

Impacting NCD Public Health Actions and Policies Collaborate Innovate Inspire

ANNUAL HIGHLIGHTS

2023 - 24

(Dr. Prashant Mathur)

Scientist G and Director, ICMR – National Centre for Disease Informatics and Research (NCDIR), Bengaluru.

Compiled and Edited by: Mrs. Chandrika K.R, Technical Officer (A), ICMR-NCDIR.

Scientific Inputs: Dr. Sukanya R, Scientist E, ICMR – NCDIR.

Designed by: Mr. Abhishek David George, Project Technical Support - III

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MAIN ACTIVITIES

- Cancer, Stroke, Cardiovascular disease Registries
- Patterns of care and survival studies
- Strengthening Medical Certification of cause of death
- Disease burden estimations
- Continuum of care studies in Diabetes and Hypertension
- Diabetes burden and quality of care study

KEY ACHIEVEMENTS

- Cancer Incidence in Five Continents Vol XII was published by International Agency of Research on Cancer in October 2023. Data of 19 Population based Cancer Registries (PBCR) of the National Cancer Registry Programme network under ICMR – NCDIR was included in the publication
- 2. Dr. Prashant Mathur, Director, ICMR-NCDIR was invited to deliver the Johnassen Clemmensen oration on 'Cancer surveillance in India Role of National Cancer Registry Programme' at the joint conference of European Network of Cancer Registries and International Association of Cancer Registries (ENCR-IACR) 2023 Scientific Conference at Granada, Spain
- 3. Dr. Prashant Mathur, Director, was elected as the Member of Scientific Council of International Agency for Research on Cancer (IARC) for a period of 4 years.
- 4. Dr. Prashant Mathur, Director, has been invited as the Steering Committee member for the CONCORD programme for the global surveillance of trends in cancer survival.
- A video to indicate the progress in cancer registration in India and the key findings from the publication on cervical cancer survival (2023) was prepared by ICMR - NCDIR and screened during the webinar hosted by WHO as part of the progress in WHO SEAR on "Cervical Cancer Elimination, Day of Action" on 17 November 2023.

Support to national or state programmes

- 6. Disseminated the findings of implementation of diabetes and hypertension program, in 3 states (Odisha, Meghalaya and Rajasthan), during the state level workshop (May to June 2023) on continuum of care for NCDs organized by WHO India country office.
- 7. Technical collaboration for deployment of e-Mor software with state Tamil Nadu CRS software to capture cause of death and generate Medical Certification of Cause of Death (MCCD) is in place.
- 8. In collaboration with the Regional Office of Health and Family Welfare, Bengaluru, four online training sessions on MCCD was conducted for medical officers and doctors of Department of Health & Family Welfare, Karnataka

CANCER

COMPLETED PROJECTS / ACTIVITIES

1. Population based Cancer Survival in Cancer Breast, Cancer Cervix and Head & Neck Cancers

Duration: 01 March 2017 to 31 March 2023

The project was conducted from 1 March 2017 till 31 March 2023 to generate reliable data on populationbased 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 were followed up regularly (for at least five years from the date of the first diagnosis of cancer).

Following publications from the project were completed.

- Sathishkumar K, Sankarapillai J, Mathew A, Nair R A, Gangane N, Khuraijam S, Barmon D, Pandya S, Majumdar G, Deshmane V, Zomawia E, Bhutia T W, Jerang K, George P S, Maliye S, Laishram R, Shah A, Debbarma S, Koyande S, Pachuau L, Pradhan P D, Jongkey G, Chaturvedi M, Das P, and Mathur P. Survival of patients with cervical cancer in India findings from 11 population based cancer registries under National Cancer Registry Programme. The Lancet Regional Health Southeast Asia. 2023; 100296. Published: October 13, 2023 DOI: https://doi.org/10.1016/j.lansea.2023.100296
- Sathishkumar K, Sankarapillai J, Mathew A, Nair RA, Gangane N, Khuraijam S, Barmon D, Pandya S, Majumdar G, Deshmane V, Zomawia E, Bhutia TW, Jerang K, George PS, Maliye S, Laishram R, Das G, Shah A, Debbarma S, Koyande S, Pachuau L, Sherpa A, Jongkey G, Chaturvedi M, Das P, Santhappan S, Mathur P. Breast cancer survival in India across 11 geographic areas under the National Cancer Registry Programme. Cancer. 2024 Jan 6. doi: 10.1002/cncr.35188. Epub ahead of print. PMID: 38183671.

The publications have described the variation in survival rate of the three cancers from Wardha, Ahmedabad urban, Manipur, Mizoram, Tripura, and Pasighat areas of the country. The 5-year survival rate of Cervical cancer ranged from 31.6% (Tripura) to 61.5% (Ahmedabad urban). Five-year survival rate by clinical stage of cancer was 65.9, 53.5, and 18.0 % for localized, regional, and distant metastasis, respectively. Cancer stage was a significant predictor of survival. The breast cancer 5-year survival ranged from 41.9 % (Pasighat) to 74.9% (Mizoram). Breast cancer patients diagnosed with local stage cancer have a 4.4 times greater 5-year survival rate than those diagnosed with distant-stage cancer. Disparities in breast and cervical cancer survival reveal significant variations in cancer survival rates across different parts of India. There is a need to identify and address inequities in the health system. The study findings have highlighted the importance of awareness, early detection, and improvement of the health care system. Adequate and equitable allocation of health care resources and financial support will aid in improving survival and reducing the survival gap within the country. Early detection programs, including cancer awareness and cost-effective screening, along with accessible and affordable multimodality treatment, survivorship care, and palliative care, have to be prioritized.

2. Patterns of Care and Survival Studies (POCSS) on Gall Bladder Cancer (GBC) in Indian Hospital Based Cancer Registries

Duration: 17 December 2018 to 16 December 2023

The study on Patterns of Care and Survival Studies (POCSS) on Gall Bladder Cancer (GBC) in Hospital Based Cancer Registries (17 December 2018 to 16 December 2023) has described the pattern of gall bladder carcinoma in the country. Majority of the Gallbladder cancer cases presented at Stage IV (53.3%) followed by Stage III (22.3%). Detection of gall bladder cancer in early stages was as less (13.8%). The pattern of treatment patients received were chemotherapy (83.8%), surgery (19.3%) and radiotherapy (8.3%). Among GBC patients, 24.0% of male patients and 15.1% of female patients were reported as dead after 3 years follow up. The survival among GBC patients were lowest in stage IV (3.5%) followed by stage III (21.9%) at the end of 3 years. Survival in GB cancers needs to be improved by early detection and treatment on time. Public health intervention in the form of GB cancer screening and early detection should be planned.

3. Incidental Gall Bladder Cancer (IGBC) and Other Pre-malignant Gall Bladder Condition in India towards early detection of Gall Bladder Cancer

Duration: 01 February 2019 to 31 January 2024

The study 'Incidental Gall Bladder Cancer(IGBC) and Other Pre-malignant Gall Bladder Condition in India towards early detection of Gall Bladder Cancer' (1 February 2019 to 31 January 2024) described the risk factors and clinical correlates for IGBC and other preneoplastic lesions. Among the study participants diagnosed with IGBC, 86.8% were unemployed and 78% reported mixed dietary pattern, 13.2% had Diabetes and Hypertension. Important pathological findings included wall thickening (38%) and cholelithiasis (96%). Extrahepatic biliary radical dilatation was noted in 5.9% of the IGBC cases. Multiple gall stones were observed in 30.9% of the cases and 2.9% had porcelain gall bladder. Other findings included chronic cholecystitis (70.86%), high grade dysplasia (48.5%), pyloric metaplasia (41.2%). Lymphocytic Infiltration was seen in 42.6% of cases in moderate grade. Rokitansky Aschoff Sinuses was seen in 44.1% cases; diffuse wall thickening was seen in 39.7% of the cases.

4. Association of air pollution with cancer incidence and mortality: A meta-analysis of observational studies

Duration: 01 March 2021 to 31 December 2022

Air pollution is a grave environmental concern globally, particularly in India, where it poses significant health risks and economic burdens. This study investigated the nexus between outdoor and indoor air pollution exposure and cancer incidence and mortality. Chronic noncommunicable diseases, including various cancers and cardiovascular ailments, are strongly linked to air pollution, as affirmed by the International Agency for Research on Cancer (IARC). Employing rigorous systematic review methods, the study scrutinised original cohort and case-control studies focusing on major air pollutants such as PM_{2.5}, PM₁₀, NO₂, and O₃ and their association with breast, liver, lung, pancreas, and urinary bladder cancers. The quality of the studies was assessed using established evaluation scales, and potential bias was meticulously analysed. The meta-analysis, incorporating data from 53 cohort studies and 8 case-control studies, revealed

compelling evidence of a significant relationship between exposure to air pollutants and heightened cancer risk across various sites.

