

ICMR National Centre for Disease Informatics and Research



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INDIAN COUNCIL OF
MEDICAL RESEARCH

NCDIR
NATIONAL CENTRE FOR DISEASE
INFORMATICS AND RESEARCH

ANNUAL HIGHLIGHTS 2021 - 2022

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KEY ACHIEVEMENTS

1. ICMR – NCDIR completed 40 years of setting up of the ICMR National Cancer Registry Programme (NCRP) set up on 11th December 1981. NCRP is the flagship program of ICMR and NCDIR, providing robust cancer statistics to guide its prevention and control efforts. The quality of data, coverage and its use has increased several folds over the past years.
2. The Volume I of the Reference Book entitled “Biomedical Ethics- Perspectives in the Indian Context” was released on 7 April 2022 and this was the first-of-its-kind book in India. It is prepared to provide an Indian perspective on research and ethical issues.
3. The Report “Sites of cancer associated with tobacco use in India-Findings from the National Cancer Registry Programme” has been released on World No Tobacco Day, 31 May 2021.
4. The Report “Clinicopathological Profile of Cancers in India: A Report of the Hospital Based Cancer Registries, 2021” and State Cancer Fact Sheets: Profile of cancer and related factors, 2021 for ten states (Delhi, Gujarat, Karnataka, Kerala, Madhya Pradesh, Maharashtra, Punjab, Tamil Nadu, Telangana & West Bengal) were released on World Cancer Research Day i.e., on 24 September 2021.
5. The first report titled, "Stroke Incidence and Mortality: A report of the Population Based Stroke Registries, India" was released on 10 November 2021.
6. The report on “Monitoring Survey of Cancer Risk Factors and Health System Response in North East Region (NER) of India, 2022” was released on 4 February 2022.
7. Integration of ICMR-NCDIR e-Mor cause of death module with Tamil Nadu CRS software is completed. All hospitals and local registrar offices in Tamil Nadu started using the CRS software to record MCCD from September 2021.
8. WHO guidance document titled “Ethics and Governance of Artificial Intelligence for Health” was released on 28 June 2021, which is a one of its kind International guidance; with one of the authors being the Head of the ICMR Bioethics Unit.
9. Council of International Organizations of Medical Sciences (CIOMS), Guidelines on “Clinical Research in Resource-Limited Settings” was released in June 2021. Substantial contribution was made from the Head, ICMR Bioethics Unit. The document helps to understand key aspects related to the research being conducted in low resource countries.

CANCER

COMPLETED PROJECTS / ACTIVITIES

1. Monitoring survey of cancer risk factors and health system response in the Northeast Region of India

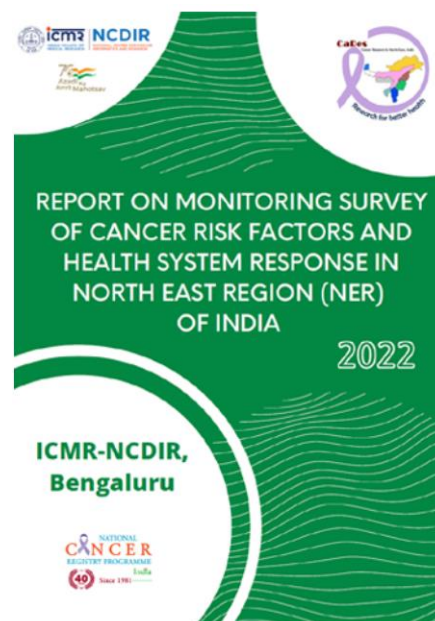
Project Duration: 1 November 2019 - 30 April 2021

This study aimed to generate key cancer and other NCD related risk factors and health system response indicators in the 12 Population Based Cancer Registries in 8 states of North East India. The target population for the survey was defined as all residents aged 18 or above residing in their usual residence. A total of 21321 respondents spread across a total of 480 Primary Sampling Units (PSUs) in the 12 registry areas participated in the survey. The survey included household and individual level interviews. Data about household characteristics, socio-demographic data, cancer related risk and lifestyle factors such as tobacco intake, alcohol consumption, dietary pattern, high risk behaviour and access to cancer related preventive care were recorded. If there happened to be a cancer patient in the family, a separate interview with the patient was conducted and treatment related history was also obtained in addition to the data that was collected from healthy individuals. The study participants were also subjected to anthropometry, blood pressure measurements and estimation of fasting blood glucose. In each PSU, a district hospital/ CHC, PHC, and private health facility were surveyed to assess the availability of cancer-specific health facilities.

Key findings: Nearly half of the respondents (48.6%) were current tobacco users, comprising 61.7% men and 34.8% women. Close to a quarter (22.8%) of the respondents reported to have consumed alcohol over the past 12 months and 18.3% reported alcohol use within the past month. The mean number of days on which either fruits or vegetables were consumed was 0.8 days in a week. According to the WHO criteria, the proportion of those who were obese was 5.2%, while the prevalence of obesity was higher (27.6 %) using Asian cut off points. The prevalence of raised blood pressure was 28.7%, of which the proportion of newly detected (20.8%) was higher than previously known (7.9%). The proportion of respondents whose blood glucose level was over 126 mg/dl was 5.1%, among whom the proportion of known diabetics was 3.3%. Close to a third (29.9%) of the cancer patients had sought health care outside of their state, the majority (63.6%) were availing of treatment at a government health facility. Over a quarter (26%) of the cancer patients were self-financing their treatment; 5.8% were covered by health insurance. Cancer screening for all three types of cancers (cervical, breast, oral) was available in 19.1% of the PHCs', 20.4 % of the CHCs' and 35.7% % of the District hospitals. A few CHCs' had a specialist in position in the following

departments: surgery (17.3%), medicine (39.8%) and gynaecology (36.7%). Less than 50% of the General Duty Medical Officers at the CHCs' and District hospitals had been trained for NPCDCS/NHM(NCD related)/State program. Likewise, the proportion of staff from other cadres who had undergone NCD-related programme management training was low in PHCs', CHCs' and District hospitals. About a quarter of the District hospitals had day-care facilities for chemotherapy (24.3%) and histopathology (21.4%).

The final report describing findings from pooled analysis of all state results was released on 4th February 2022 on the event of World Cancer Day.



2. Utilization and adherence to clinical treatment guidelines in cancer care and changes in care practice during the COVID-19 pandemic

Project Duration: 24 July 2020-23 July 2021

The study aimed to describe the adherence to clinical treatment guidelines in cancer care and the determinants of adherence during the COVID-19 pandemic. A cross-sectional survey was conducted among the medical practitioners providing cancer care at hospitals with a Hospital-Based Cancer Registry (HBCR) under the National Cancer Registry Program (NCRP) ICMR-NCDIR. The study results would help devise strategies to overcome barriers and reinforce the facilitators to maintain the continuum of care in cancer.

Key findings: A total of 75 principal investigators who are involved in the provision of cancer care participated in the survey. 96% of the respondents perceived clinical guidelines to be very important for cancer treatment administration. During the COVID-19 pandemic, 58.9% of doctors had followed the cancer patient care guidelines. The most important

characteristics that influenced adherence to cancer treatment guidelines were lack of knowledge about the guidelines, lack of skills to follow the guidelines and lack of training to administer a particular guideline.

3. Data quality review meetings with all PBCRs in August 2021

All PBCRs under NCRP network with staff participated in the workshop. Data quality of each of these workshops was discussed and methods of improvements suggested. These PBCRs along with their sources of registration (SoRs) cover 139 million of Indian population. Subsequent meetings with SoRs was held for sensitisation for 12 PBCRs covering 400+ sources.

ANNEXURE I -Meeting with Sources of Registration at host institutions of various PBCRs				
Sl. No.	Registry (PBCR)	Host Institute	Date of meeting	Participating centers/hospitals/ Pathology labs.
1.	Hyderabad District	Nizams Institute of Medical Sciences	12 th Nov 2021	25
2.	Nagpur Rural	RST Regional Cancer Hospital and Research Center	26 th Sept 2021	17
3.	Patna	IGIMS,Patna	25 th Feb 2022	15
4.	Barshi Rural	Nargis Dutt Memorial Hospital,Barshi	22 nd Oct ,2021	05
5.	Kolkata	CNCI,Kolkata(New Campus)	22 March 2022	17
6.	Kamrup Urban District	Dr. B Barooah Cancer Institute	24 Nov 2021	18
7.	Mizoram State	Civil Hospital,Aizawl	8 TH & 9 TH Nov 2021	33
8.	Sikkim State	STNM, Gangtok	13 Nov 2021	31
9.	Wardha District	MGIMS, Wardha	29 th March 2022	30
10.	Patiala District	Government Medical College	25 th Nov 2021	22
11.	Gautam Buddha Nagar-NOIDA	National Institute of Cytology and Preventive Oncology (NICPR)	15 th Dec 2021	13

4. Profile of Cancer and Related Factors for Ten States - Factsheet

The Cancer Fact Sheet presents the epidemiological profile and pattern of cancer from 10 states, based on the findings from the 'Report of National Cancer Registry Programme 2020'. In addition, related information on the socio-demographic profile, health status indicators and health infrastructure are also presented. These have a significant bearing on the occurrence and outcome of cancer. The factsheets were released on 24 September 2021.

State Wise Factsheet



Profile of Cancer and Related Factors -Karnataka (Sample)

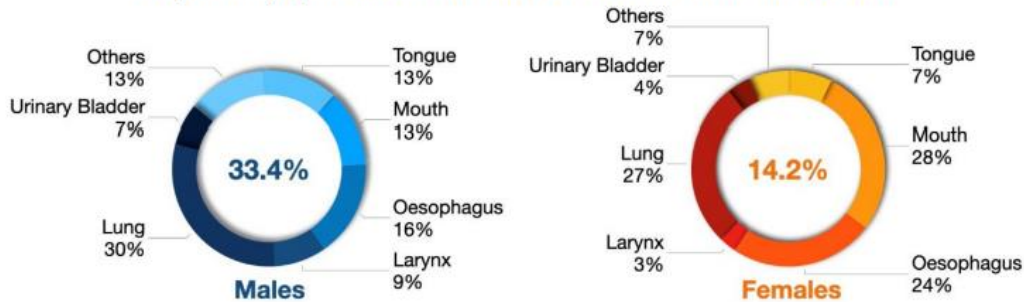
Average Annual number of Incidence and rates per 100,000 of all ages



Cumulative risk of developing cancer of any site in 0-74 years of age group



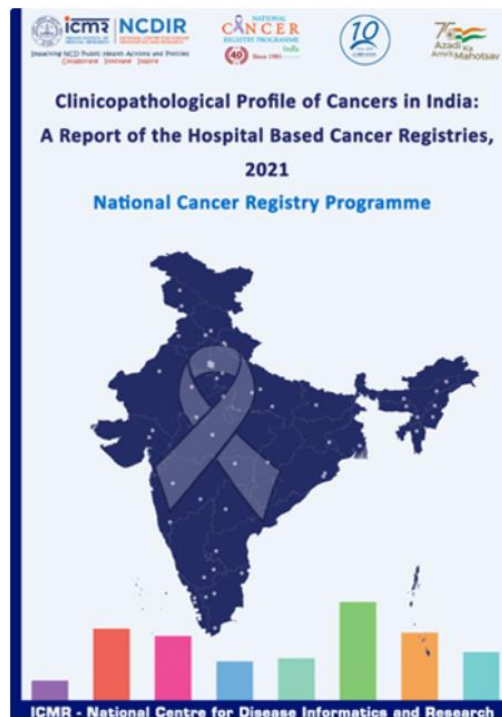
Proportion (%) of Cancer Sites associated with the use of tobacco



Others - Lip, Other oropharynx, Hypopharynx, and Pharynx Unspecified

5. Clinicopathological Profile of Cancers in India: A Report of Hospital Based Cancer Registries, 2021, released on 24 September 2021

The Report consolidates the data collected during the time period 2012-19 from 96 Hospital Based Cancer Registries under National Cancer Registry Programme. The data pertains to all diagnosed and treated cases of confirmed malignancies reported to these centres from many parts of the country. Registries whose data sets were complete and finalized have been included for the referenced period.



