
	Hyderabad	Dr. Subhash Kaul
	Lucknow	Dr. UK Misra

4.00- 4.30pm Refreshment break

Session II continued....

4.30-5.00pm	Lessons for stroke surveillance from the Indian studies	Dr. MV Padma
5.00-5.30pm	Discussions led by Chairs	

Day 2: 14th November 2006, (Tuesday)

Session III: Issues in Stroke Surveillance

Chairpersons: Dr. D Nagaraj, Dr. S Prabhakar
Rapporteur: Dr. Ashoo Grover

09.30-10.15am Country presentations: Experiences and future plans (10 min each)
SEAR representatives

Dr Sohel Reza Choudhury	(Bangladesh)
Dr Gun Choerungroj	(Thailand)
Dr. Dwi Sushilowati	(Indonesia)

Discussions led by Chairs

10.15- 10.30am	Hospital/Clinic Based Stroke Surveillance	Dr. Kameshwar Prasad
10.30-10.45am	Community Based Stroke Surveillance	Dr. K Anand

10.45-11.15am Refreshment break

11.15-12.45pm Panel discussion on “National requirements for Stroke Surveillance”
Panelists: *Dr. Gourie Devi, Dr. Bela Shah, Dr. J Mahanta, Dr. Cherian Varghese, Dr. Gun Choerungroj*

12.45-2.00pm LUNCH BREAK

Session IV: Methodological Issues for Stroke Surveillance: Tools, techniques and quality

Chairpersons: Dr. PM Dalal, Dr. Ashok Kumar
Rapporteur: Tripti Khanna

2.00- 2.45pm

Medical Certification for cause of Death	Mr. SK Jha
Verbal Autopsy tool	Dr. Geetha Menon
Challenges for valid data collection	Dr. T Trueslen

2.45-3.45pm Panel discussion on “Identifying appropriate methodology for Stroke surveillance”

Panelists: *Dr. K Prasad, Dr. MM Mehndiratta, Dr. Sanjay Zodpey, Dr. KR Thankappan, Dr. A Nanda Kumar, Dr. Sobel Choudhry*

3.45-4.00pm Refreshment break

Session V: Inter-sectoral/disciplinary perspectives for stroke surveillance

Chairpersons: Dr. R Tandon, Dr. J Leowski
Rapporteur: Dr. Meenakshi Sharma

4.00-5.30pm (10 min presentations) followed by panel discussion

Intersectoral partners and their role	Dr. Arvind Pandey
Cardiologist's perspective:	Dr. S Dwivedi
Public health perspective:	Dr. KR Thankappan

Panel discussion on "Inter-sectoral/disciplinary perspectives for stroke surveillance"

Panelists: *Dr. Ashok Kumar, Dr. S Narayan, Dr. Prem Sagar, Dr. D Nagaraj, Dr. S Malik, Dr. Dwi Sushilowati*

Day 3: 15th November 2006, Wednesday

Session VI: Strategies for Sustaining Stroke Surveillance

Chairpersons: Dr. PH Anathanarayanan, Dr. J Mahanta
Rapporteur: Dr. Geetha R Menon

10.00-10.15am Integrated Disease Surveillance Program in India Dr. Bela Shah

10.15- 12.30pm Panel discussion on "Strategies for sustaining Stroke surveillance"

Panelists: *Dr. AK Timary, Dr. MV Padma, Dr. Kavita Venkatraman, Dr. NC Borah, Dr. J Leowski*

12.30- 1.00pm **Finalization of recommendations**
Chair: Dr. LM Nath, Dr. R Tandon
Moderators: Dr. K Anand, Dr. MV Padma
Rapporteur: Dr. Ashoo Grover

1.00pm **Vote of Thanks**

End of workshop and Lunch

ICMR-WHO Workshop on Stroke Surveillance in India

13-15th November 2006

**Venue: Conference Room,
Indian Council of Medical Research, Ansari Nagar, New Delhi**

LIST OF PARTICIPANTS

Participants

1. Dr. PM Dalal

Research Director,
Lilavati Hospital & Research Centre, Mumbai 400 050

2. Dr. D Nagraja

Director/Vice Chancellor & Professor of Neurology, NIHMANS, Bangalore-560029

3. Dr. Sunil K Narayan

Professor and Head of the Department of Neurology,
Jawaharlal Institute of Postgraduate Medical Education and Research, Dhanvantri Nagar,
Pondicherry - 605006

4. Dr. G Gururaj

Department of Epidemiology
National Institute of Mental Health and Neuro Sciences (NIMHANS), Bangalore - 560029

5. Dr. S Prabhakar

Prof & Head, Department of Neurology
PGIMER, Chandigarh-160012

6. Dr. A Nanda Kumar

Officer-in-charge
National Cancer Registry Program, "Srinivasa Nilaya" No.557, 7th Main, New BEL Road,
Dollars Colony, Bangalore-560094

7. Dr. Sanjay Zodpey

Professor, Department of Preventive and Social Medicine, Govt. Medical College, Nagpur

8. Dr. KR Thankappan

Prof & Head, Achutha Menon
Center for Health Science Studies, Sree Chitra Tirunal Institute for Medical Sciences and
Technology, Trivandrum 695 011, Kerala