Moreover, the analysis underscored a concerning increase in mortality rates associated with different forms of cancer, both in males and females, attributable to air pollution exposure. Regionally, the Western Pacific and European regions exhibited particularly pronounced associations between air pollution and cancer incidence and mortality. PM_{2.5}, a major pollutant, emerged as a significant contributor to cancer mortality, affecting sites such as breast, lung, liver, and urinary bladder. In conclusion, this study underscored the critical role of air pollution, especially PM_{2.5}, in exacerbating cancer risk and mortality, highlighting the urgent need for effective mitigation strategies and regulatory measures to safeguard public health.

The findings were published in JCO Global oncology journal: Ramamoorthy T, Nath A, Singh S, Mathew S, Pant A, Sheela S, Kaur G, Sathishkumar K, Mathur P. Assessing the Global Impact of Ambient Air Pollution on Cancer Incidence and Mortality: A Comprehensive Meta-Analysis. JCO Glob Oncol. 2024 Mar;10:e2300427. doi: 10.1200/GO.23.00427. PMID: 38513187.

5. WHO South East Asia Region Cancer Profile

Duration: 01 April 2023 to 30 October 2023

This project aimed to bring out the cancer burden and trends at the regional and country level for 2015 - 2022. This activity comprised the preparation of a report on the situational analysis of cancer burden and national response in the region along with country-specific analysis, which included a description of cancer burden, risk factors, population attributable fractions, comprehensive evaluation of existing cancer control policies, plans, and programs, as well as the analysis of cancer treatment capacity and the availability of national cancer research agenda.



Technical review meeting for review of report on WHO south – east Asia region cancer profile on 13 October 2023

6. Cancer Epidemiology Training Programme (CanEST)

Duration: 01 May 2020 to 31 March 2024

Cancer Epidemiology Training Programme (CanEST) was initiated in October 2021 and completed in March 2024. This training was aimed to train Research Scientists working in Cancer registries that are a part of the National Cancer Registry Programme in cancer epidemiology, survival and trend analysis, advocacy and development of action plan and scientific writing. A total of 6 trainings were conducted for the Research

Scientists/ Co-Investigators of the Cancer registries. A three-day program was conducted for the Principal Investigators of the cancer registries. A total of 55 participants were trained.



Cancer epidemiology and surveillance training programme from 11 to 13 December 2023

7. National Burden of Noncommunicable Diseases and associated risk factors – Cancer working group

Duration:10 April 2021 to 13 April 2023

Brief Background:

The primary objective of the BOD-NCD project is to generate evidence-based, valid and comparable national and sub national estimates of the burden of Cancer and related conditions on the population of India. This study attempted to estimate the burden of cancer in terms of Disability adjusted life years (DALYs).

The following publications have been done.

- Kulothungan V, Sathishkumar K, Leburu S, Ramamoorthy T, Stephen S, Basavarajappa D, Tomy N, Mohan R, Menon GR, Mathur P. Burden of cancers in India - estimates of cancer crude incidence, YLLs, YLDs and DALYs for 2021 and 2025 based on National Cancer Registry Program. BMC Cancer. May 2022 https://doi.org/ 10.1186/s12885-022-09578-1.
- Kulothungan V, Ramamoorthy T, Sathishkumar K, Mohan R, Tomy N, Miller GJ, Mathur P. Burden of female breast cancer in India: estimates of YLDs, YLLs, and DALYs at national and subnational levels based on the national cancer registry programme. Breast Cancer Res Treat. 2024 Mar 4. doi: 10.1007/s10549-024-07264-3. Epub ahead of print. PMID: 38433127.

ONGOING PROJECTS / ACTIVITIES

1. Population Based Cancer Registries in India

The Population Based Cancer Registries (PBCRs) collect data on the new occurrence of cancer and deaths in a defined geographical area for a specific time period. In this period, there are 38 Population Based Cancer Registries under the National Cancer Registry Programme (NCRP), the earliest being established in 1981.

In addition to the 38 NCRP PBCRs that contributed data this year, the data from PBCRs under Tata memorial Centre (TMC) and from Tamil Nadu Cancer Registry Programme (TNCRP) were also received at ICMR-NCDIR.

Thus, the number of PBCRs totalled to 48 (38 of NCRP, 9 of TMC and 1 from state TNCRP) covering 18% of the Indian population.

- An e-Cancer Notification software has been devised to enable sources of registrations within a PBCR to send out an alert to the PBCR centre about a potential case in the registry. This is expected to improve the coverage and reduce time delays in case collection. Meeting with 5 PBCRs was conducted to sensitize the concept of e-Cancer Notification.
- Cancer Incidence in Five Continents Vol XII was published by International Agency of Research on Cancer in October 2023.
 Data of 19 Population based Cancer Registries (PBCR) of the National Cancer Registry Programme network under ICMR – NCDIR was included in the publication.
- Three articles were published in peer reviewed scientific journals using the PBCR data.
- PBCR Data Review meetings with Principal Investigators and training workshops for PBCR staff were organized at ICMR-NCDIR, Bengaluru.



PBCR Data Review Meeting in October 2024



PBCR Staff training workshop in February 2024



Date	Training/ Workshop	
07 August 2023	Meeting of PI/Co-PIs from 9 PBCRs on Registry Methods, Staff	
	and Data Status	
16 August 2023	Online meeting for e-Cancer Notification with 6 PBCRs	
05 to 06 October	PBCR Data Review Meeting with PIs	
23		
22 to 23 February	Training Workshop for 23 staff from PBCRs	
24		
29 Feb to 01	Training Workshop for 34 staff from PBCRs	

March 2024	
22 March 2024	Training of 7 PBCRs on PBCR survival - breast, cervix and head &
	neck

2. Hospital Based Cancer Registries (HBCRs) Network

The following 51 new hospitals have been registered for Hospital Based Cancer Registries under the network of NCDIR-NCRP during 2023-24.

SI No.	Name of the Institution	
1	Adesh Medical College and Hospital, Kurukshetra	
2	All India Institute of Medical Sciences Guwahati	
3	All India Institute of Medical Sciences Rajkot	
4	Apex Hospital, Varanasi	
5	Ashwini Rural Medical College Hospital and Research Centre, Solapur	
6	Bangalore Medical College and Research Institute, Bengaluru	
7	Bhagat Phool Singh Government Medical College Khanpur Kalan, Sonipat	
8	Bharati Vidyapeeth Deemed to be University Medical College Hospital & Research Centre, Pune	
9	Dr M K Shah Medical College and Research Centre & Smt SMS Multispeciality Hospital, Ahmedabad	
10	Dr Rajendra Prasad Government Medical College, Kangra	
11	Dr Yashwant Singh Parmar Government Medical College, Nahan	
12	ESIC Medical College and Hospital Gulbarga, Kalaburagi	
13	ESIPGIMSR ESIC Medical College and Hospital Joka,	
14	Government Doon Medical College, Dehradun	
15	Government Medical College and Hospital, Ariyalur	
16	Government Medical College and Hospital, Nagpur	
17	Government Medical College and Hospital, Nilgiris	
18	Government Medical College Kadapa, YSR District Kadapa	
19	Government Medical College, Namakkal	
20	Gujarat Adani Institute of Medical Sciences, Kachchh	
21	Hitech Medical College and Hospital, Khordha	
22	Jagadguru Sri Shivarathreeshwara Medical College, Mysuru	
23	Jawaharlal Nehru Medical College, Wardha	
24	Jay Prabha Medanta Super Superspeciality Hospital, Patna	
25	Jubilee Mission Medical College and Research Institute, Thrissur	
26	Kamineni Academy of Medical Sciences and Research Centre, Hyderabad	
27	Karpaga Vinayaga Institute of Medical Sciences and Research Centre, Kancheepuram	
28	KLE Centenary Charitable MRC, Belagavai	
29	Max Superspeciality Hospital, Mohali	
30	Mysore Medical College and Research Institute, Mysuru	
31	Narayana Multispeciality Hospital, Mysuru	
32	NC Medical College and Hospital Israna, Panipat	