Key Findings: The total number of cancer patients that were registered from 96 HBCRs from 2012 – 2019 included 705,395 cases, of which 52.9% were males and 47.1% were females. A total of 203,442 (33.3%) cases were cancers in sites associated with tobacco use, of which 155,305 cases were in males (48.7%) and 48,137 were in females (16.5%). Among women, gynaecologic cancers (including breast cancer) accounted for over half (51%) of all cancers. Cancers of the head and neck region accounted for nearly one-third (31.2%) of the cancers among males. Cancers in sites associated with tobacco use comprised 48.7% of cancers whilst Childhood cancers (0-14 years) comprised 7.9% of all cancers. The age group of 45 to 64 years reported the highest proportion of cancer from all sites except for prostate cancer (over 65 years).

Cancers of lung were diagnosed at a stage of spread to distant sites followed by gall bladder cancer and prostate cancer. Over one-third of patients with cancers of the tongue, larynx, thyroid, corpus uteri kidney (including children), bladder and retinoblastoma had localized disease at the time of presentation. Chemotherapy was the most typical treatment modality for many cancers regardless of the clinical extent of disease at presentation. Most cancer patients were initiated on cancer-directed treatment within 8 to 30 days of diagnosis, regardless of the organ site and clinical extent.

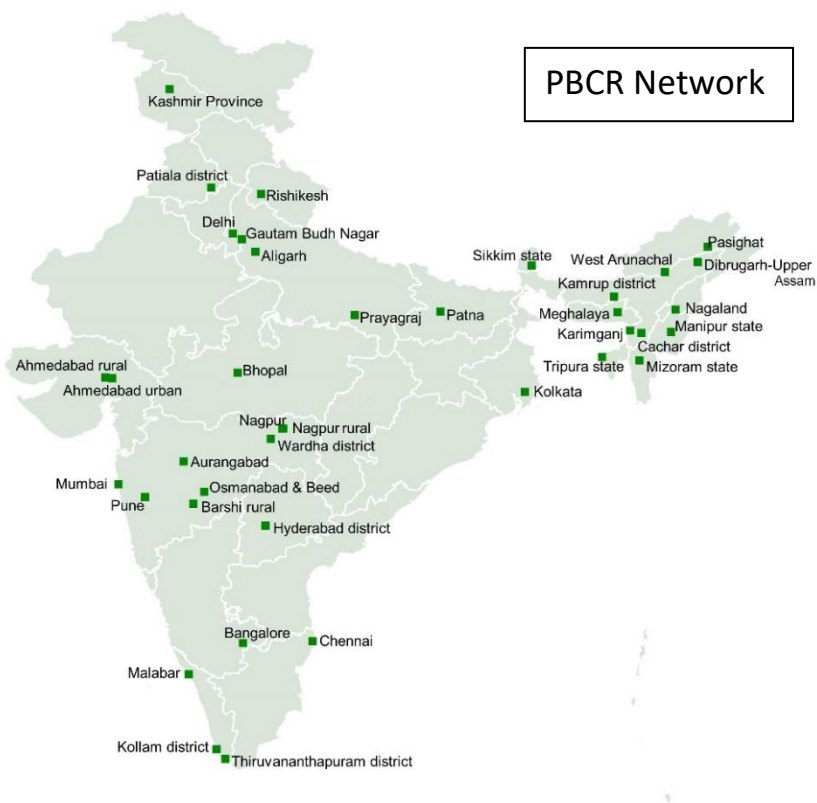
The report was released on World Cancer Research Day, 24th September 2021. The entire report can be accessed at [https://ncdirindia.org/All Reports/HBCR 2021/](https://ncdirindia.org/All_Reports/HBCR_2021/)

ONGOING PROJECTS / ACTIVITIES

1. Population Based Cancer Registries (PBCR)

PBCR s are continuously collecting data as an ongoing activity.





Ongoing Activities of PBCR

1. Data from 38 population Based Cancer Registries is being checked for quality through communication with registries.
2. Data quality is being closely monitored which includes duplicate removal, unlikely checks and matching of incidence with mortality data.
3. There are data review meetings and training workshops held on a regular basis with all PBCRs. The newer staff who joins undergoes a thorough training on abstraction of cases, coding as per international classification of diseases, data entry into the software.
4. The finalised data is tabulated and published in form of reports as tobacco related cancers, childhood cancers and region-specific factsheets.
5. Methods to improve the data collection through various sources of registration is an ongoing activity of PBCRs for which continuous interaction through phone and emails takes place.



Data quality review meetings with all PBCRs in August 2021

2. Population Based Cancer Survival on Cancers of Breast, Cervix and Head & Neck

Background

The project was initiated in 2017 to generate reliable data on population-based cancer survival in cancers of the breast, cervix and head & neck; and survival based on clinical stage/extent of disease across the Population Based Cancer Registries (PBCRs) wherever feasible.

Patients diagnosed in 2012 are followed up regularly

(for at least five years from the date of the first diagnosis of cancer).

- ❖ Follow-up data collection is continuing
- ❖ Data review meeting organized with 25 PBCRs (web), April, 2021
- ❖ Plan of survival analysis initiated for the report

(One of the investigators with a cancer patient during home visit follow-up – Dibrugarh PBCR)



3. Hospital Based Cancer Registries (HBCRs) Network

30 new centres have been registered for Hospital Based Cancer Registries under the network of NCDIR-NCRP during 2021-22.

The HBCR Network



Training Activities under HBCRs

- Online Training of newly registered Hospital Based Cancer Registries (HBCRs) under NCDIR on 29th June 2021 and 13th January 2022
- Data review meetings for Hospital Based Cancer Registries on 13-10-2021 & 21-10-2021 (2 batches)
- Online Training on Coding using ICD for Cancer on 3rd, 4th & 5th March 2022

4. Patterns of Care and Survival Studies (POCSS) on Cancers in Childhood, Lymphoid and Hematopoietic Malignancies, other Gynaecological Malignancies in Chennai, Bangalore, Thiruvananthapuram, Delhi and Mumbai

Background

This study aims to fill the knowledge gap by generating information systematically through a multicentric approach that will encompass patients from different parts of India. The objectives include-

- to estimate demographic and disease-free survival for Childhood, Haematolymphoid and Gynaecological malignancies (except cervix uteri).
- to assess the epidemiological and clinical determinants of survival for these three cancers.

List of participating centres

SI. No	Centre Name
1	All India Institute of Medical Sciences (AIIMS), New Delhi
2	Rajiv Gandhi Cancer Institute & Research Centre, New Delhi
3	Medanta Cancer Institute, Gurugram
4	Kidwai Cancer Institute, Bengaluru
5	Vydehi Institute of Medical Sciences, Bangalore
6	Cancer Institute (WIA), Chennai
7	Regional Cancer Centre, Thiruvananthapuram
8	Tata Memorial Hospital-Mumbai

Data review meeting:

Online data review meeting with the centre investigators and project staff was conducted on 11th October 2021.

Activities Underway:

- Data abstraction and data entry into the designated portal by the centres.
- Data review meetings for completion of data and follow-up data.
- Quality checks for the centres are prepared based on the transmitted data and sent to the centres for minimisation of errors.
- Interim data analysis

5. Patterns of Care and Survival Studies (POCSS) on Gall Bladder Cancer (GBC) in Hospital Based Cancer Registries under ICMR- National Cancer Registry Programme (NCRP)

List of Participating Centers

S. No	Centre Name
1	Regional Cancer Centre Kamala Nehru Memorial Hospital, Prayagraj
2	Sanjay Gandhi Post Graduate Institute of Medical Sciences, Lucknow
3	Indira Gandhi Institute of Medical Sciences, Patna
4	Mahavir Cancer Sansthan and Research Centre, Patna
5	Dr. B. Borooah Cancer Institute, Guwahati
8	Dr. B.R. Ambedkar Institute Rotary Cancer Hospital, New Delhi
6	Chittaranjan National Cancer Institute, Kolkata
7	Post Graduate Institute of Medical Education & Research, Chandigarh
9	All India Institute of Medical Sciences, Rishikesh
10	North-East Cancer Hospital & Research Institute, Guwahati

Activities Underway:

- Data abstraction and data entry into the designated portal by the centres.
- Trainings and workshops at regular intervals to train the registry staff and interact with the PIs for completion of data
- Periodic online meetings with the centres for the abstraction and follow up related issues.
- Quality checks for the centres are prepared based on the transmitted data and sent to the centres for minimisation of errors.
- Interim data analysis

Meetings:

1. A virtual progress review meeting was held by the Expert Group of Task force projects on Gall Bladder Cancer on 29th July 2021, ICMR Headquarters, New Delhi
2. A centre wise data review meeting was conducted with the centre PIs and CO PIs on 12th October 2021.

6. Incidental Gall Bladder Cancer and Other Premalignant Gall Bladder Condition in India towards early detection of Gall Bladder Cancer

List of Participating Centers:

S. No	Centre Name
1	Indira Gandhi Institute of Medical Sciences, Patna
2	Sanjay Gandhi Post Graduate Institute of Medical Sciences, Lucknow
3	Assam Medical College & Hospital, Dibrugarh
4	Vydehi Institute of Medical Sciences, Bengaluru
5	Government Medical college, Chandigarh

Activities underway:

- Data abstraction and data entry into the designated portal by the centres.
- Trainings and workshops at regular intervals to train the registry staff and interact with the PIs for completion of data
- Periodic online meetings with the centres for the abstraction and follow up related issues.
- Quality checks for the centres are prepared based on the transmitted data and sent to the centres for minimisation of errors.
- Interim data analysis
- Quality assurance activities:
 - Slide reviews performed by the Quality Assurance team at AIIMS Delhi
 - Training workshops organized for the centre pathologists and registry staff.

Meetings and workshops:

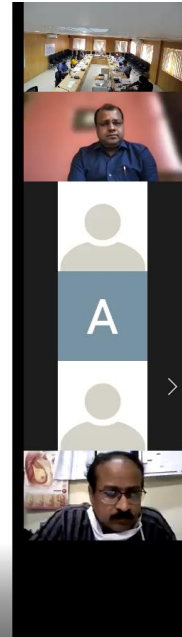
- A virtual progress review meeting was held by the Expert Group of Task force projects on Gall Bladder Cancer on 29th July 2021, ICMR Headquarters, New Delhi.
- A virtual pathological training workshop and data review meeting was held on 7th October 2021.
- Workshop on Quality assurance and hands on training for pathologists for Incidental Gall Bladder Cancer and Other Pre-malignant Gall Bladder Condition in India towards early detection of Gall Bladder Cancer was conducted on 29th March 2022.