9. Dr. J Mahanta

Director, Regional Medical Research Center, N.E.Region, East-Chowkidingheepost Box No.
105 Dibrugarh - 786001

10. Dr. S. Dinesh Nayak

Associate Professor, Department of Neurology
Sree Chitra Tirunal Institute for Medical Sciences and Technology,
Trivandrum 695 011, Kerala

11. Dr. Madhumita Bhattacharjee

Senior Research Officer
Lilavati Hospital & Research Centre, Mumbai 400 050

12. Dr. SK Das

52/1 A, Shambhunath Pandit Street,
Bangur Institute of Neurology, Kolkatta-700025

13. Dr. NC Borah

Director,
Institute of Neurological Sciences, Dispur, Guwahati-781006

14. Dr. Subash Kaul

Prof & Head, Department of Neurology,
Nizam's institute of Medical Sciences, Hyderabad-500482

15. Prof. UK Misra

Head, Department of Neurology,
SGPGI, Lucknow- 226014

16. Dr. Arvind Pandey

Director,
National Institute of Medical Statistics
Ansari Nagar, New Delhi

17. Dr. Gourie Devi

Flat No.9, Doctors Apartments,
Vasundhra Enclave, New Delhi-110096

18. Dr. LM Nath

E-21, Defence Colony, New Delhi

19. Dr. Kameshwar Prasad

Professor, Department of Neurology
AIIMS, New Delhi

20. Dr. MV Padma

Professor, Department of Neurology
AIIMS, New Delhi

21. Dr. K Anand

Associate Professor,
Centre for Community Medicine, AIIMS, New Delhi

22. Dr. MM Mehndiratta

Professor, Department of Neurology
GB Pant Hospital, New Delhi-110002

23. Dr. R Tandon

SIaram Bhartia Hospital,
Qutab Institutional Area, New Delhi

24. Dr. S Dwivedi

Head Department of Medicine
UCMS & GTB Hospital, Shahdara Delhi-92

25. Dr. Prem Sagar

Head. Department of Neurosurgery,
Ram Manohar Hospital, Baba Kharak Singh Marg, New Delhi

26. Dr. Chitra Sarkar

Professor, Department of Neuro-Pathology,
CN Center, AIIMS, New Delhi

27. Mr. SK Jha

Registrar General Office of India, New Delhi

28. Dr. KR Thankappan

Professor & Head
Achutha Menon Center for Social Sciences
Sree Chitra Tirunal Institute for Medical Sciences and Technology,
Trivandrum 695 011, Kerala

Ministry of Health and Family Welfare and Directorate of Health Services, Govt. of India, New Delhi

1. Dr. RK Srivastava

Director General Health Services,
Ministry of Health and Family Welfare,
Nirman Bhavan, New Delhi

2. Dr. AK Tiwary

Deputy Secretary,
Ministry of Health and Family Welfare
Nirman Bhavan, New Delhi

3. Dr. PH Ananthanaraynan

DDG (M), Directorate of Health Services,
Nirman Bhavan, New Delhi

WHO Participants

1. Dr. J Leowski

Regional Adviser, Noncommunicable Diseases, Regional Office for South-East Asia, World Health House, Indraprastha Estate, Mahatma Gandhi Marg, New Delhi 110 002

2. Dr. Cherian Varghese

Cluster Coordinator – Non Communicable Diseases and Mental Health (NMH), WHO India Office, 534, “A” Wing, Nirman Bhawan, Maulana Azad Road, New Delhi – 110 011

3. Dr. Kavita Venkatraman

National Consultant, WHO India Office, 534, “A” Wing, Nirman Bhawan, Maulana Azad Road, New Delhi – 110 011

5. Dr Ruth Beaglehole Bonita

Retired Professor of Epidemiology
Chair, ISS-WHO International Stroke Surveillance Coordinating Committee
Geneva Switzerland

6. Dr Sohel Reza Choudhury

Associate Professor of Epidemiology and Research National Heart Foundation Hospital and Research Institute, Plot No. 7/12, Mirpur 2
Dhaka 1216, Bangladesh

7. Dr Gun Choerungroj

Bureau of Noncommunicable Diseases
Department of Disease Control
Ministry of Public Health
Tiwanon Road, Nonthaburi 11000
Thailand

8. Dr. Thomas Clement Truelsen

International Stroke Society
Copenhagen, Denmark

9. Dr. Dwi Sushilowati

Researcher, National Institute of Health Research and Development (NIHRD)
Ministry of Health, Republic of Indonesia, Jl.
Percetakan Negara No. 29 Jakarta

Division of Non-communicable Diseases, ICMR, New Delhi

1. Dr. Bela Shah
2. Dr. Narender Kumar
3. Dr. D.K. Shukla
4. Dr. Tripti Khanna
5. Dr. Tanvir Kaur
6. Dr. Prashant Mathur
7. Dr. Meenakshi Sharma
8. Dr. Ravinder Singh
9. Dr. Ashoo Grover
10. Dr. Geetha R Menon

Acknowledgements

- Mr. Vijay Shankar, Sr. Administrative Officer
- Mr. SS Behl, Section Officer
- Ms. Anju Kumar, Assistant
- Mr. Anil Lakehra, Assistant