33	NKP Salve Institute of Medical Sciences Research Centre & Lata Mangeshkar Hospital, Nagpur	
34	Post Graduate Institute of Child Health, Noida	
35	Pt B D Sharma Post Graduate Institute of Medical Sciences, Rohtak	
36	Punjab Institute of Medical Sciences, Jalandhar	
37	Sarojini Naidu Medical College and Hospital, Agra	
38	Shri Siddheshwar Cancer Hospital and Research Centre, Solapur	
39	Sonam Nurbo Memorial Hospital, Leh (Ladakh)	
40	Sri Lalithambigai Medical College and Hospital Faculty of Medicine Unit of Dr MGR	
	Educational and Research Institute, Tiruvallur	
41	Sri Muthukumaran Medical College Hospital and Research Institute, Kancheepuram	
42	Sri Narayani Hospital and Research Centre, Vellore	
43	Symbiosis Medical College for Women & Symbiosis University Hospital Research Centre, Pune	
44	Tertiary Cancer Care Centre Government Medical College, Kottayam	
45	Thanjavur Medical College, Thanjavur	
46	United Institute of Medical Sciences, Allahabad	
47	Vedantaa Institute of Medical Sciences, Palghar	
48	Vels Medical College and Hospital, Tiruvallur	
49	Vijayanagar Institute of Medical Sciences, Ballari	
50	Viswabharathi Medical College and General Hospital, Kurnool	
51	Zulekha Yenepoya Institute of Oncology, Dakshina Kannada	



Training Activities under HBCRs

Date	Description
17 October 2023 and 22 March 2024	Online Training of newly registered HBCRs
6 – 7 November 2023	Two days training for the
30 November – 1	HBCR staff was
December 2023	conducted in four
7 – 8 December 2023	batches at ICMR-NCDIR,
14 – 15 December 2023	Bengaluru

The HBCR network map

Training Workshop for staff of Hospital Based Cancer Registries



30 Nov and 1 Dec 2023

7 to 8 Dec 2023

3. Call for Concept Proposals for Prevention and Control of Cancer in the North Eastern States in India (CaRes NER Programme) 2023

A total of 13 applications under 'Call for proposals 2023' of which 8 were eligible by the scope of the call. A Technical Review Committee meeting was arranged on 21 June 2023, during which the eight PI applicants presented their proposals, and three have been shortlisted for funding. These include-

- a) A Pilot Model for Multi Sectoral Collaboration to Deliver Integrated Messaging and Create Awareness for Promoting Early Detection of Cancers at the grassroot level". PI: Dr Ravi Kannan, Cachar Cancer Hospital and Research Centre, Silchar, Assam.
- b) Prevention & Early identification of cancer among women (Breast & cervix cancer) through behaviour targeting model for early signs along with virtual library of cancer survivors (Health Coach) in the North East: Dr Toms Thomas, Shri Ramasamy Memorial University (SRMU), Sikkim
- c) Implementation of Multimodal Intervention for improving Access to Diagnostic and Treatment Facilities of Commonest Cancers in the North Eastern Region of India A Multimethods study": Dr Shanthosh Priyan, NEIGRIHMS, Shillong.

4. A study on patterns of care and survival of head and neck, breast and cervical cancers in India (POCSS) under the Hospital Based Cancer Registries of National Cancer Registry Programme

Objectives:

Primary: To describe the clinical features, patterns of care and overall survival of head and neck, breast and cervical cancers among patients availing of care at the study hospital

Secondary: To estimate the disease-free survival among patients of head and neck, breast and cervical cancers.

The above study was in progress at ICMR-NCDIR since 2006. 20 Hospital based Cancer Registries which continue to transmit high quality data were considered to continue the POCSS study from April 2022. These centers have been selected based on their regional representation and to include Government and Private hospitals. Also, all the TCCCs/SCIs/RCCs are contributing data for this study. The patients who have been receiving the treatment at the hospital for cancers of the head and neck, breast and cervix are being included in the study.



Participating Centers (POCSS)

5. DHR-ICMR Advanced Molecular Oncology Diagnostic Services (DIAMOnDS)

Owing to India's increasing cancer burden and disparities in access to diagnostic and prognostic tests for cancer, DHR-ICMR Advanced Molecular Oncology Diagnostic Services (DIAMOnDS), a multicentric study, was initiated on 1 April 2019. This study aims to set up zonal molecular oncopathology labs to provide essential, high-end advanced diagnostic services to cancer patients and research facilities for basic, translational, and clinical research. The diagnostic facilities will be provided in ten leading cancer hospitals nationwide. This study was initially initiated for lung and breast cancers, wherein the biomarkers are available for these cancer patients. NCDIR will serve as a Data Management Centre for the DIAMOnDS centres with the objectives (i) to facilitate data management for the project (ii) to link the biomarkers in breast and lung cancer test results to the NCRP registries to improve cancer data for patient management and research.

A total of 18 institutions are part of this project. Six institutions joined the project in the last six months (i.e, July 2023 onwards) namely, Regional Cancer Centre- Thiruvananthapuram, Govt Medical College - Jammu, Govt Medical College - Tanda, All India Institute of Medical Sciences, Patna, Post Graduate Institute of Medical Sciences – Rohtak and NIMS - Hyderabad.



Meetings/ Trainings under DIAMOnDS

Date	Description	
22 August 2023	DHR-ICMR Advanced Molecular Oncology Diagnostic Services Technical Evaluation Committee / Review Meeting	
17 January 2024	Sensitization Training for DHR- ICMR Advanced Molecular Oncology Diagnostic Services	
4 March 2024	Data Review Meeting for DHR- ICMR Advanced Molecular Oncology Diagnostic Services	

Participating Centers (DIAMOnDS)

6. Development of Cancer Atlas in Andhra Pradesh

The Government of Andhra Pradesh has signed an MoU with ICMR-NCDIR, seeking technical support for developing the Andhra Pradesh cancer atlas on 1 December 2023, which would help pave the way for establishing a fully functional cancer registry for cancer surveillance, measure cancer burden, and inform health planning. Developing an Application Programme Interface between Andhra Pradesh's Dr. YSR Aarogyasri Health Care Trust and NCDIR's National Cancer Registry Programme (NCRP) database is underway, which would help automate data transmission. 61 centres have registered under the project.

7. A Situational analysis of cancer care services in India

A cancer care centre is an essential element and leader in providing cancer care services. They also play an integral role in cancer control programmes. While planning for the delivery of cancer-related services and identifying gaps in these services in the country, it would be essential to recognise the existing capacity of the health system through a situational analysis. This study aims to assess the availability and distribution of cancer care services according to geographic location, identify disparities in the availability of cancer care services, and propose a framework for strengthening cancer care provision in India. Study tools have been developed and endorsed by an Expert Group. Development of a portal for electronic data capture is underway. District-wise mapping of cancer-care-related health facilities has been completed for 11 states.

8. HTAIn (Health Technology Assessment in India) Resource centre:

The following studies are ongoing under HTAIn at the Resource Centre at NCDIR.

- a) Markov modelling to compare two collection strategies for HPV DNA testing: self-sampling and healthcare provider-dependent sampling
- b) Determination of cost-effectiveness of low-dose CT in lung cancer screening in India using Markov model
- c) An umbrella review of systematic reviews on the clinical effectiveness of Low Dose Computed Tomography (LDCT) in lung cancer screening
- d) A systematic review and meta-analysis of clinical performance of urine self-sampling for human papillomavirus (HPV) for cervical cancer screening

9. Rajasthan Cancer Atlas

The project envisions creating a state-wide cancer registration system to learn the similarities and differences in patterns of cancer across this state for cancer surveillance, measure cancer burden, and inform health planning. This would be done with optimum use of software and electronic transmission of data to NCDIR. Knowing patterns of cancer would provide important leads in undertaking etiological research, targeting cancer control measures and examining clinical outcomes. ICMR- NCDIR is providing technical support in implementing the Atlas. The duration of the project is 3 years (1st March 2022 to 28th February 2025). A total of 105 registered hospitals have been provided access to transmit the data.