March 29th 2022

Third workshop on Quality assurance and hands-on training for pathologists for Incidental Gall Bladder Cancer and Other Pre-malignant Gall Bladder Condition in India towards early detection of Gall Bladder Cancer

NATIONAL CENTRE FOR DISEASE INFORMATICS AND RESEARCH
NATIONAL CANCER REGISTRY PROGRAMME
Indian Council of Medical Research, Bengaluru

Quality Assurance Team, AIIMS, New Delhi
Prasenjit Das (Addnl Prof), Siddhartha Datta Gupta (Ex-Prof)



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7. DHR-ICMR Advanced Medical Oncology Diagnostic Services (DIAMOnDS)

ICMR - NCDIR is serving as a Data Management Centre for the DIAMOnDS centres (a multi centric study initiated by Department of Health Research) with the objectives-

- to facilitate data management for the project
- to link the biomarkers in breast and lung cancer test results to the NCRP registries to improve cancer data for patient management and research.

Study Centres

S. No.	Centre Name
1	All India Institute of Medical Sciences, New Delhi
2	Christian Medical College, Vellore, Tamil Nadu
3	Cachar Cancer Hospital, Silchar, Assam
4	Regional Institute of Medical Sciences, Imphal, Manipur
5	Tata Memorial Hospital-Mumbai
6	Super specialty Cancer Institute, Lucknow
7	Tata Medical Center, Kolkata
8	All India Institute of Medical Sciences, Jodhpur, Rajasthan
9	Jawaharlal Institute of Postgraduate Medical Education and Research, Puducherry
10	All India Institute of Medical Sciences, Bhopal
11	All India Institute of Medical Sciences, Bhubaneswar
12	Cancer Institute (WIA), Chennai

Online training workshop was conducted for the DIAMOnDS centres on 8th April 2021,



Data review meetings were conducted with centre investigators and project staff on 16th August 2021 and on 15th September 2021 an individual centre meeting was conducted for RIMS Imphal.

Activities underway at ICMR-NCDIR



8. Call for proposals under CaResNER 2021

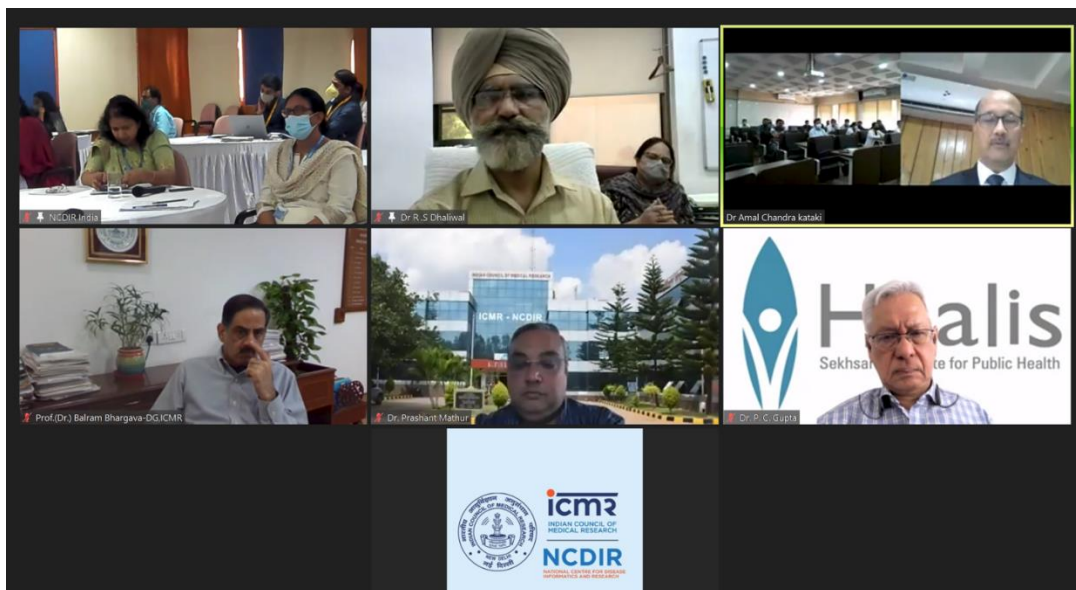
Following the successful implementation of 'Call for proposals' in 2019-2020 and 2020-2021, a similar round of call was made for the year 2021-22, as a part of the CaRes NER multidisciplinary programme. Under this national call, proposals were invited from interested investigators in which the project could demonstrate an ambition to establish or develop a systematic approach to the use of research to inform health policy and practice. The shortlisted proposals will undergo a final review by five members of a Technical Review Committee.

9. Cancer Epidemiology Surveillance Training (CanEST) Programme

Cancer Epidemiology and Surveillance training programme (CanEST) was developed by in-house specialists experienced in handling Registry data, in consultation with National subject experts. The specific objectives of this training were to (a) Develop skills to analyze,

interpret data and infer current registry data more efficiently and initiate and develop a strengthened surveillance system for Cancer in a defined geographical area. (b) Develop Research protocol for undertaking epidemiological research, both hospital-based and population-based; initiate, and oversee all phases of research activity. (c) Comprehend current Policies, Programmes, and Practices and help strengthen Cancer Prevention and Control. (d) Network with the Government Health system, the Private sector, and NGOs in Cancer Prevention and Control.

The training was inaugurated on 22 October 2021 by Prof. Balram Bhargava, Secretary DHR & Director General, ICMR.



Key progress:

In the reporting period, two rounds of training were conducted at NCDIR (22-28 Oct 2021 & 07-12 Mar 2022) and 19 Research Scientists from Population and Hospital-based Cancer Registries were trained on the basic concepts of epidemiology and biostatistics, cancer epidemiology and surveillance, and action plan development. Each training included two guest lectures delivered in an online mode by experts in the field.



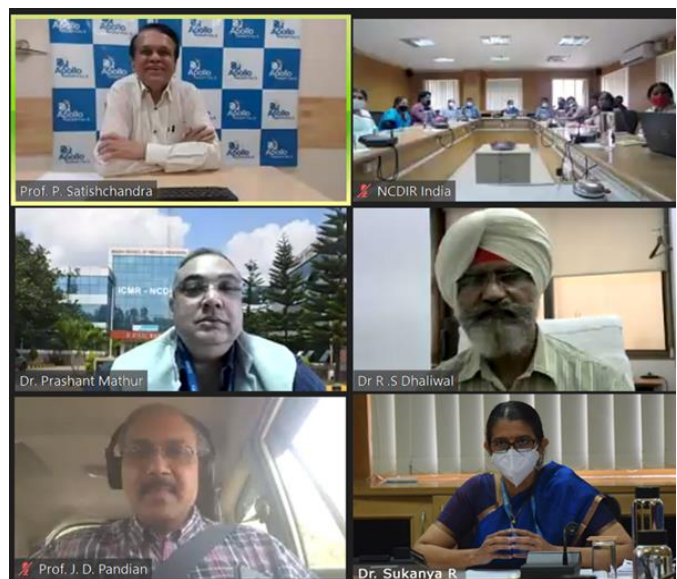
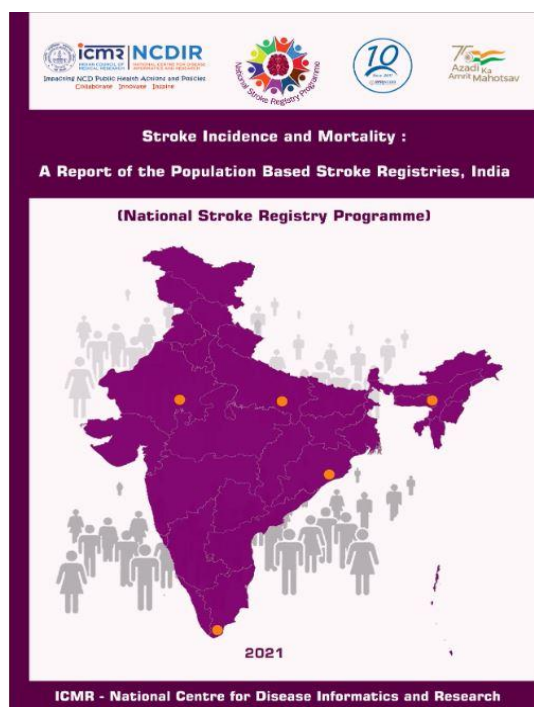
STROKE

Completed Activities

1. Patterns of Stroke care in Ayushman Bharat – Pradhan Mantri Jan Arogya Yojana (AB PM-JAY) empanelled Hospitals

ICMR-NCDIR collaborated with National Health Authority (NHA) to describe the patterns of stroke, stroke care and outcomes in beneficiaries treated in empanelled hospitals of Ayushman Bharat PM-JAY scheme. The study revealed patterns of stroke care in 11 states/UTs and the need for strengthening data collection methods through the AB PM-JAY scheme to monitor stroke management in empanelled hospitals.

2. Online Release of the Report- ‘Stroke Incidence and Mortality: A Report of the Population Based Stroke Registries (PBSR), India’



The first comprehensive PBSR report was released online on 10th November 2021 by Dr. Satishchandra, Chairperson, Research Area Panel- Stroke. The members of the Scientific Advisory Committee (SAC), Research Area Panel, Directors, Heads, and Scientists of ICMR Headquarters and Institutions, Investigators of the Population and Hospital Based Stroke Registries, and the NCDIR staff participated in the event.

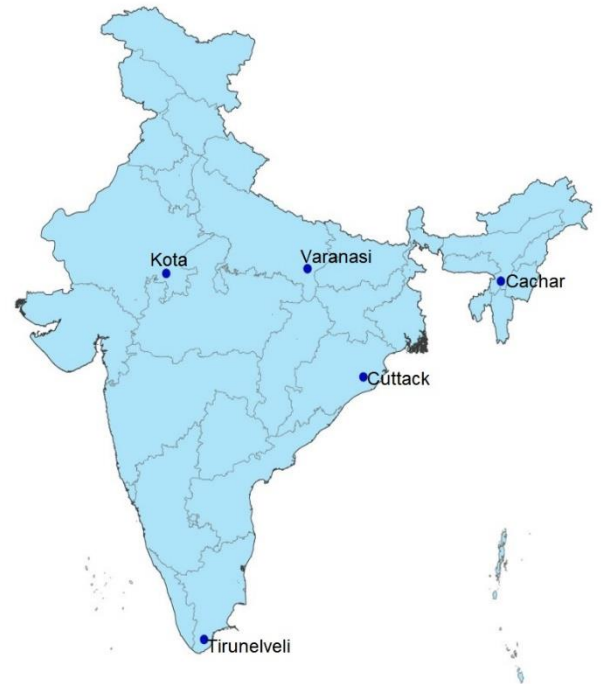
The report described the incidence and mortality patterns of stroke in five populations in the north, northeast, west, south, and east regions in India. The report has been disseminated among the stakeholders.

