Methods

The NSRP is planned, coordinated and supervised by ICMR-NCDIR. Periodic trainings are conducted for registry staff on various aspects of working of the registry, training on International Classification of Diseases (ICD) coding, process of data collation, and maintenance of data quality. Review meetings are held periodically with the Principal Investigators and staff of the registries with the objectives of discussing the various aspects of working of the registry with primary focus on data quality.

The PBSR centre is established in a tertiary care institution. The staff of PBSR visit hospitals, nursing homes, clinics, general physicians, imaging centres, physiotherapy and rehabilitation centres (called sources of registration-SoR) and collect data on all first-ever stroke patients in the registration area who are resident for at least one year in the defined geographical area. A nodal person is identified in each SoR to provide data on defined variables from their electronic or manual health records and data of stroke cases is extracted on a standardized core form.

The data collected by the registry staff is reviewed by the Principal Investigator (PI) and co-investigators (neurologists or physicians) at the PBSR. Data on clinical and vital status are collected at day 28 after onset of stroke. Stroke cases are followed up by PBSR team through repeat hospital visits or telephonic follow-up or by house visits to record vital status as on 28 days after the date of onset of stroke. Death certificates from the local registrar offices of birth and death of the Civil Registration System are collected to include all deaths with 'stroke' as cause of death.

These are matched with registered incident cases and through a follow-back process, some cases are converted as incident records by tracing their clinical records. Cases with death certificates mentioning stroke as the cause of death and not reported earlier by any of the sources, is registered as 'Death Certificate Only (DCO)' cases.

Data is recorded through a web-based electronic information system developed at ICMR-NCDIR, and transmitted online using authenticated login credentials. Data are encrypted, and data security and confidentiality are maintained. Data is subjected to verification of quality and finalised by each PBSR centre. The coordinating unit collates and analyses the data to prepare the consolidated report of a year.

Definitions, Statistical Terms and measurements

Stroke Registry : A stroke registry is a continuous systematic collection of data on the occurrence and characteristics of stroke, and tracks persons with the disease from a defined population (Population Based Stroke Registry), or attending a hospital (Hospital Based Stroke Registry) over time, and includes diagnostic, treatment, and outcome information of stroke cases collected through review of health, vital, or other records through an active method of data abstraction.

Stroke: Stroke is defined as "rapidly developing clinical signs of focal (or global) disturbance of cerebral function, with symptoms lasting 24 h or longer or leading to death, with no apparent cause other than of vascular origin".

Types of stroke: There are three major stroke sub groups as follows:

Ischemic stroke: Sudden occlusion of arteries supplying the brain either due to a thrombus formed directly at the site of occlusion (thrombotic ischemic stroke), or in another part of the circulation, which follows the blood stream until it obstructs arteries in the brain (embolic ischemic stroke). Diagnosis is by neuroimaging.

Intracerebral haemorrhage: Bleeding from one of the brain's arteries into the brain tissue. Diagnosis is by neuroimaging.

Subarachnoid haemorrhage: Arterial bleeding in the space between the two meninges, pia mater and arachnoid. Typical symptoms are sudden onset of very severe headache and usually impaired consciousness. Diagnosis is by neuroimaging, or lumbar puncture.

Population Based Stroke Registry (PBSR): PBSR is housed in a medical institution which collects information on incidence of first-ever stroke in residents of a defined geographical area by a PBSR team. The PBSRs registers first-ever incident stroke cases (also called "first in a lifetime cases") of age ≥18 years among residents of at least one year in the defined geographic area.

Sources of Registration (SORs): SORs are hospitals, nursing homes, clinics, general physicians, imaging centres, physiotherapy and rehabilitation centres, and civil registration departments (for death certificate with stroke). The PBSR collaborates with as many SORs in a given area to record all incident cases of stroke.

Age-Group: Age group ≥18 years has been included in analysis. The age groups are classified as 18-29, 30-44 in 15-year age groups till 75+.

Stroke Incidence: Incidence of stroke is the number of new cases of first-ever stroke occurring among residents in a well-defined population during a year.

Stroke Mortality: Stroke mortality is a measure of number of deaths due to stroke in a specified population during a specified period of time.

Incidence rate:

Crude Incidence Rate (CR) is computed by taking the number of new stroke cases that occurred in a particular year, divided by estimated population of the same year and multiplying by 100,000.

$$\text{Crude Incidence Rate(CR)} = \frac{\textit{New cases of stroke of a particular year}}{\textit{Estimated population of the same year}} \times 100{,}000$$

Age Specific Incidence Rate (ASpR) is computed by taking the number of new stroke cases of particular year in the given age group, divided by estimated population of the same year for the given age group and multiplying by 100,000.

$$\text{Age Specific Rate (ASpR)} = \frac{\textit{New cases of stroke of a particular year in the given age group}}{\textit{Estimated population of the same year for the given age group}} \times 100{,}000$$

Age Standardised Rate (ASR):

Crude rates represent the actual burden of illness in the population and changes over time. However, the comparison of crude rates can sometimes be inadequate, particularly when the population structures are not comparable for factors such as age or sex. The age standardised rate corrects for this by applying age specific rates in each age group to a constant standard population and allows for valid comparisons between groups over time. An age standardised rate is the best summary statistic for comparing the impact of non-communicable diseases like heart disease, stroke, cancer and diabetes that are heavily influenced by age. However, the absolute value of the age standardised rate is less meaningful, since it has been statistically constructed based on the choice of a standard population.