Rajasthan Cancer Atlas meeting

Meetings/ Trainings

Date	Description
28 July 2023 8 Sept. 2023 10 Nov. 2023 31 January 2024	Rajasthan Cancer Atlas meeting
5 March 2024	Training for the centres

STROKE

ONGOING PROJECTS / ACTIVITIES

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

The objective of PBSR (Population-Based Stroke Registry) is to generate reliable data on the magnitude and incidence of stroke events in defined populations. The PBSRs are located in the following five places:

- 1. Cuttack (urban and rural)
- 2. Kota (urban)
- 3. Tirunelveli (urban and rural)
- 4. Cachar (urban and rural)
- 5. Varanasi (urban)

The PBSR collects data on all cases of first-ever stroke in individuals aged over 18 years who have been residents of the defined geographical area for at least one year. This data is gathered from all health facilities and imaging centers within that area where these patients seek admission, diagnosis, or treatment for stroke. The network of facilities, known as Sources of Registration (SoR), includes hospitals, clinics, AYUSH centers, physiotherapy centers, imaging centers, and even some places of worship frequented by stroke patients.

Field investigators regularly visit these SoRs to gather information on the socio-demographic profile, clinical details, imaging findings, and type of stroke, which is then recorded in a standard core form. This information is entered into an online portal developed by ICMR-NCDIR and transmitted to ICMR-NCDIR, where the data undergoes several levels of quality and duplicate checks before being finalized for analysis.

The PBSR data from 2018-2022 has been finalized, and the preparation of the five-year report is ongoing. The data collection and quality check process for the years 2023-24 is also in progress.

Date	Description	
07 November 2023	PBSR training workshop for PBSR staffs from five registries conducted at ICMR-NCDIR, Bengaluru	
18 January 2024	PBSR Data review meeting with centre PIs	
06 to 09 June 2023	Site visit was conducted by ICMR-NCDIR staff to the following PBSR to review the PBSR work and verification of data quality at PBSR Cuttack	

Meeting / Training Activities under PBSRs

Visit to Sources of Registration (SoR) of PBSR / HBSR at Cuttack



2. Hospital Based Stroke Registries (HBSR) in India

The Hospital Based Stroke Registry (HBSR) collects data on persons with first-ever or recurrent stroke, who have received treatment in the respective hospital over time. All the cases presenting within 4 weeks of onset of stroke, from all departments (Neurology, Medicine, Neurosurgery, Radiology, Rehabilitation and Ayurvedic departments) and wards of the hospital will be included in the study. Data regarding identifying information, clinical presentation, severity of stroke, diagnosis, risk factors, co-morbidities and treatment information, functional status at discharge and vital status are collected in the core form. All registered cases are followed up at 28 days & 3 months during hospital visits or by other means of communication like telephone / letters. The data is entered in HBSR online software which has in-built quality checks like consistency, duplicity and range checks. The online data is transmitted to ICMR-NCDIR.

The 115+ medical colleges with DM Neurology and DNB Neurology were invited to initiate HBSR program.

The following 52 new hospitals have been registered for Hospital Based Stroke Registries under the network of NCDIR-NSRP during 2023-24.

SI. No	Name of the Institute
1	Agartala goverment medical college and govind ballav pant hospital
2	All India Institute of Medical Sciences, Raebareli
3	Amaltas Institute of Medical Sciences, Dewas
4	All India Institute of Medical Sciences, Guwahati

5	All India Institute of Medical Sciences Nagpur
6	All India Institute of Medical Sciences Patna
7	Amala Institute of Medical Sciences, Thrissur
8	Apollo Speciality Hospitals, Nellore
9	Bharati Hospital and Research Centre, Pune
10	Calcutta National Medical College and Hospital, Kolkata
11	CARE CHL Hospitals, Indore
12	Chengalpattu medical college. Kancheepuram
13	Choithram Hospital and Research Centre, Indore
14	Christian Medical College, Vellore
15	Davanand medical college. Ludhiana
16	First neuro brain and spine super speciality hospital. Dakshina Kannada
17	Fortis Flt Lt Raian Dhall Hospital
18	Fortis Hospital Ltd. Bannerghatta Road. Bengaluru
19	Fortis Hospital, Noida
20	Fortis Hospitals Limited, Cunningham Road, Bengaluru
21	Fortis Hospitals Limited, Mumbai
22	Fortis Hospitals Limited, Faridabad
23	Fortis Memorial Research Institute, Gurgaon
24	Ganga care hospital ltd. Nagpur
25	Government Medical college Srinagar
26	Government Medical college Kottavam
27	Government Medical College Surat
27	Government Medical College Hospital Chennai
20	Hi-Tech Medical College and Hospital, Bhubaneswar
30	Himalayan Institute of Medical Sciences, Debradun
30	Indira Gandhi Institute of Medical Sciences, Patna
32	Institute of Human Behavior and Allied Sciences New Delhi
32	Institute of Post Graduate Medical Education and Research IPGMER SSKM Hospital
34	lawaharlal Institute of Postgraduate Medical Education & Research, Puducherry
35	Jubilee mission medical college and Research Institute. Thrissur
36	North Fastern Indira Gandhi Regional Institute of Health & Medical Sciences, Shillong
30	KMCT Medical College Hospital
20	Kokilahan Dhirubhai Ambani Hospital and Medical Research Institute, Mumbai
20	Latha Super Speciality Hespital NTP
39	Madras Medical College, Channai
40	Maitra Hospital Kazhikodo
41	New Civil Hospital GMC Surat
42	New CMI Hospital GMC, Sulat
45	DD Hindwia Hospital and Modical Research Contro. Mumbai
44	
45	PT BDS PGIIVIS, RUIILak
40	Pushpagin institute Of Medical Sciences and Research Centre, Pathanaminitia
47	St. John's Medical College Hospital, Bengaluru
48	S L Raneja Hospital and Research Contro
49	Sarvouaya nospital and Research Centre
50	Sevenninis nospital, visaknapatnam
51	Superspeciality Hospital GMC Srinagar
52	Uppal Neuro Hospital, Amritsar



Meeting / Training Activities under HBSRs

Date	Description
11 July 2023	
14 December	Online Training of newly
2023	registered HBSRs
14 March 2024	
30 to 31 Oct 2023	Two days training for the
08 to 9 Nov 2023	HBSR staff was
	conducted in two
	batches at ICMR-NCDIR,
	Bengaluru
06 to 08 June	Training at HBSR
2023	Bhubaneshwar and
	Cuttack
19 January 2024	HBSR Data review
	meeting with centre
	Principal Investigators

The HBSR network map

DIABETES

COMPLETED PROJECTS / ACTIVITIES

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)

Duration: 01 March 2018 to 28 February 2024



DNMS Participating centers in India

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.

Key Activities:

- The field investigators from all the centres reported the data at NCDIR server. The follow up protocol document was prepared and shared with C- PIs for more clarity on follow up survey.
- Three study sites at (Palghar, Raichur and Agartala) have completed the follow up survey. NIIRNCD, Jodhpur site has done 51% coverage of baseline survey
- Project implementation, data transmission and quality was reviewed through periodic meetings, monthly reports and microplan of survey activities
- The center PIs participated in DNMS EQAS (external quality assurance system), and joint meeting was conducted to review the findings of EQAS.

• An annual review meeting of C -PI and Co-PIs was conducted on 12th Feb 2024. Centre wise interim analysis was discussed. The findings were compared to other population-based studies. Final data sets are analyzed for preparing report.



Community level interaction in Nimmi Village



Data verification IN MRHRU village Palghar district (Maharashtra)



Diabetes Screening camp at MRHRU Village in Raichur, Karnataka



DNMS Agartala Site, Tripura Team



DNMS Annual review meeting on 12 February 2024

Key Findings:

The three survey sites namely Mumbai, Raichur and Agartala had completed the baseline and first year follow up of the survey. The prevalence of diabetes was highest in Raichur (10.9%), followed by Mumbai (5.5%) and lowest in Agartala (3.2%). The prevalence of prediabetes was 7.2% in Mumbai, 28.4% in Raichur, and 4.1% in Agartala. More than three fourth of known diabetic individuals were on treatment in Mumbai (76.1%), Raichur (81.6%), and less than half in Agartala (42.4%). Nearly 99.5% of the eligible adults in survey area reported inadequate intake of fruits & vegetables across the 3 sites. The prevalence of behavioural NCD risk factors varied across the sites. Nearly one third of individuals in Mumbai (33%) reported to have insufficient physical activity, however it was only less than one tenth in Raichur (7.2%) and Agartala (6.3%) site. The current tobacco use was lowest in Mumbai (17.7%), highest in Agartala (35%) and Raichur (34.2%) sites. However, the prevalence of current alcohol consumption was highest in Mumbai (22.2%), 18.4% in Agartala and 12% in Raichur. The prevalence of Obesity (BMI ≥30.00 kg/m²) was 2.4% in Mumbai, 3.6% in Raichur, and 5.9% in Agartala.