ONGOING PROJECTS / ACTIVITIES

1. Development of Population Based Stroke Registry (PBSR) in different regions of India

PBSR Centres:

Sr. No	PBSR Centres
1	Cuttack - PBSR Cuttack (urban and rural), SCB Medical College
2	Kota – PBSR urban Kota, Govt Medical College
3	Cachar – PBSR Cachar District, Silchar Medical College
4	Tirunelveli – PBSR Tirunelveli (urban and rural), Tirunelveli Medical College
5	Varanasi – PBSR Varanasi urban, Institute of Medical Sciences, BHU



Data Collection for 2020-2021 is being completed by the centres. The Data quality check is in progress.

PBSR site visit: Field visits started with an on-site visit to PBSR Varanasi from April 6th to April 10th 2022. Dr M V Padma Srivastava, Prof of Neurology and Head, Centre of Neurosciences, AIIMS, New Delhi participated in the review of the PBSR.





2. Development of Hospital Based Stroke Registries (HBSR) in different regions of India



HBSR Centres: Thirty five centres registered between April 2021 to March 2022.

Type of HBSR Centre/ year	Total
Participating centres	09
North East Region Centres (NER) (under the project Development of HBSR under NER)	04
Registered Centres	22
Total	35

Online registration of hospitals interested in participating in the Hospital Based Stroke Registry has been initiated.

Hospital Based Stroke Registry (HBSR)

The objective of HBSR is to describe the patterns of care and treatment in patients with stroke in hospitals. HBSR collects data on persons with stroke over time who have received treatment in the respective hospital. Hospitals treating stroke patients in different parts of India can join as participating centres.

The HBSR includes all persons of age ≥ 18 years with first-ever or recurrent stroke presenting within a month of onset of stroke to the reporting institution/hospital. The HBSR includes data on all patients with stroke from different geographic areas who seek treatment in that hospital. Data on diagnosis, treatment, and outcome information of stroke patients is collected through review of medical, imaging and other records and data is abstracted in a Core form.

HBSR will facilitate in assessing quality of care available for stroke patients in different treatment settings. This will help in improving preventive, curative and rehabilitative services for stroke in India.

[Click here to register as HBSR centre](#)

[View guidelines for setting up of HBSR](#)

[Click here to login as HBSR centre](#)



The HBSR core form was revised and software updated.

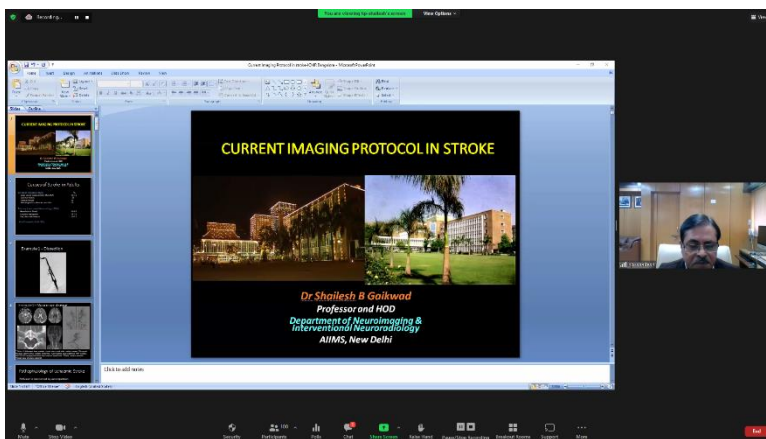
Standard format for recording imaging findings of stroke has been developed which needs to be filled by the radiologists of participating HBSRs. The purpose is to streamline the recording of imaging findings for the Stroke Registry. A procedure manual and a short guide for the radiologists was developed and shared with all centres. Training for radiologists was conducted on March 4, 2022.

NATIONAL CENTRE FOR DISEASE INFORMATICS AND RESEARCH
 Indian Council of Medical Research
HOSPITAL BASED STROKE REGISTRIES
 Standard reporting format to record imaging findings

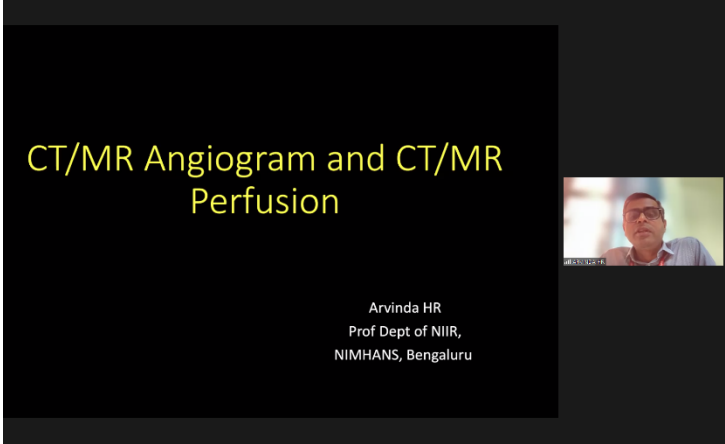
- *Format is to be filled by the Radiologists*
- *To report only the findings from the first imaging for all types (not to be used for repeat imaging)*

Trainings conducted:

Sr.No	Context of Training Programme	Date of Training
1.	HBSR Sensitization & training programme for PIs and Co PIs	16 th July 2021
2.	HBSR Training programme for PIs, Co-PIs and staff	26th November 2021
3.	HBSR Training programme for PIs, Co-PIs and staff of HBSR -NER centres	18th February 2022
4.	Sensitisation and Training Programme on standard reporting format for imaging findings for stroke registrie	4th March 2022



4th March 2022-
Sensitization and Training
programme on Standard
reporting format for
imaging findings for Stroke
registries



DIABETES

COMPLETED PROJECT

1. Access to Health Care among Individuals with Diabetes during COVID Pandemic in a Rural Setting in Karnataka

Project duration: 25 March 2021 to 31 August 2021

The study aimed to describe the management of diabetes among individuals in a rural setting during the lockdown due to COVID-19 and to identify the challenges faced by diabetes individuals in accessing treatment for their diabetes. Diabetes individuals identified in the study area of Devanahalli were interviewed. The study commenced in March 2021.

The objectives of the study were

- to identify the challenges faced by diabetes individuals in accessing treatment for their diabetes.
- to describe the modalities used by the patients to access medical care.
- to describe how the healthcare providers (primary level to secondary level) supported diabetes management.

Methodology: ICMR-NCDIR had conducted a community-based study to understand access to care for diabetes mellitus among 69 diabetes individuals in three villages in Devanahalli taluk. These patients were interviewed over phone following oral consent during the lockdown period using questionnaire on physician consultation, medicines, laboratory investigations & life style NCD risk factors.

Key Findings:

- Majority (95.7%) had reported that they monitored the blood glucose levels in the baseline. During the pandemic period the proportion who continued to do blood glucose monitoring reduced to 75.4%. The reasons for decreased blood glucose monitoring was reported as closure of laboratories, clinics and hospitals, non-availability of transport and glucometer strips, crowded hospitals and lockdown restrictions.
- 85.5% had reported blood glucose levels under control in the baseline, as compared to 70.5% who reported blood levels under control during the COVID-19 pandemic.
- Nearly three fourth (72.5%) had reported regular medication intake in baseline which reduced to two-third (65.6%) in the follow-up. The reasons for decreased medicine intake for diabetes was reported as non-availability of pharmacy and transport, change of medicine brands and change of health facility of consultation due to the pandemic.

- More than two third (67%) preferred to use teleconsultation during the COVID-19 pandemic.

ONGOING PROJECTS

1. A National Model to Measure Burden and Map Quality of Care for Type 2 Diabetes Mellitus Rural Population in India, involving Medical Colleges through Primary Health Care Setup- A Feasibility Study (DNMS)

Diabetes National Model Study (DNMS) aims to develop a model to measure burden and map quality of care for type 2 diabetes mellitus in rural India, involving medical colleges through primary health care setup.

The objectives of the study are –

- To describe the quality of care available for diabetes care and received by diabetes individuals at primary, secondary and tertiary settings for diabetes care in rural populations.
- To determine the association between known exposures/risk factors with prediabetes and diabetes.
- To estimate the burden of pre-diabetes, diabetes and its complications, and comorbid NCD conditions in defined rural populations.

Following are the implementing centres for this project:

- a) Grant Medical College and JJ group of Hospitals, Mumbai.
- b) Raichur Institute of Medical Sciences, Raichur.
- c) Agartala Medical College, Tripura.
- d) ICMR- National Institute of Implementation Research on Non-Communicable Diseases (NIIRNCD), Jodhpur (Newly identified).

Key Activities:

- Virtual training for PI, Co PIs and project staff of Agarwal Medical College was completed in April 2022.
- Except for newly identified centre, all other 3 centres had completed pilot testing of survey from during April to June 2021.
- Review meeting was held in July 2021 with PI / Co PIs along with all field staff to discuss the findings of pilot testing.
- DM RAP meeting (Virtual mode) was held on 13th July 2021 to review the Diabetes related projects at ICMR-NCDIR.
- The field investigators are collecting and reporting the data collection at ICMR-NCDIR server.
- To capture the survey coverage, monthly report format was developed.

- For proper implementation of the project, PI and Co-PIs were given the microplanning template.
- For effective supervision by PI & other ICMR staff/experts, supportive supervision checklist (SSV) checklist was developed.
- The key project staff were oriented on above tools for effective implementation of project.
- Joint meeting of ICMR Directors, Nodal officers of MRHRU of ICMR Institutes and site PIs of DNMS was held on 8th October 2021 to discuss DNMS project, implementation, progress & supervision.
- From October 2021 regular monthly meetings are being conducted to with each PI to monitor the progress in survey coverage and resolve project implementation issues.
- Every month quality check reports are presented to PI to improve on data quality (from Dec 2021 onwards).
- Annual review meeting (in-person) was conducted on 14th March 2022 to review the annual progress of DNMS project and also discuss quality check report and findings of interim analysis.



DNMS Annual review meeting held on 14th march 2022

Software development:

The DNMS dash board has been developed to monitor the progress of survey and the centres were oriented on the dashboard features.

2. Setting up of Non-alcoholic Fatty Liver disease (NAFLD) registry in India

The NAFLD registry was proposed to be setup in different parts of India due to increasing prevalence of NAFLD with increase in obesity and type 2 diabetes mellitus in Indian population. The aim of the registry is to understand the burden, disease trends, variations, progression of NAFLD in India.

The objectives of the study are:

- To generate reliable data on Non-Alcoholic Fatty Liver Disease with respect to pattern of occurrence, associated comorbidities, management practices, treatment outcomes and progression of NAFLD in Indian population
- To establish Hospital Based NAFLD Registry Programme in different parts of India, to obtain data on the above-mentioned objectives.

Ongoing activities:

- The coreform has been prepared and brainstorming meeting with RAP members was conducted to finalise the coreform.
- List of potential centres has been identified and they will be invited to participate in the registry.

CARDIOVASCULAR DISEASES

Completed Project

1. A Study on the Magnitude and Pattern of causes of Heart Failure (HF) - a Feasibility Study

Project Duration: 14 February 2018 – 31 March 2022

The study had been designed as a multi-centre, prospective study in five centres in small to medium sized towns in North, South, East, North West and South West regions of India with objectives to understand the patterns of cause, care and outcomes of heart failure patients along with assessing the feasibility of effective functioning of heart failure registries in different geographies of India.