Stroke incidence increases as age increases. In order to compare rates of stroke between two populations, the rates are standardized using a common population like the world standard population. This is calculated according to the direct method by obtaining the age specific rates and applying these rates to the standard population in that age group. The world standard population approximates the proportional age distribution of the world and is given below:

Age Distribution of World Standard Population

Age Group	World Standard Population
00-04	12,000
05-09	10,000
10-14	9,000
15-19	9,000
20-24	8,000
25-29	8,000
30-34	6,000
35-39	6,000
40-44	6,000
45-49	6,000
50-54	5,000
55-59	4,000
60-64	4,000
65-69	3,000
70-74	2,000
75+	2,000
All ages	100,000

$$ASR = \frac{\sum_{(i=1)}^{A}(a_i w_i)}{\sum_{(i=1)}^{A} w_i}$$

Where, a_i is the age specific rate(ASpR) in age class i :

w_i is the standard population in age class I ;

'A' represents the number of age intervals.

Or expressed in simpler terms thus:

$$ASR = \frac{\sum (ASPR) \times (\text{No. of persons in std. world population in that 5yr age group})}{100{,}000}$$

Mortality rate:

Crude Mortality Rate (CMR) is computed by taking the number of deaths with stroke during a year, divided by estimated population of the same year and multiplying by 100,000.

$$\text{Crude Mortality Rate(CMR)} = \frac{\textit{Number of stroke deaths during a year}}{\textit{Estimated population of the same year}} \times 100{,}000$$

Age Specific Mortality Rate (ASMR) is computed by taking the number of deaths due to stroke that occurred during a year for a particular age group, divided by estimated population of the same year for the given age group and multiplying by 100,000.

$$\text{Age Specific Mortality Rate(ASMR)} = \frac{\textit{Number of stroke deaths during a year for a particular age group}}{\textit{Estimated population of the same year for the given age group}} \times 100{,}000$$

Crude Case Fatality Rate (CCFR):

Crude Case Fatality Rate is computed by taking the number of deaths due to stroke that occurred within 28 days after onset of stroke, divided by estimated population of the same year and multiplying by 100,000.

$$\text{CCFR} = \frac{\textit{Number of stroke deaths occurred within 28days after onset of stroke}}{\textit{Estimated population of the same year}} \times 100{,}000$$

95% confidence intervals: 95% confidence intervals (CIs) are calculated to estimate the range that would contain the true population value of incidence or mortality rates at 95% level of confidence.

Disease classification: ICD-10 is the 10th revision of the International Statistical Classification of Diseases and Related Health Problems (ICD), a medical classification list by the World Health Organization (WHO). ICD-10 codes used for coding of type of stroke are I60, I61, I63 and I64, in first-ever stroke cases.

Population Estimation: The census populations of 2001 and 2011 were used in this report to calculate the estimates of population for the years 2018 and 2019 using the Difference Distribution method for estimation of populations by five yearly age groups.

Difference Distribution Method: This method makes use of age wise population distributions of immediately preceding two census years. If a_{i01} and a_{i11} denote the populations of the i^{th} five yearly age group for i = 1, 2, 3, …,16 for the census years 2001 and 2011, respectively. Then, find the difference (d_{i1101}) in the population for each age group and express it as the proportion (D_{1101})

$$d_{i1101} = a_{i11} - a_{i01} \quad \text{for } i = 1, 2, 3, \ldots, 16$$
$$D_{1101} = \sum d_{i1101} \quad \text{for } i = 1, 2, 3, \ldots, 16$$
$$p_{i1101} = (d_{i1101}/D_{1101}) \quad \text{for } i = 1, 2, 3, \ldots, 16$$

The estimate of age wise group populations for the year x can be calculated using the two populations:
(i) Base Population (P_{01}) and
(ii) Population at time x (P_x)

Case I: When x lies between 2001 and 2011

Let $D_{x01} = (P_x - P_{01})$, then

$a_{ix} = a_{i01} + (D_{x01} * p_{i1101})$ for i = 1, 2, 3, …, 16

Case II: When x > 2011

Let $D_{x11} = (P_x - P_{11})$, then

$a_{ix} = a_{i11} + (D_{x11} * p_{i1101})$ for i = 1, 2, 3, …, 16

The population at time x, P_x can be calculated using the formula given below. If we assume that a population P_0 grows to P_t after a period "t", then

$P_x = P_0 * (1+r)^x$ when $0 < x < t$, and

$P_x = P_t * (1+r)^x$ when $x > t$

where "r" is the annual growth rate and is given as:

$r = (P_t / P_0)^{(1/t)} - 1$,

The census populations of 2001 and 2011 were used to calculate the estimates of population for the years 2012-2019 using the difference distribution method for calculating inter census growth rate. So, $P_t = P_{2011}$, $P_0 = P_{2001}$ and t =10. The projected population for year 2018-19 is given in table 1.2.