Conversion rates from normal status to prediabetes based on Impaired Fasting Glucose (IFG) was highest in Raichur 29.1%, followed by Mumbai (21.0%), and Agartala (3.6%). Conversion rates from normal to Impaired Glucose Tolerance (IGT) was highest in Agartala (32.1) followed by Raichur (5.4%) and 2.1% in Mumbai. Across the sites less than one fifth (18.0%) of public health facilities reported stock of essential medicines for management of type 2 diabetes mellitus, however, this was more than half (57.1%) in private health facilities. Overall availability of essential technologies for diabetes mellitus was 46.0% across the (public and private) facilities. Across the study sites more than 85% of known diabetic individuals reported using private health facilities for diabetes care.

CARDIOVASCULAR DISEASES

COMPLETED PROJECTS/ACTIVITIES

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

Duration: 01 April 2021 to 31 March 2024

The registry was established to understand about the pattern of clinical presentation, availability of diagnostic services for CVD cases and Heart failure cases and treatment received by heart failure cases in north east region of India.

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.

Activities:

- As per plan, three new potential participating centres were identified, in the year 2023-24 and invitations were sent to the identified institutes to participate in HBCVDR-NE registry. All the three centres had accepted the invitation.
- The project staff from 5 centres were trained in HBCVDR software. After software training, the follow up meetings were held to review the data quality and feedback was given to improve the data quality in software.
- Action points were given to Co Principal Investigators for improving the reporting of number of cases in registry and for internal coordination within the institute to report all cases.
- Internal data validation tool was used by centres, and they were regularly sending the filled internal data validation tool on monthly basis to NCDIR. Quality check reports were sent to C- PIs, to improve the data quality.
- Onsite data validation was done for 10 participating centre in the month of Nov- Dec 2023. The data was of good quality in most of the centres.

Following HBCVDR- NER participating centres were part of the study.

SI. No	Name of the Institute
1.	Christian Institute of Health Sciences & Research, Dimapur, Nagaland
2.	Gauhati Medical College & Hospital, Indrapur, Guwahati, Assam
3.	Northeastern Indira Gandhi Regional Institute of Health and Medical Sciences, Shillong,
	Meghalaya
4.	Zoram Medical College, State Referral Hospital, Falkawn, Mizoram
5.	Tomo Riba Institute of Health & Medical Sciences, Naharlagun, Arunachal Pradesh
6.	Regional Institute of Medical Sciences Lamphelpat, Imphal, Manipur
7.	New STNM Hospital, Gangtok, Sikkim
8.	Sikkim Manipal Institute of Medical Sciences, Sikkim
9.	Agartala Medical College, Tripura
10.	Jorhat Medical College, Jorhat Assam
11.	Silchar Medical College, Silchar, Assam
12.	Assam Medical College, Dibrugarh, Assam
13.	Apollo Hospitals Guwahati, Assam

Key findings:

- A total of 16,512 CVD cases were reported by 13 participating centers and 60.9% were males.
- Majority of the cases belonged to the age group of 45-64 years (45.9%) followed by >65 years (36.7%). Nearly 17% of cases belonged to the age group of 18-44 years.
- More than half of the cases (54.2%) reported in registry were from outpatient departments of the hospital. The most common co- morbid condition among CVD cases was hypertension (50%) followed by diabetes (30.4%).
- Consumption of smokeless tobacco (27.3%), tobacco smoking (25.3%), alcohol (15.6%) and hyperlipidemia (3.8%) were the major modifiable risk factors among the CVD cases.
- Nearly one third of CVD cases had Acute Coronary Syndrome (32.3%), 8.4% had chronic stable angina and <1% had diseases of aorta.
- Under the diseases of the heart, heart failure was most common (26.2%) condition followed by cardiomyopathy (23.6%), Rheumatic Heart Disease (9.3%) and Non Rheumatic Valvular Heart Disease (6.8%).
- Atrial fibrillation was the most common rhythm disorder among all the cases (12.5%) followed by disorders of atrioventricular AV node (7.9%) and Supraventricular Tachycardia (SVT) (1.4%).
- The study on the profile of cardiovascular diseases (CVD) and Heart Failure Registry in the North-East region of India provided significant insights into the epidemiology and patient demographics of CVD in this area.

NON COMMUNICABLE DISEASES

COMPLETED PROJECTS / ACTIVITIES

1. Assessing progress of India in reduction of premature mortality due to four Non -communicable Diseases towards achieving the WHO 25x25 goal and Sustainable Development Goals

Duration: 01 January 2022 to 30 June 2023

The publication on Assessing progress of India in reduction of premature mortality due to four Noncommunicable Diseases towards achieving the WHO 25x25 goal and Sustainable Development Goals has described the understanding of the country's progress towards the World Health Organization (WHO) 2025 goal and the Sustainable Development Goals (SDGs). By analyzing data from 2001 to 2030, the research reveals a 13.9% reduction in combined premature mortality from cancer, diabetes, cardiovascular disease (CVD), and chronic respiratory disease (CRD) between 2010 and 2025, and a 15.6% reduction from 2015 to 2030. Notably, CRD showed the most significant reduction, with an average annual percent change (APC) of 5.2%, reflecting effective interventions. The detailed disease-specific trends indicate that while there has been substantial progress, achieving the WHO's 25% reduction target by 2025 or the SDGs' one-third reduction by 2030 will require intensified and sustained efforts.

Kulothungan V, Ramamoorthy T, Mohan R, Mathur P. Assessing progress of India in reduction of premature mortality due to four noncommunicable diseases towards achieving the WHO 25_25 goal and the sustainable development goals. Sustainable Development. 2023;1–11. DOI: <u>https://10.1002/sd.2761</u>

2. Assessment of Continuum of Care for Diabetes and Hypertension in India-2022

Duration: 01 February 2023 to 30 June 2023

Health facility assessment for NCD services was conducted to understand the current status and scope for improving continuum of care for diabetes and hypertension in India through a cross-sectional survey of health facilities and patient exit interviews were conducted in 9 districts of 4 states in India. State and district NCD program managers were interviewed to understand the key challenges in program implementation. Majority of the public health facilities were implementing NP-NCD program. Only one fourth of the patients were offered opportunistic screening. Vacancy of general physicians was significant in Community Health Centres and Sub-district Hospitals. Less than one fifth of the patients from public (18.6%) and private (11.9%) reported receiving reminders for follow-up. The essential anti-diabetic medicines were less available in subcenters, compared to other levels of facilities.

Key recommendation is to improve case detection at health facilities by implementing opportunistic screening services at secondary level care and ensure availability of essential medicines at sub-centre level. Community workers under the supervision of medical officers can ensure continuum of care at community level. To recruit NCD specific staff for implementation of program at secondary level of facilities. State NCD officers can plan and implement integrated health promotion strategy, by using mass media and other channels for communications to promote healthy lifestyle in the communities.

<u>Achievement</u>

- The NCD Division of MoHFW and WHO India Country Office has used the survey findings as baseline performance of the districts on CoC indicators for Diabetes and Hypertension.
- WHO and NHSRC, New Delhi will be conducting implementation research in these districts, to improve the program.

Future Planned Activities

• Planning for dissemination of survey findings with key stakeholders (state and districtNCD officials), with support of NCD Division of WHO India Country Office.



Onsite visit by NCDIR staff to NCD clinic in Odisha and Madhya Pradesh

ONGOING PROJECTS / ACTIVITIES

1. Implementation research to improve clinical outcomes of diabetes and hypertension cases by empowering public and private sector primary care physicians in India

National level population-based survey reported that less than one tenth (8.2%) of those being treated for high blood pressure had blood pressure under control and among those with high blood glucose level, only 15.7% had blood glucose under control.

There are serious challenges to meet the national goals, for reducing premature mortality due to diabetes and hypertension. It is essential to study the current clinical practices of physicians in public and private sectors and redesign the primary care delivery to provide comprehensive care for diabetes and hypertension patients and to improve the disease control status.