The objectives of the study were

- to understand the different causes of heart failure.
- to understand the pattern of care received and survival outcomes of patients suffering from heart failure.
- to assess the possibility of establishing the similar heart failure registry in different parts of India.

Activities:

- The data was analysed and presented to RAP CVD members on 21st April 2021.
- The data quality was reviewed by data management team.
- The training and orientation for PIs, Co-PIs and project staff of HF study was held on 21st October 2021.
- The follow-up action plan of the RAP meeting were shared with the PIs.
- The data is being analysed for preparation of report.

Ongoing Project

1. Hospital Based Study on Profile of Cardiovascular Diseases (CVDs) and Heart Failure Registry in North-East region (NER) of India (HBCVDR-NE).

The registry was established to know about the presentation, pattern and quality of CVD care and strength of weakness of infrastructure, resources, co-morbidities, in-depth data of metabolic and behavioral risk factors, influence of risk factors on severity and outcome etc.

Objectives of the study are:

- to develop Hospital Based Cardiovascular Disease Registries in North-East region of India to understand the different causes of CVDs.
- to understand care received by patients and survival outcomes of heart failure (HF) cases.

Following are the identified participating centres (2021-2022):

1. Christian Institute of health sciences, Nagaland
2. Gauhati Medical College & Hospital, Indrapur, Gauhati
3. North Eastern Indira Gandhi Regional Institute of Health and Medical Sciences (NEIGRIHMS) Shillong, Meghalaya
4. Regional Institute of Medical Sciences Lamphelpat, Imphal
5. Zoram Medical College, State Referral Hospital, Falkawn, Mizoram
6. Agartala Medical College, Agartala, Tripura
7. Tomo Riba Institute of Health & Medical Sciences, Naharlagun, Arunachal Pradesh.

Activities:

- PIs and CO-PIs were oriented on the project implementation on 20th October 2021.
- The project staff were trained in software.
- The four centres are transmitting data in software.
- The five potential participating centres for second year (2022-2023) of HBCVDR-NE are identified and invitation letters were sent.

Software development: The software application for HBCVD was developed.

MORTALITY

Completed Activities

1. Guidance for the appropriate recording of COVID-19 related deaths

The guidance document was published and disseminated in May 2020, which was further released from the Office of Registrar General of India (ORGI) to all the States and Union Territories in July 2021.

2. Strengthening Medical Certification of Cause of Death (MCCD) by development of mortality audit systems framework, online MCCD modules and standardize e-Mor application -Technical collaboration with WHO

The phase I of this project has been completed. The various deliverables completed under this project include:

- Content of training module on Medical Certification of Cause of Death (MCCD) has been developed.
- IRIS software training was conducted by experts of IRIS Institute. The purpose was to understand use of IRIS software for standardization of e-MoR software.
- Position paper on the framework of MCCD audit at hospital was developed. It has been reviewed by experts, CBHI, DGHS and the WHO. The report, 'Framework for audit of Medical certification of cause of death at health facility' has been developed for publication in collaboration with CBHI, DGHS and WHO- India.

3. Implementation of NCDIR electronic Mortality software (NCDIR e-Mor) in hospitals of the National Cancer Registry Programme (NCRP) network in North East India

The project was closed in participating centres after the completion of the 5-year period (April 2017-March 2022). The final report is under preparation.

Ongoing Projects / Activities

1. Implementation of NCDIR electronic Mortality software (NCDIR e-Mor) – strengthen Medical Certification of Cause of Death (rest of India)

NCDIR e-Mor software has been implemented in the hospitals across India. Review of data quality was shared with centres in meeting held on December 9th 2021. Training on recording sequence of cause of death was done through virtual mode.

Details of e-Mor centres	No. of Centres
Participating Main centres	16
NER region	16
Total	32

2. NCDIR Collaborations in Setting up Statewide e-MoR program for strengthening MCCD systems

Initiative was taken with the state registrar offices to strengthen MCCD by providing technical assistance.

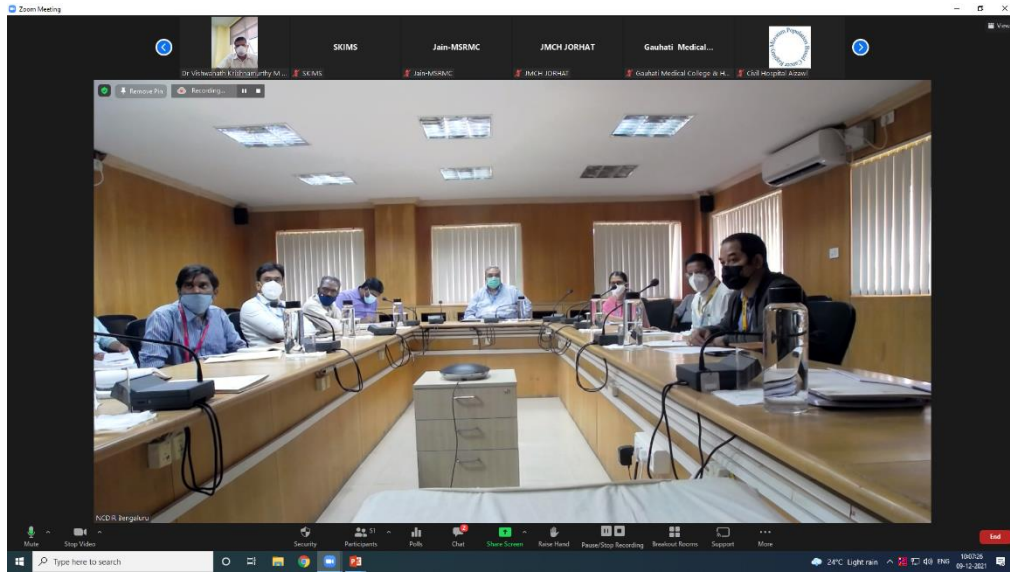
- a. **Tamil Nadu:** Integration of ICMR-NCDIR e-Mor cause of death module with Tamil Nadu CRS software is completed. All hospitals and local registrar offices in Tamil Nadu started using the CRS software to record MCCD from September 2021.
- b. **Karnataka** – Integration of MCCD component of e-Mor software with the e-Janma software (CRS software) is planned by the Directorate of Economics and Statistics (Chief Registrar of Births and Deaths, Karnataka). The plan of work with budget was submitted to DES in Dec 2021.

3. Strengthening the Medical Certification of Cause of Death (MCCD) practices in public and private healthcare facilities in India: Research to implementation

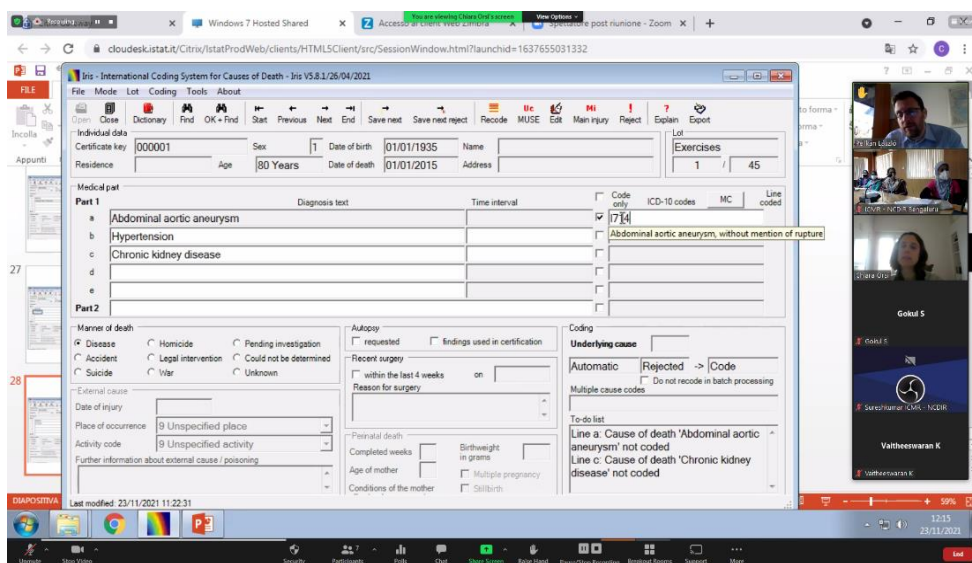
A collaborative study to assess the implementation of MCCD at the system and health facility level in 12 districts of six states of Andhra Pradesh, Karnataka, Tripura, Delhi, Rajasthan and Punjab has been initiated. AIIMS, New Delhi, and PHFI, Gurugram are the collaborating centres.

Meetings:

1. Expert Group Meeting was conducted on “Development of Mortality Audit Framework for hospitals in India” in hybrid mode on November 12, 2021 at ICMR-NCDIR, Bengaluru.
2. Data review Meeting of e-Mor Centres and training on MCCD was conducted in Hybrid mode on December 9, 2021.
3. A meeting was conducted on November 17, 2021 for further discussion on integration of e-Mor Software with e-JanMa web-based application through virtual conference as a part of technical collaboration between DES, Karnataka and ICMR-NCDIR.



Trainings: IRIS training was provided by IRIS Institute in virtual mode from November 22-26, 2021 at ICMR-NCDIR, Bengaluru.



ICMR BIOETHICS UNIT

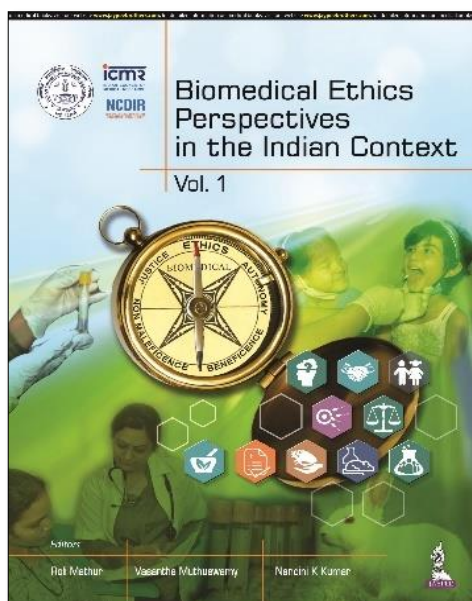
Completed Activities

1. Publication of Volume I of the Reference Book entitled “Biomedical Ethics- Perspectives in the Indian Context”
2. ICMR Training on Ethical Issues in Research for Ethics Committees in Rajasthan
3. Public Webinar on Ethics, Compassion, Dignity in End-of-Life Care & Death
4. WHO guidance on Ethics & Governance of Artificial Intelligence for Health
5. Council of International Organizations of Medical Sciences (CIOMS), Guidelines on “Clinical Research in Resource-Limited Settings”
6. ICMR - Central Ethics Committee on Human Research

1. Publication of the Volume I of the Reference Book entitled “Biomedical Ethics- Perspectives in the Indian Context”

Editors : Dr. Roli Mathur, Dr. Vasantha Muthuswamy and Dr. Nandini K. Kumar

ICMR Bioethics Unit under the aegis of ICMR had collated a reference book on biomedical ethics which was published by Jaypee Medical Publishers. This was the first-of-its-kind book in India with a comprehensive and unique compilation of topics addressing ethical aspects in various kinds of research in Indian context. The contributors to the book were national-level experts in their respective domains who have shared their expertise and knowledge on specialised topics that have been articulated in a manner to understand the intrinsic ethical challenges faced by researchers, clinicians, students and ethics committee members involved in biomedical and health research in India. The book was finalised after a thorough and stringent external peer review and review by the editors. The chapters of the book include, History and Evolution of Codes and Guidelines, Informed Consent Process, Ethics of Research Involving Children, Ethical Issues in Epidemiological Studies, Research Ethics in Participants with Mental Illness, Ethics of International Collaboration in Biomedical and Health Research: An Indian Perspective, Ethical Issues in Assisted Reproductive Technologies, Status of Traditional Medicine: Integrative and Ethical Perspectives in India, Ethical Considerations in Organ and Tissue Transplantation, and Ethical Practices and Guidelines for Animal Experimentation in Biomedical Research. The book is comprehensively curated to serve as a tool for teaching and training purposes. It is intended to provide guidance to students, researchers and ethics committee members. The book was released on World Health Day 7th of April 2022 by DG, ICMR and being disseminated to various medical institutions and research organisations across the country.



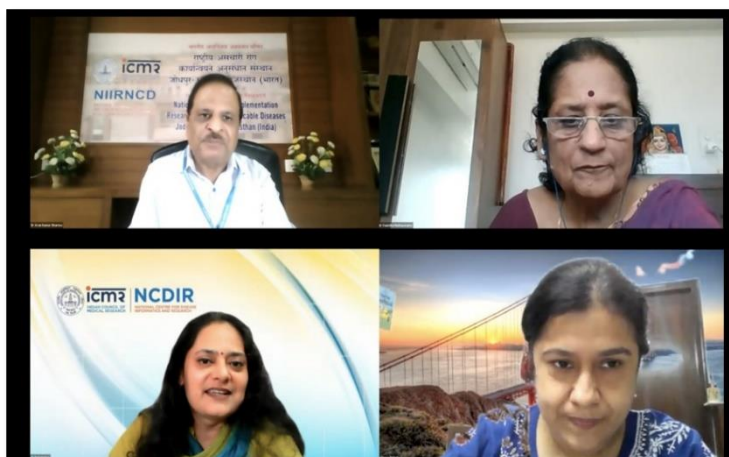
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2. ICMR Training on Ethical Issues in Research for Ethics Committees in Rajasthan

A half-a-day online training program was organized on 30 June 2021 by ICMR - National Institute of Implementation Research on Non-Communicable Diseases (ICMR-NIIRNCD), Jodhpur, Rajasthan, in association with ICMR Bioethics Unit, covering topics such as Roles and Responsibilities of ethics committee members, ICMR National Ethical Guidelines, Registration of ECs, New Drugs and Clinical Trial Rules 2019, Vulnerability and Consent. Around 70 delegates (ethics committee members, faculty, scientists, researchers, etc.) from ICMR - NIIRNCD Jodhpur as well as various institutions in and around Rajasthan benefitted from the training.



3. Public Webinar on Ethics, Compassion, Dignity in End-of-Life Care & Death

In the context of India's 75th Independence Day celebrations, a "Public Webinar on Ethics, Compassion, Dignity in End-of-Life Care & Death" was held on 24 August 2021. The program engaged with the public at large and informed them about the existing provisions related to End-of-Life Care and tried to understand their perspectives on EOLC. The program was an effort to engage the public to create a better understanding of the role of stakeholders, including that of the caregiver in imparting home-based care to terminally ill patients, ethical issues in utilizing technologies in prolonging the life of people suffering in their death bed, and ICMR's Initiatives on End of Life Care towards a dignified death. The program was live-streamed on YouTube for wider outreach. The program was helpful in connecting and sharing knowledge that may be useful in the development of a comprehensive National End of Life Care Policy in the future.

ICMR NCDIR
National Centre for Disease Control
Ministry of Health and Family Welfare, Government of India

75
Azadi Ka Amrit Mahotsav

ICMR Bioethics Unit, ICMR-NCDIR, Bengaluru
Invites you to join the

**Public Webinar on
Ethics, Compassion, Dignity in
End of Life Care & Death**

On 24th August 2021 from 11:00 AM to 12:15 PM (IST)

This webinar will help you understand about,

- Providing home-based care for the loved ones, who are terminally ill
- Ethical challenges in utilizing technology to prolong life of the people suffering in their death bed
- Caregiver's role to assure a dignified death
- ICMR's initiatives on End of Life Care

Who can attend?
Anyone from public, involved or interested in caregiving of patients on life sustaining treatment

Speakers

<p>Dr. Vasantha Mathuram Chairperson, ICMR-CECHR, Former Sr DOG, ICMR, Mumbai</p>	<p>Dr. M. R. Balagopal Chairman, Patient Welfare, Tiruchendur</p>
<p>Dr. Susana Bhattacharjee Professor and Head, Palliative Medicine, ICMR-ABCI, New Delhi</p>	<p>Dr. Raj Kumar Masi Director, Critical Care, Palliative & Critical Care, Tamil Nadu, Chennai</p>
<p>Ms. Harshada Gupta Executive President, Caring2000, New Delhi</p>	<p>Dr. Rishi Mathur Scientist F and Head, ICMR Bioethics Unit, ICMR-NCDIR, Bengaluru</p>

No registration fee
To join the Zoom webinar, click on the link
<https://zoom.us/j/197976439483?pwd=THh3YVVMNmNlWkxwMlU0c0EwRjZkZ09k>

To join the YouTube Live, click on the link
<https://www.youtube.com/channel/UCe-9052QV9D1R2V5h80vA1g>

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Website: <https://ethics.nclindia.org>

4. WHO Guidance on “Ethics and Governance of Artificial Intelligence for Health”

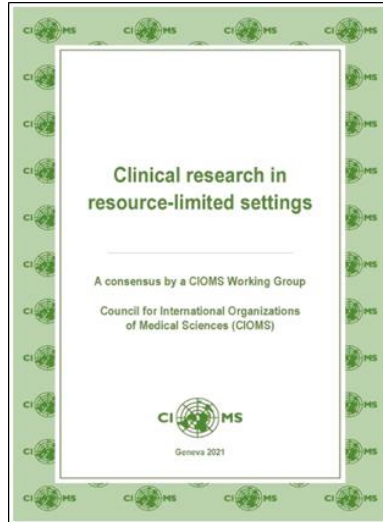
Participants from more than 25 countries and different agencies across the world joined to prepare the above mentioned guidance document. These guidelines were released on 28th June 2021 as ‘Ethics and Governance of Artificial Intelligence for Health’ in which Head, ICMR Bioethics Unit, is one of the authors. As a stake holder in the preparation of the document, the ICMR Bioethics Unit was able to bring in the concerns and suggestions based on the national interest and also as a nation representing the Low to Middle Income countries.

Reference: <https://www.who.int/publications/i/item/9789240029200?s=08>



5. Council of International Organizations of Medical Sciences (CIOMS), Guidelines on “Clinical Research in Resource-Limited Settings”

Head of the ICMR Bioethics Unit was appointed as Member of the Executive Committee of CIOMS as well as member of the Working Group for preparing the Guidelines for Ethical issues related to the conduct of research in low resource settings. The contributions from the Head, ICMR Bioethics Unit were substantial in preparing the document and was able to bring in the concerns of Low and Middle-Income Countries. The guidelines on ‘Clinical Research in Resource-Limited Settings’ were released on 17th June 2021, and the spirit of this report is to provide balanced arguments to promote good quality clinical research in resource-limited settings. The document is intended to guide the government agencies, regulatory bodies, research communities and other relevant stakeholders of research. The document provides a comprehensive set of recommendations to all major stakeholders involved in research. Reference: <https://cioms.ch/publications/product/clinical-research-in-low-resource-settings/>



6. ICMR - Central Ethics Committee on Human Research

As per the New Drugs and Clinical Trial Rules, 2019, it is mandatory to register all ethics committees involved in the review of biomedical and health research with the Department of Health Research (DHR). In this context, the ICMR Bioethics Unit received the provisional registration certificate (EC/NEW/INST/2021/1879) on 9th July 2021. ICMR-CECHR reviews research of national importance with complex ethical issues being led by ICMR or referred to it by the government ministries and departments. It is also involved in the process of guideline development and policymaking.

ICMR Bioethics Unit at ICMR-NCDIR, Bengaluru serves as the Secretariat for the ICMR CECHR. The members as well as the alternate members of the committee has met regularly over the course of the second wave of the pandemic, and has reviewed 13 large multicentre studies including both non-COVID and COVID-19 related health research. The committee has fast tracked research proposals involving nationwide COVID-19 vaccination trials to facilitate ease of conducting research in emergency situations. During the year, ICMR CECHR has organised 5 virtual full committee review meetings along with 3 expedited review meetings.

OTHER PROJECTS / ACTIVITIES

Ongoing Project

“Developing A Public Health Informatics Platform in India for a systems view of Health and Diseases” Under Epidemiology Data Analytics (EDA) Of Interdisciplinary Cyber Physical Systems (ICPS) Programme of the Department Of Science And Technology (DST), GOI.

A mapping review of the data repositories and their data access has been done to describe the need for the establishment of countrywide public health data repository on Non-Communicable Diseases in India

Project Review meetings were attended by ICMR-NCDIR on January 25, 2022 and March 22, 2022 wherein the participating institutions provided updates on their projects and the expert members gave valuable feedback. Following the review meetings, 6 months’ extension of the project has been requested.

Webinars Conducted By ICMR-NCDIR

- **Public Webinar - Reducing Health Inequalities in NCDs - Towards a Healthier Nation Date: 7th April 2021**



ICMR- NCDIR, Bengaluru organised a webinar ‘Reducing health inequalities in NCDs - Towards a healthier nation’ based on the World Health Day theme “Building a fairer, healthier world”. The webinar aimed to educate the public and health professionals about the stark disparities within communities that impact health outcomes. Public Health experts Dr Rajani Ved, and Dr Yogesh Jain, explained the impact of inequities on NCDs and the framework of health system response to reduce inequities. Dr Vipul Aggarwal, Dy CEO, National Health Authority shared on the role of the Ayushman Bharat Pradhan Mantri Jana Arogya Yojana. The Question & Answer session discussed the challenges

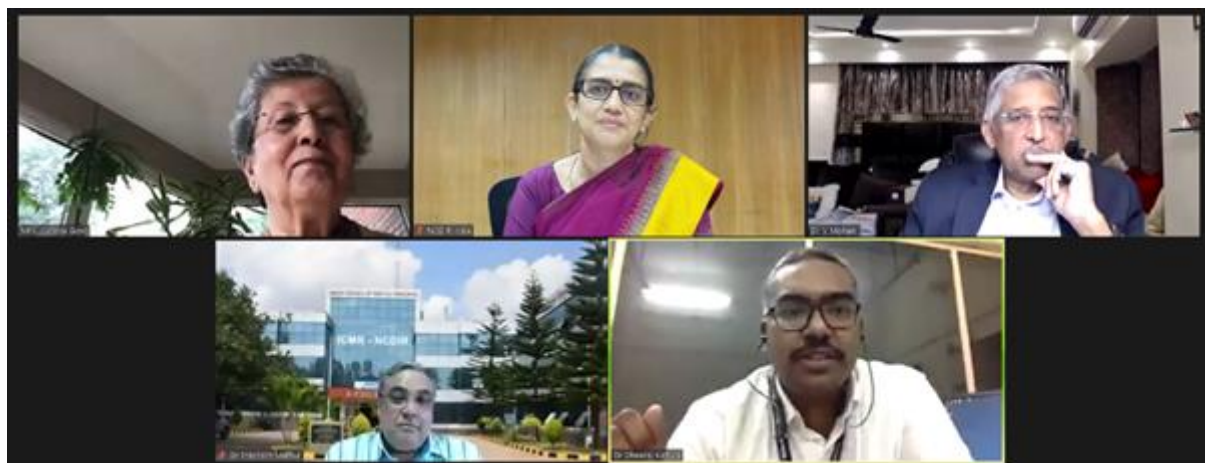
and opportunities to reduce health inequities for prevention and control of Non-communicable diseases in India.