Primary objectives:

- To redesign the primary care for diabetes and hypertension by empowering primary care physicians to provide comprehensive care to improve the clinical outcomes.
- To develop a reliable information system for real time monitoring (cohort) of patients (by modifying the recording and reporting formats) at facility level

Key activities completed:

IEC approval for the study has been obtained and funding has been initiated. Support letters to State MD NHMs were sent in March 2024. Project staff have been recruited. Orientation meetings with state NCD officials was completed and with potential collaborators i.e. medical colleges for survey data collection was completed.

2. Statistical Modelling Approach to Spatially Map the District-Level Heterogeneity in the Prevalence of Diabetes and Hypertension and their Associated Risk Factors among Indian Adults

Brief Background:

Noncommunicable diseases (NCDs) are a leading cause of premature mortality and morbidity in low- and middle-income countries, driven by metabolic, behavioural, and environmental risk factors. In India, hypertension and diabetes prevalence has surged, with significant increases noted in recent surveys. The WHO's Global Action Plan aims to reduce hypertension and diabetes by 25% by 2025, but achieving this requires district-level data on prevalence and risk factors. This study aims to investigate the spatial variation in the prevalence of diabetes, hypertension, and associated risk factors among adults across Indian districts, and to study the trends in diabetes and hypertension prevalence from 2000 to 2020. Geographic Information Systems (GIS) and spatial epidemiology can help identify vulnerable populations and inform targeted interventions.

Current status:

Reviewing of the literature and finding historical available data sources for diabetes and hypertension in India by district is ongoing.

Publication:

 Seenappa K, Kulothungan V, Mohan R, Mathur P. District-Wise Heterogeneity in Blood Pressure Measurements, Prehypertension, Raised Blood Pressure, and Their Determinants Among Indians: National Family Health Survey-5. International Journal of Public Health. 2024 Mar 18;69:1606766. https://doi.org/10.3389/ijph.2024.1606766

MORTALITY

ONGOING PROJECTS/ACTIVITIES

1. NCDIR Collaborations for strengthening MCCD systems

Background and rationale:

ICMR- NCDIR works with the Civil Registration System (CRS) in several states by 1) Sensitization of officials on strengthening MCCD and 2) support with software applications for recording MCCD by the Civil Registration System (CRS).

A. Tamil Nadu

MoU was signed on 11th April 2023 between ICMR – National Centre for Disease Informatics and Research, and Directorate of Public Health and Preventive Medicine (DPH&PM), Dept of Health and Family Welfare, Govt of Tamil Nadu for strengthening mortality statistics through the deployment and use of the integrated e-Mor software developed by ICMR-NCDIR with the CRS software in the hospitals across the state of Tamil Nadu.



Deployment and support of NCDIR e-Mor software in Tamil Nadu CRS software to capture cause of death and generate MCCD is ongoing. Quality checks to avoid ill-defined terms and modes of dying were incorporated. ICMR-NCDIR provided online training on implementation of MCCD audit framework in medical college hospitals of Tamil Nadu for faculty of medical colleges, organized by Dept of Public Health and Preventive Medicine, Govt of Tamil Nadu on 6 June 2023.

B. Karnataka

Online trainings on strengthening Medical Certification of Cause of Death in Karnataka was conducted for the medical officers and doctors of Dept of Health, Karnataka. The training was conducted by Regional Office for Health and Family Welfare, Karnataka and ICMR-NCDIR. The training was attended by Medical Officers, Belagavi and Kalaburagi Division on 10 to 11 October 2023; Medical Officers of Bengaluru and Mysuru Division on 21, 22 and 25th March 2024

Orientation training programme on "Family of International Classification (ICD-10 & ICF) by Regional Office for Health and Family Welfare, Benagluru for Medical and Non-Medical Personnel' involved in MRD, MCCD, CRS from govt hospitals of South India. ICMR-NCDIR conducted sessions on MCCD and ICD-10 coding.

C. Training Manual on MCCD

Inputs were provided to finalize the course curriculum of MCCD and preparation of Training Manual on MCCD by Dr. Sukanya R, Scientist E, as member of the Expert Committee. The training manual was officially released by the Chief Registrar, Office of the Registrar General of India (ORGI), on March 18, 2024.

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

Background:

Improving MCCD requires changes in the system and improving the quality of recording MCCD. The implementation research study was planned to identify the barriers of MCCD at system and health facility levels and identify solutions for further intervention and evaluation.

Objectives:

- To conduct a baseline assessment of the civil registration and vital statistics system to understand the barriers and facilitators for implementation at state level of medical certification of cause of death (MCCD)
- To conduct a baseline assessment of MCCD in selected tertiary and secondary healthcare facilities.
- To identify, implement and evaluate actions with stakeholder consultation to address the barriers identified to improve MCCD practices at the facility and systems level.
- Using the above, to develop a framework and supporting resources for national level roll-out for the improvement of quality of MCCD through multiple iterations

Methodology:

This is an implementation research study conducted in 6 states of India - 3 states/UTs where the Civil registration system is under the Dept. of Health (i.e., Tripura, Punjab and Andhra Pradesh), and 3 states/UTs where it is under the Department of Planning, Economics and Statistics (Karnataka, Delhi and Rajasthan). In each state, 2 districts (1 each from high and low death registration coverage categories) have been selected. In each district, 8 health facilities (4 public and 4 private) rendering secondary and tertiary level care with inpatient facility have been selected.

Baseline assessment of Medical certification of cause of death (MCCD) in the health system and civil registration system was completed in all 6 states. Data cleaning and data analysis was completed. Review meetings were conducted with collaborating centers. Reports for the state-level stakeholder discussions was planned so that state specific interventions could be identified.

Based on the barriers identified, discussions would be held with the relevant stakeholders to identify solutions at the facility and system levels. The solutions would be subsequently implemented and evaluated as regards their effectiveness. Intervention on training on MCCD and use of the MCCD e-audit tool is being planned in all the states.

3. Setting-up a system for Medical Certification of Cause of Death for non-institutional deaths in a selected area of Kolar Taluk, Karnataka Feasibility and Validity

Background and Rationale:

The current coverage of Medical Certification of Cause of Death in India is only 22.5%. This is largely attributed to significant proportion of deaths occurring outside the hospital (non-institutional deaths). The

cause of death in such cases is unlikely to be certified by any doctor. The present study attempts to address this gap by developing a system to provide MCCD for non-institutional deaths in the country. This is first of the kind study attempting to address the gap of coverage as well as reliability of MCCD for non-institutional deaths.

Objectives:

- To assess the feasibility of Physician derived cause of death (PhyCoD) approach for deducing cause of death in non-institutional deaths in a selected area of Kolar Taluk, Karnataka
- To validate the PhyCoD approach for determining cause of death for non-institutional deaths

Methods:

The duration of the study will be between Mar 2024-Feb 2026. Doctors of selected major hospitals in Kolar taluk and PHC medical officers and private practitioners of 2 selected PHC areas of the taluk would be trained in arriving at Cause of Death in non-institutional deaths using the PhyCoD tool. The cause of death deduced by this approach will be validated against the gold standard autopsy wherever possible. The approach will also be tested for inter-rater reliability.

Activities completed:

- Recruitment of project staff
- IEC clearance

Expected outcome:

- Development of a tool for physicians for deducing Cause of Death in non-institutional deaths
- Increased coverage of non-institutional deaths under MCCD
- Improved accuracy of the cause of death reporting for non-institutional deaths
- Reduced delay of the cause of death reporting for non-institutional deaths

OTHER PROJECTS / ACTIVITIES ONGOING PROJECTS / ACTIVITIES

Immune response to precautionary third dose of COVISHIELD/COVAXIN among healthy adult population: an ICMR Cohort study, India.

The cohort study is a multi-centric study involving ICMR Institutes and was initiated to study the immune response to the third dose of COVID vaccine. The follow-up which was planned for one year after taking third dose of COVID vaccine was extended for one more year. A total of 19 participants enrolled for the study and the follow up of study participants is ongoing.

SOFTWARE DEVELOPMENT

1. A portal for HBCR core form

A portal has been developed to capture the data as per the revised HBCR core form.