- **Public Webinar on Ethics, Compassion, Dignity in End of Life Care & Death on 24th August 2021**



In the context of 75th Independence Day celebration (Azadi ka Amrit Mahotsav), ICMR Bioethics Unit, ICMR-NCDIR had organised a public webinar on Ethics, Compassion, Dignity in End of Life Care & Death on 24th August 2021. The webinar was intended for public participant involved or interested in caregiving of patients on life sustaining treatment. Eminent speakers talked about provision of home-based care for people who are terminally ill, ethical issues that may arise while their loved ones are in the death bed requiring life support technologies, caregiver's role in decision-making for assuring compassion and dignity to the ailing relatives, and about the ICMR's initiatives in End of Life Care & Death. The webinar was also live streamed on YouTube. About 150 attendees benefitted by participating in this webinar.

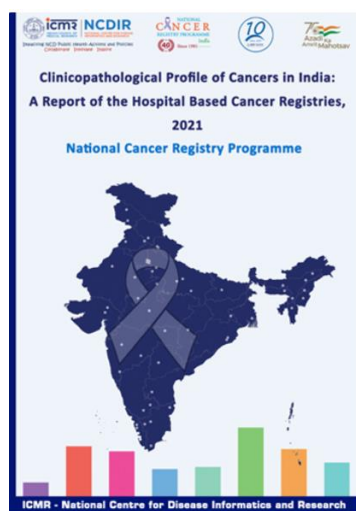
- **Public webinar on Lifestyle and Non communicable diseases on 26th August 2021**



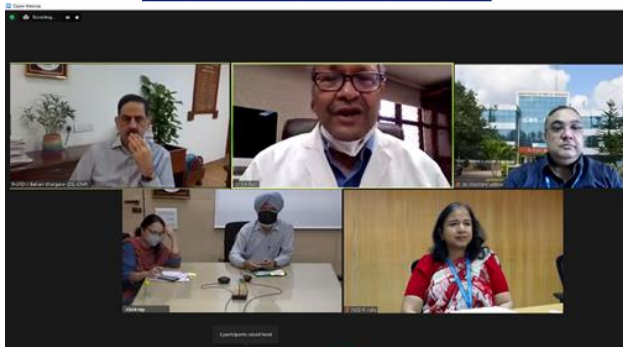
ICMR-NCDIR, Bengaluru had organised a public webinar on the topic 'Lifestyle and Noncommunicable diseases' on 26th August 2021 to commemorate 75 years of Independence celebrations - Azadi ka Amrit Mahotsav, an occasion to engage with citizens. Eminent speakers explained the current burden of NCD risk factors in India. Importance of dietary habits and physical activity in reducing onset of diabetes was highlighted through examples. Ill effects of alcohol and tobacco usage, prevention strategies and principles for management for deaddiction were presented. Experience of working with communities in cancer screening, understanding the needs of cancer patients and survivors was shared. The webinar ended with a clear message that NCDs can be curbed through a holistic approach to address lifestyle risk factors. Around 200 attendees (general public, students and medical doctors) benefitted by this webinar. The webinar was also live streamed on YouTube.

- **Release of Reports through webinars**

1. **Clinicopathological profile of cancers in India: A Report of Hospital Based Cancer Registries, 2021' and 'State Cancer Fact Sheets' on the occasion of World Cancer Research Day 24th September 2021 and**
2. **Profile of cancer and related factors-State wise Factsheets' by Guest of Honour, Dr G.K.Rath, Head, National Cancer Institute, Jhajjar and. Chief, DRBRAIRCH, AIIMS, New Delhi.**



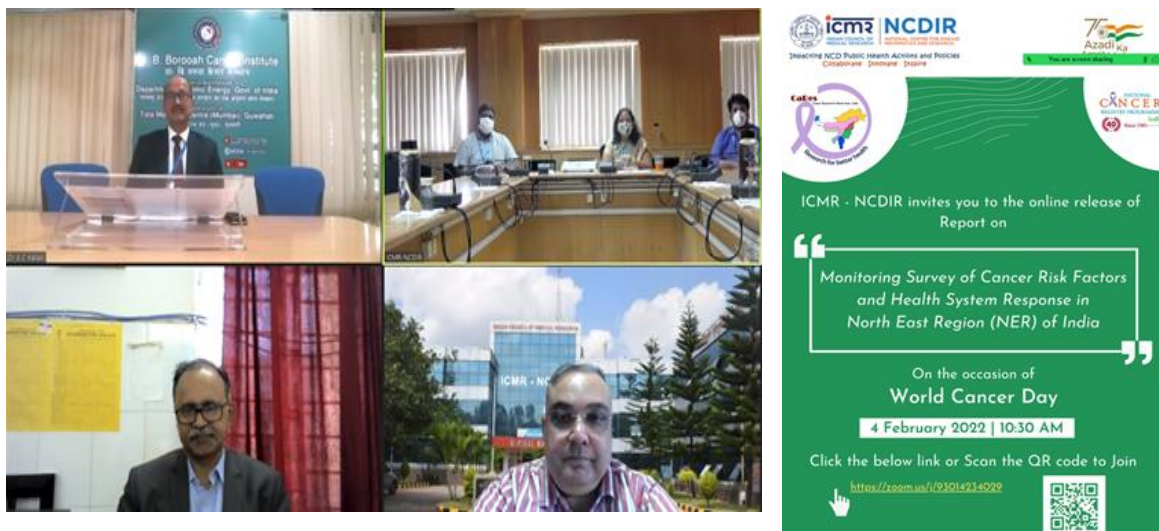
State Wise Factsheet



3. Stroke Incidence and Mortality: A Report of the Population Based Stroke Registries, 2021'
10th November 2021 by Dr. Satishchandra, Chairperson, Research Area Panel-Stroke.



4. Report on Monitoring Survey of Cancer Risk Factors and Health System Response in North East Region (NER) of India: 4th February 2022



Webinars hosted by ICMR-NCDIR for other institutions

- International Malaria Symposium Confirmation on World Malaria Day on April 26, 2021 - ICMR-NIMR
- Mini Symposium on Ecosystem Restoration, World Environment Day, 5th June 2021, ICMR-NIREH Bhopal

Internship Programme

SI No	Name of Intern	Topic
1.	Dr. Garima Goutam	Gap analysis of NCRP-PBCR standards versus EHR standards of Ministry of Health and Family Welfare, Govt of India and the guidelines set by National Digital Health Mission using Fast Healthcare Interoperability Resources.
2.	Ms. Rufia	Patterns of Care and Survival Study(POCSS) on Breast Cancer
3.	Ms. Sai Laxmi	Improvement in Mortality: Incidence ratio through Population based cancer survival study
4.	Dr. Deepika Yadav	Review of data capture and reporting in National Cancer Registry Programm.
5.	Dr. Hari Prakash	Application of Drugrefsets in SNOMED for recording medicines in the registry

PUBLICATIONS / REPORTS/ GUIDELINES / BOOKS / POLICY

Publications

1. GBD 2019 Diabetes Mortality Collaborator. Diabetes mortality and trends before 25 years of age: an analysis of the Global Burden of Disease Study 2019. The Lancet Diabetes & Endocrinology. 2022 Mar 1;10(3):177-92.
2. Mathur P, Leburu S and Kulothungan V (2022). Prevalence, Awareness, Treatment and Control of Diabetes in India From the Countrywide National NCD Monitoring Survey. Front. Public Health 10:748157. doi: 10.3389/fpubh.2022.748157
3. Mathur P, Nath A, Sathish KK . Adolescent and young adult cancers in India–Findings from the National Cancer Registry Programme. Cancer Epidemiology 78 (2022) 102124. <https://doi.org/10.1016/j.canep.2022.102124>
4. Shakuntala T S, Sathishkumar K, Das P, Sudarshan KL, Kotian CM, Santhappan S, Vishwakarma MB, Sureshkumar N, Mathur P. Descriptive Epidemiology of Gastrointestinal Cancers: Results from National Cancer Registry Programme, India. Asian Pac J Cancer Prev, 23 (2), 409-418
5. Ramamoorthy T, Kulothungan V, Mathur P. Prevalence and Correlates of Insufficient Physical Activity Among Adults Aged 18–69 Years in India: Findings From the National Noncommunicable Disease Monitoring Survey. J Phys Act Health. 2022 Feb 11;1(aop):1–10.
6. Global Burden of Disease 2019 Cancer Collaboration. Cancer Incidence, Mortality, Years of Life Lost, Years Lived With Disability, and Disability-Adjusted Life Years for 29 Cancer

- Groups From 2010 to 2019_ A Systematic Analysis for the Global Burden of Disease Study. JAMA Oncol (Internet) doi:10.1001/jamaoncol.2021.6987.
7. GBD 2019 Adolescent and Young Adult Cancer Collaborators. The global burden of adolescent and young adult cancer in 2019: a systematic analysis for the Global Burden of Disease Study 2019. *The Lancet Oncology* December 2021.
 8. Shanker N, Mathur P, Das P, Sathishkumar K, Martina Shalini AJ, Chaturvedi M. Cancer scenario in North-East India & need for an appropriate research agenda. *Indian J Med Res.* 2021 Jan;154(1):27-35
 9. Mathur P, Nath A. Strengthening Cancer Surveillance in India: Role of the National Cancer Registry Programme. *Indian Journal of Surgical Oncology* 2021 [internet], <https://doi.org/10.1007/s13193-021-01473-8>
 10. NCD Risk Factor Collaboration (NCD-RisC). Worldwide trends in hypertension prevalence and progress in treatment and control from 1990 to 2019: a pooled analysis of 1201 population-representative studies with 104 million participants. *The Lancet.* August 24, 2021; [https://doi.org/10.1016/S0140-6736\(21\)01330-1](https://doi.org/10.1016/S0140-6736(21)01330-1)
 11. Nath A, Shalini MAJ, Mathur P. Health system challenges and opportunities in tackling non-communicable diseases in rural areas of India. *The National Medical Journal of India* 2021; 34(1):29-35.
 12. Sarveswaran G, Rangamani S, Ghosh A, Bhansali A, Dharmalingam M, Unnikrishnan AG, Vikram NK, Mathur P, Misra A. Management of Diabetes mellitus through teleconsultation during COVID-19 and similar scenarios – Guidelines from Indian Council of Medical Research (ICMR) expert group. *Diabetes & Metabolic Syndrome: Clinical Research & Reviews* 2021. <https://doi.org/10.1016/j.dsx.2021.102242>
 13. Mathur R. Gene Editing – Ethical Pathways to Connect Science & Society. *Asian Biotechnology and Development Review* 2021.23(1):39-50.
 14. Krishnan A., Mathur, P., Kulothungan V., Salve HR., Leburu S., Amarchand R. et al. Preparedness of primary and secondary health facilities in India to address major noncommunicable diseases: results of a National Noncommunicable Disease Monitoring Survey (NNMS). *BMC Health Serv Res* 21, 757 (2021).
 15. Sathishkumar K, Vinodh N, Badwe RA, Deo SVS, Manoharan N, Malik R, Panse NS, Ramesh C, Shrivastava A, Swaminathan R, Vijay CR, Narasimhan S, Chaturvedi M, Mathur P. Trends in breast and cervical cancer in India under National Cancer Registry Programme: An Age-Period-Cohort analysis. *Cancer Epidemiology* 2021 [internet] 2021. ISSN 1877-7821, <https://doi.org/10.1016/j.canep.2021.101982>."
 16. India State-Level Disease Burden Initiative Neurological Disorders Collaborators. The burden of neurological disorders across the states of India: the Global Burden of Disease Study 1990–2019. *Lancet Glob Health* [Internet] 2021."
 17. Ranganathan P, Chinnaswamy G, Sengar M, Gadgil D, Thiagarajan S, Bhargava B, Booth CM, Buyse M, Chopra S, Frampton C, Gopal S, Grant N, Krailo M, Langley R, Mathur P, Paoletti X, Parmar M, Purushotham A, Pyle D, Rajaraman P, Stockler MR, Sullivan R, Swaminathan S, Tannock I, Edward Trimble, Badwe RA, Pramesh CS, on behalf of the

National Cancer Grid of India. The International Collaboration for Research methods Development in Oncology (CReDO) workshops: shaping the future of global oncology research. Lancet Oncol [Internet]. 2021

18. Mathur P, Kulothungan V, Leburu S, ICMR-NNMS investigator group, et al. Baseline risk factor prevalence among adolescents aged 15–17 years old: findings from National Non-communicable Disease Monitoring Survey (NNMS) of India. BMJ Open 2021;11:e044066"
19. Vijayan B, Ramanathan M, Rangamani S, Joe W, Gopinathan S, Mishra US. Treatment and rehabilitation of stroke patients in India: A gendered analysis based on repeated cross-sectional national sample surveys on health, 2014 and 2019, Health Care for Women International, 2021. DOI: 10.1080/07399332.2021.1931226"
20. World Health Organization Ethics and COVID-19 Working Group. COVID-19 and mandatory vaccination: Ethical considerations and caveats. policy brief, 13 April 2021. WHO reference number: WHO/2019-nCoV/Policy_brief/Mandatory_vaccination/2021.1

Reports

1. Report on Monitoring Survey of Cancer Risk Factors and Health System Response in North East Region (NER) of India
2. Stroke Incidence and Mortality: A Report of the Population Based Stroke Registries, India
3. Profile of Cancer and Related Factors for Ten States
4. Clinicopathological Profile of Cancers in India: A Report of the Hospital Based Cancer Registries, 2021
5. Report on Sites of Cancer Associated with Tobacco use in India

Contributions in International Guidelines

1. Clinical research in resource-limited settings: A consensus by a CIOMS Working Group Council for International Organizations of Medical Sciences (CIOMS) 17th June 2021. Available at: https://cioms.ch/wp-content/uploads/2021/06/CIOMS_ClinicalResearch_RLS.pdf
2. Ethics and governance of artificial intelligence for health, 28 June 2021 | Guideline. Available at: <https://www.who.int/publications/i/item/9789240029200?s=08>
3. COVID-19 and mandatory vaccination: Ethical considerations and caveats, Policy brief, 13 April 2021, Available at: <https://apps.who.int/iris/bitstream/handle/10665/340841/WHO-2019-nCoV-Policy-brief-Mandatory-vaccination-2021.1-eng.pdf?sequence=1&isAllowed=y>

Book

Biomedical Ethics- Perspectives in the Indian Context: Vol I, - Edited By Dr. Roli Mathur, Dr. Vasantha Muthuswamy and Dr. Nandini K. Kumar

MEETINGS / TRAINING PROGRAMMES / WORKSHOPS/ WEBINARS CONDUCTED AT NCDIR, BENGALURU

1. Webinar on Reducing Inequalities in NCDs-Towards a Healthier Nation on World Health Day
2. Online training for DHR-ICMR Advanced Medical Oncology Diagnostic Services (DIAMOnDS)
3. Meeting of the Research Area Panel on Stroke
4. Training of recruited field staff under Diabetes National Model Study at Agartala Medical College, Tripura
5. Meeting of the Research Area Panel on Cardiovascular Diseases
6. Training for Civil Hospital Shillong on Implementation of NCDIR e-Mor for strengthening MCCD system in Hospitals of the National Cancer Registry Programme (NCRP) network in North East India
7. Review Meeting on Population Based Cancer Survival on Cancers of Breast, Cervix and Head & Neck
8. Discussion on disease registries in NDHM
9. HBCR Report Review meeting
10. Review Meeting on Population Based Cancer Survival on Cancers of Breast, Cervix and Head & Neck
11. Meeting with experts on WHO MCCD project
12. Meeting regarding Cancer Registration activities in the State of Rajasthan
13. Demonstration of e-MoR to team of Maharashtra
14. Online release of the Report on sites of Cancer associated with Tobacco
15. Meeting of the Central Ethics Committee on Health Research
16. ICMR Central Ethics Committee on Human Research (CECHR)
17. Training of Hospital Based Cancer Registries
18. Meeting of ICMR Central Ethics Committee on Human Research (CECHR)
19. Online training program organized by ICMR-National Institute of Implementation Research on Non-Communicable Diseases (ICMR-NIIRNCD), Jodhpur, (Raj.) in association with ICMR Bioethics Unit, National Centre for Disease Informatics and Research (ICMR- NCDIR), Bengaluru
20. ORIENTATION PROGRAMME- Hospital Based Study on Profile of cardiovascular Diseases and Heart failure Registry in North-East region of India for Principal and Co-Principal Investigator
21. Meeting of the Research Area Panel RAP Diabetes
22. Sensitisation and training for 6 new HBSR centres
23. Training Workshop for Childhood Cancer Study
24. Meeting of the Research Area Panel on Cancer
25. Orientation on Health Technology Assessment
26. Virtual meeting for the review of the revised draft of Institutional End of Life Care Policy by Authors
27. Sensitization Programme on Prevention of Sexual Harassment of women at Workplace under the Internal Committee
28. DIAMOnDS project Data Review meeting for the centres
29. Training of Population Based Cancer Registries
30. Public webinar on Ethics, Compassion, Dignity in End of Life Care & Death
31. Public webinar on the topic 'Lifestyle and Noncommunicable Diseases'
32. Expert group meeting to review Heart Failure study (RAP experts & PIs from all centres)
33. Discussion on Plan for mentees for GBD training
34. WHO Continuum of care discussion

35. Data review meeting on Patterns of Survival Studies Patterns of Care and Survival Studies (POCSS) on Cancers in Childhood, Lymphoid and Hematopoietic Malignancies, other Gynaecological Malignancies in Chennai, Bangalore, Thiruvananthapuram, Delhi and Mumbai
36. Meeting of ICMR Central Ethics Committee on Human Research (CECHR)
37. Virtual meeting of ICMR Central Ethics Committee on Human Research (CECHR)
38. GBC Team discussion regarding training
39. Meeting with Dr Subhadra Menon regarding Public engagement at NCDIR
40. Release of Clinicopathological Profile of Cancers in India: A Report of the Hospital Based Cancer Registries, 2021
41. Meeting with WHO team to discuss project titled Rapid Assessment of Continuum of care for Diabetes and Hypertension in India
42. Hindi Samaroh
43. Expert group meeting for COC project
44. Training Workshop on Quality assurance & Quality checks for Incidental Gall Bladder Cancer and Other Pre-malignant Gall Bladder Condition in India towards early detection of Gall Bladder Cancer
45. Joint meeting to discuss Diabetes National Model Study (DNMS) project by involving ICMR Nodal Officers of MRHRU, medical college faculty deputed as MRHRU Nodal Officers, PIs of DNMS and MRHRU Scientists.
46. NCDIR Institution Ethics Committee meeting
47. Online Data review meeting for the Investigators concerning the haematolymphoid cancer of the project of Patterns of Care and Survival Studies (POCSS) on Cancers in Childhood, Lymphoid and Hematopoietic Malignancies, other Gynaecological Malignancies
48. Virtual Meeting on 'Discussion on Pilot testing for WHO CoC project '
49. Team Training for WHO CoC project '
50. Data Review Meeting on POCSS on Gall Bladder Cancer
51. Data Review Meeting for Hospital Based Cancer Registries (HBCR)
52. Team training for WHO CoC project - Rapid Assessment of Continuum of Care for Diabetes and Hypertension in India
53. Hospital Based Cardiovascular Disease Registry training of PI and Staff of North East Centres
54. Data Review Meeting for Hospital Based Cancer Registries
55. Cancer Epidemiology and Surveillance Training (CanEST) on 22 October 2021 to 28 October 2021
56. Meeting on PBCR forms
57. Release of Population Based Stroke Registry Report
58. Expert group meeting on Development of Mortality Audit Framework for hospitals in India
59. Telemedicine panel session
60. Meeting with GBD regarding Mentors for NCDIR mentees
61. Meeting regarding asset transfer from ROHC to NCDIR
62. Meeting of the Scientific Advisory Committee of NCDIR
63. E MoR annual data review meeting for all centres - hybrid
64. NCDIR Institution Ethics Committee Meeting
65. Meeting with IARC regarding Assistance for NCRP data submission
66. Meeting to review findings and write up of WHO CoC project
67. Training for new HBCRs - 16 centres
68. Webinar on 'Preparing for the Call for research proposal under CaResNER Programme'
69. Release of the Report on Monitoring Survey of Cancer Risk Factors and Health System Response in North East Region (NER) of India 2022
70. Expert Group Meeting for Review of Informative Short Educational Movies on National Ethical Guidelines, 2017
71. Online SAC meeting to discuss the proposal on 'State level NCD Monitoring survey in India'

72. Virtual meeting of ICMR Central Ethics Committee on Human Research (CECHR)
73. Training workshop for newly registered HBCRs
74. Training on ICD 10 coding for HBCRs
75. Expert Group Meeting for Review of Informative Short Educational Movies on National Ethical Guidelines,2017
76. Sensitization and Training Programme on Standard reporting format for imaging in stroke registry
77. Can EST 2nd batch for Cancer Registry Scientist B
78. Meeting with PHFI and AIIMS regarding the proposal 'Strengthening the Medical Certification of Cause of Death practices in public and private healthcare facilities in India: research to implementation'
79. Annual Review Meeting of the Diabetes National Model Study (DNMS)
80. Source of Registration meeting - PBCR Kolkata

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