	≡ HBCR Core Form								
NCDIR NCDIR	Reference No: 9990000027								
Dashboard									
Dataentry Form	– I. Identifying Information / De	mographic Details							
Search	1. Name of the Reporting Institution	(RI) :-		HBCR			Centre Code :	999	
Quality Checks	2. HBCR Registration Number (First 2	digits are for year of registra	tion and the next	t 5 digits for actual registration number)					
Logout	3.(a) Name of Department						(b) Unit Number		
	4. Hospital Registration Number (MR	D No / CR No./Unique Hospi	tal Identification	Number)					
	5. Date of Reporting at RI				dd-mm-yyyy				
	6. Case Registered Through (Patient's first reporting at RI)				Select				
	7. Type of Referral				Select				
	Name of Facility			City					
	District			Pin					
	Hospital/LAB/N.H.			Date	dd-mm-yyyy				
	8. Date of First Diagnosis (Date of first of the dates in 5 or 7 above)	attendance to any hospital t	which led to diag	nosis of cancer - generally the earliest	dd-mm-yyyy				
	9. Full Name of Patient								
	First Name			Second Name			Last Name	Sava	
	10.1 Age (in completed years)			10.2 Date of Birth	dd-mm-yyyy			Partial Save	
	11. Sex 12. Unique Identification / Beneficiar	 Male y Number (Please Enter a 	 Fen Ill applicable) 	nale	Others			Update	

2. DNMS follow up software was deployed to the study sites for data entry in FY 2023-24. The software had dashboard for C- PIs. The key indicators to assess the survey progress were included in DNMS dashboard.



3. The existing software application for HBCVD was updated with QC module.

(Indian Council of Medical Research)										
- Hospital Based Study on Profile of Cardiovascular Diseases and Heart Failure Registry in North-East region of India										
NCDIR A Home C Add CVD Record Q Search & Edit Z Follow Up 🖕 Data - Juliy 18 2024 10:43:16 🕞 Logout										
									User	Loged in as : ncdir
				DATA Qu	uality C	hecks				
PARTI	PARTI	(HF Confirm	ed Cases)							
		onsistency (Check hfc	Onknown / Blar	nk	O Duplicate Ch	leck			
	Date	of Admission	on :	01-01-2023 From		31-12-2023 To				
	Sele	ct Centre Na	ame :	Regional Institute	e of Medical	Sciences Lamphel	oat, Imphal			~
View										
Note: Duplicate Check, Unknown / Blank, Consistency Check, List										
Re Numi	f ber [‡]	Centre Name	Reg No	OPD [‡]	IPD [‡]	Admission Date	↓ FullName	Age [‡]	Sex [‡]	Error ¢ Description
204000	10224	Regional nstitute of Medical Sciences amphelpat, Imphal	2200224	2022/051/0067055		20-12-2022	POTSHANGBAM PREMILA DEVI	53	2	Date of Diagnosis is blank
204000	0224	Regional nstitute of Medical Sciences	2200224	2022/051/0067055		20-12-2022	POTSHANGBAM PREMILA DEVI	53	2	NYHA is blank

4. HBSR centres Dashboard

A dashboard for HBSR centres regarding data status based on various fields.



NCDIR Dashboard - A dashboard for ICMR-NCDIR to monitor HBSR data status.

Centres	Details for Received Cases	Year : 20 - 202	l - 2024 As on: 08/05/20					
SI. No.	Sl. No.		τα	tal	Partial		Complete	
		/ Tear		%		**		%*
1	All India Institute of Medical Sciences, Bhopal	480	827	172.3	1	0.1	826	99.9
2	All India Institute of Medical Sciences, Bhubaneshwar	1530	942	61.6	1	0.1	941	99.9
3	All India Institute of Medical Sciences, Delhi	2000	592	29.6	161	27.2	431	72.8
4	All India Institute of Medical Sciences. Jodhpur	292	1646	563.7	40	2.4	1606	97.6
5	All India Institute of Medical Sciences. Mangalagiri		939		31	3.3	908	96.7
6	All India Institute of Medical Sciences. Raipur	460	709	154.1	10	1.4	699	98.6
7	All India Institute of Medical Sciences. Rishikesh	600	947	157.8	4	0.4	943	99.6
8	Ashwini Hospital. Cuttack	558	1941	347.8	44	2.3	1897	97.7
9	Atal Institute of Medical Superspecialities, Shimla	440	873	198.4	73	8.4	800	91.6
10	Christian Medical College & Hospital, Ludhiana	1136	644	56.7	48	7.5	596	92.5

6. Created a quality check tool that utilizes fuzzy matching, distance, and a customized score-based algorithm to detect duplicate records within the registry. This tool is specifically tailored to manage PBCR, HBCR, and mortality records within the registry

PUBLICATIONS / REPORTS/ GUIDELINES / BOOKS / POLICY

2023-24

- 1. Nath A, Mathur P, Sudarshan KL, Kaur Rajput G, Mascarenhas L. An assessment of childhood cancer care services in India gaps, challenges and the way forward. Lancet Reg Health Southeast Asia. 2023 Jun 20;16:100235.
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- 4. Kulothungan V, Ramamoorthy T, Mohan R, Mathur P. Assessing progress of India in reduction of premature mortality due to four noncommunicable diseases towards achieving the WHO 25× 25 goal and the sustainable development goals. Sustainable Development. 2023 Sep 19;1-11.
- 5. Mathur P, Kulothungan V, Nath A, Vinay Urs KS, Ramakrishnan L. Awareness, behavior, and determinants of dietary salt intake in adults: results from the National NCD Monitoring Survey, India. Scientific Reports. 2023 Sep 23;13(1):15890.
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- 11. Kapoor G, Arora RS, Radhakrishnan V, Nath A, Malhotra P, Cyriac SL, Gangadharan VP, Sadashivudu G, Ramamoorthy T, Sudarshan KL, Mathur P. Profile of Childhood Cancers From Hospital-Based Cancer Registries in India, 2012-19. Indian Pediatr. 2024 Jan 15;61(1):39-44.
- 12. Sathishkumar K, Sankarapillai J, Mathew A, Nair RA, Gangane N, Khuraijam S, Barmon D, Pandya S,

Majumdar G, Deshmane V, Zomawia E, Bhutia TW, Jerang K, George PS, Maliye S, Laishram R, Das G, Shah A, Debbarma S, Koyande S, Pachuau L, Sherpa A, Jongkey G, Chaturvedi M, Das P, Santhappan S, Mathur P. Breast cancer survival in India across 11 geographic areas under the National Cancer Registry Programme. Cancer. 2024 Jan 6. doi: 10.1002/cncr.35188. Epub ahead of print. PMID: 38183671.

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

No.	Title of Meeting
1	Meeting – Signing of MoU for Strengthening Mortality statistics through e-Mor in Tamil Nadu on 11 April 2023
2	Team Training for Site Principal Investigators and Data collection team for Continuum of Care project Phase II on 19 April 2023
3	Meeting with National Health Authority regarding transfer of data to NCRP format held on 13 and 21 April 2023
4	Training Workshop regarding implementation of MCCD audit framework in Medical College Hospitals of Tamil Nadu in collaboration with Dept of Public Health and Preventive Medicine, Govt of Tamil Nadu) on 6 June 2023
5	Team Training at HBSR Bhubaneshwar on 06 June 2023
6	Team Training at HBSR Cuttack on 07 – 08 June 2023
7	Meeting with Co - PIs of DNMS sites to discuss deployment of follow-up software at study sites on 26 June 2023
8	Training for 16 New Hospital Based Cancer Registries on 30 June 2023
9	Training on HBSR for participating centres on 11 July 2023
10	Online Training of newly registered HBSRs on 11 July 2023
11	HBCVD-NER software training for project staff of Jorhat Medical College & Hospital, Assam on 12 July 2023
12	Hospital Based Cardiovascular Disease Registry - Northeast Region (HBCVDR- NER) Software training for JMCH, Jorhat Assam on 12 July 2023
13	Software training for HBCVDR-NE centre-JMCH, Jorhat on 12 July 2023
14	Meeting of Medical Certification of Cause of Death (MCCD) practices in public and private healthcare facilities in India: Research to implementation on 21 July 2023
15	Orientation training programme on "Family of International Classification (ICD-10 & ICF) by Regional Office for Health and Family Welfare, Karnataka in collaboration with ICMR-NCDIR for Medical and Non-Medical Personnel' on 24 July 2023 14 August 2023 09 November 2023
16	Monthly meeting to review implementation of DNMS project for AGMC, Agartala on 26 July 2023
17	Monthly meeting to review implementation of DNMS project for RIMS, Raichur & NIIRNCD, Jodhpur on 28 July 2023
18	Strengthening Cancer Registry in Rajasthan State on 28 July 2023
19	Monthly meeting of site PI of GMC, Mumbai to review implementation of DNMS project on 31 July 2023
20	Meeting with State Govt. of Uttar Pradesh on 11 August 2023 to strengthen Cancer Registry in the State
21	Review of progress of work and data status for POCSS Gallbladder cancer on 18 th August 2023
22	Data Review Meeting for Project Staff of HBCVDR- NER project on 24 August 2023
23	HBCVDR- NER Data Review Meeting for Project Staff on 24-25 August 2023
24	Discussion on setting up of HBCR in HCG centres and its data transmission status on 28 August 2023
25	Data review meeting of GMC, Mumbai, RIMS, Raichur & NIIRNCD, Jodhpur on 30 August 2023

26	Data review meeting of AGMC, Agartala on 4 September 2023
27	Hospital Based Cardiovascular Disease Registry - Northeast Region (HBCVDR- NER) Software
27	training for AGMC, Agartala, Tripura on 7 September 2023
28	Software training for HBCVDR-NE centre-AGMC, Agartala on 07 September 2023
29	Meeting regarding Cancer Atlas in Rajasthan State on 08 th September 2023
30	Cervical Cancer Modelling Workshop Conducted by National Disease Modelling Consortium (NDMC), IIT-Bombay in collaboration with Institute for Disease Modeling (IDM). Date: 20 – 22 September 2023
31	Conducted session on Digital health for advancing NCD care in India during the 63rd Annual Conference of National Academy of Medical Sciences (NAMSCON 2023) at M.S. Ramaiah Medical College, Bengaluru on 7 – 8 October 2023
32	Training workshop on 'Strengthening Medical Certification of Cause of Death in Karnataka' by Regional Office for Health and Family Welfare, Karnataka in collaboration with ICMR-NCDIR on 10 to 11 October 2023
33	Technical review meeting for review of report on WHO Southeast Asia region cancer profile on 13 th October 2023
34	Visit to MRHRU, Jaipur DNMS site on 16- 19 October 2023
35	Sensitization Training for Principal Investigators of new HBCRs on 17 th October 2023
36	Training of 13 newly registered Hospital Based Cancer Registries under NCDIR on 17 October 2023
37	Cyber Hygiene and Security" in connection with Vigilance awareness week on 19 October 2023
38	Team Training at DNMS Jaipur site from 16 – 19 October 2023
39	Expert meeting for POCSS Breast and Head & Neck cancers on 26 October 2023
40	HBSR training program on 30 October 2023
41	Training of participating hospitals regarding Andhra Pradesh Cancer Atlas on 30 Oct 2023
42	Two days training for the HBSR staff was conducted in two batches at ICMR-NCDIR, Bengaluru a. 30 – 31 October 2023, b. 08 - 09 November 2023
43	Orientation for Hospitals under Andhra Pradesh cancer atlas on 31 October 2023
44	HBSR training program on 31 October 2023
45	Training Workshop for Hospital Based Cancer Registries on 06th November 2023
46	Training Workshop for the staff Hospital Based Cancer Registries Batch 1 - 6 and 7 November 2023 (25 Hospitals) Batch 2 – 30 November to 1 December 2023(23 Hospital) Batch 3 - 7 to 8 December 2023 (18 Hospitals) Batch 4 - 14 to 15 December 2023 - 20 hospitals.
47	Training workshop - Population Based Stroke Registry on 07 November 2023
48	Training workshop - Hospital Based Stroke Registry on 08 to 09 November 2023
49	Discussion on Rajasthan Cancer Atlas on 10th November 2023
50	Online training and discussion on Atlas core form with all the registered centre for the project Rajasthan Cancer Atlas (RCA) on 10 November 2023
51	Meeting with POCSS Gallbladder cancer centres (online) on 20 November 2023
52	Team Training at DNMS Mumbai site from 27 to 30 November 2023
53	Visit to MRHRU, Mumbai DNMS site on 27 – 30 November 2023
54	Discussion on protocol for the situational analysis of cancer care service in India on 13 December 2023

55	Cancer Epidemiology and Surveillance Training Programme (Can-EST) from 11 to 13 December 2023
56	Hospital Based Cardiovascular Disease Registry - North East Region (HBCVDR- NER) Software training, for Assam Medical College, Dibrugarh, Assam on 14 December 2023
57	Software training for HBCVDR-NE centre-Assam Medical College, Dibrugarh on 14 December 2023
58	HBSR training program on 14 December 2023
59	Online Training of newly registered HBSRs on 14 December 2023
60	Training of project staff of Assam Medical College & Hospital, Dibrugarh, Assam for study titled "Hospital Based Study on Profile of Cardiovascular Diseases and Heart Failure Registry in North- East Region of India" on 14 December 2023
61	Hospital Based Cardiovascular Disease Registry - Northeast Region (HBCVDR- NER) Software training, for Silchar Medical College, Silchar, Assam on 18 December 2023
62	Software training for HBCVDR-NE centre-Silchar Medical College, Silchar on 18 December 2023
63	Training of project staff of Silchar Medical College & Hospital, Silchar, Assam for study titled "Hospital Based Study on Profile of Cardiovascular Diseases and Heart Failure Registry in North- East Region of India" on 18 December 2023
64	Meeting with DNMS project centre-NIIRNCD, Jodhpur on 19 December 2023
65	Post training follow-up meeting with project staff of HBCVDR-NER project from AMCH, Dibrugarh & SMCH, Silchar, Assam on 20 December 2023
66	HBCVDR-NER Post training follow-up meeting with project staff of AMCH, Dibrugarh & SMCH, Silchar, Assam on 20 December 2023
67	Monthly meeting to review implementation of DNMS project for RIMS, Raichur & AGMC, Agartala on 4 January 2024
68	Monthly meeting to review implementation of DNMS project for GMC, Mumbai on 5 January 2024
69	Hospital Based cancer - Northeast Region (HBCVDR- NER) Software training for Apollo Hospitals, Guwahati, Assam on 8 January 2024
70	Software training for HBCVDR-NER centre-Apollo Hospitals, Guwahati on 08 January 2024
71	Sensitization on NCD, Disease Registries for the Post graduate Students of AFMC Pune on 15 January 2024
72	Sensitization Training for DHR-ICMR Advanced Molecular Oncology Diagnostic Services (DIAMOnDS) on 17 January 2024
73	PBSR Data Review Meeting on 18 January 2024
74	HBSR Data review meeting with centre PIs on 19 January 2024
75	Meeting of the collaborating institutes pertaining to the project "Strengthening the Medical Certification of Cause of Death (MCCD) practices in public and private healthcare facilities in India: Research to Implementation" to discuss plan for interventions and manuscript preparation on 22 to 23 January 2024
76	A Virtual workshop on Quality checks & Quality assurance for the data under the project on IGBC on 25 January 2024
77	Meeting regarding Progress of Rajasthan Cancer Atlas on 31 January 2024
78	Annual review meeting with C-PIs & Co-PIs of DNMS centres on 12 February 2024
79	Meeting on MCCD software for ICD-10 coding for officials of the SBHI & VS division, Maharashtra on 13 February 2024
80	Training Workshop of Population Based Cancer Registries(PBCR) Batch 1 - 22 and 23 February 2024 Batch 2 - 29 February and 1 March 2024
81	Cyber Security Awareness Session on 28 February 2024

82	Data Review Meeting for DHR-ICMR Advanced Molecular Oncology Diagnostic Services (DIAMOnDS) on 4 March 2024
83	Training for the centres under Rajasthan Cancer Atlas on 5 March 2024
84	Meeting with Central Council for Research in Ayurvedic Sciences (CCRAS) on 14 March 2024
85	Online Training of newly registered HBSRs on 14 March 2024
86	Sensitization Training of 12 newly registered Hospital Based Cancer Registries under NCDIR on 22 March 2024
87	Training on Population Based Cancer Survival on Cancers of Breast, Cervix and Head & Neck on 22 March 2024
88	Training (online) on Medical Certification of Cause of death for medical doctors of Dept of Health , Karnataka by ICMR-NCDIR and Regional Office for Health and Family Welfare, Karnataka on 21, 22 and 25 March 2024
89	Orientation meeting with state Level stakeholders of Haryana, Maharashtra & Uttar Pradesh to discuss Implementation Research Project on 27 March 2024



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