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NCDIR
NATIONAL CENTRE FOR DISEASE
INFORMATICS AND RESEARCH

Impacting NCD Public Health Actions and Policies
Collaborate Innovate Inspire

ANNUAL HIGHLIGHTS

2024-25

II Floor of Nirmal Bhawan, ICMR Complex
Poojanahalli Road, Off NH-7,
Adjacent to Trumpet Flyover of KIAL
Kannamangala Post, Bengaluru - 562 110 (India)

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Published on behalf of the Director, ICMR-NCDIR, Bengaluru.

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MAIN ACTIVITIES

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

KEY ACHIEVEMENTS

1. Cancer has been made notifiable in Himachal Pradesh through Government order dated 3 September 2024, based on the recommendations of the National Centre for Disease Informatics and Research.
2. The Rajasthan Cancer Atlas implemented by the Dept of Health, Rajasthan created a state-wide cancer registration system to assess the district wise patterns of cancer in Rajasthan through electronic data systems supported by ICMR-NCDIR.
3. Cancer registry network expanded with the inclusion of hospitals of the Armed Forces, and hospitals affiliated with the National Board of Examinations and the Ayushman Bharat Pradhan Mantri Jan Arogya Yojana.
4. Software for notification of cancer / stroke cases by the sources of registrations in a Population Based Cancer Registry (PBCR) / Population Based Stroke Registry (PBSR) area was implemented. This software envisaged an alert system for early reporting to the PBCR / PBSR of a new case for cancer and stroke registration respectively.
5. A software tool for conversion of cancer registry data from ICD-10 to ICD-11 was developed to facilitate coding of registry data.
6. The e-audit tool to review completeness and accuracy of cause of death written in MCCD forms (Form 4) has been developed and implemented in select hospitals. The e-Audit tool shall facilitate improving the quality of medical certification of cause of death in hospitals.

CANCER

COMPLETED PROJECTS / ACTIVITIES

ONGOING PROJECTS / ACTIVITIES

1. Population Based Cancer Registries in India (PBCR)

The Population Based Cancer Registries (PBCRs) collect data on the new occurrence of cancer and deaths in a defined geographical area for a specific period. At present, there are 37 Population Based Cancer Registries under the National Cancer Registry Programme (NCRP).

Data from PBCRs cover 18% of the Indian population that includes data from 37 PBCRs, data from the Tamil Nadu Cancer Registry Programme and the PBCRs under the Tata Memorial Centre. The PBCR data for 2015-2020 has been finalized.

An advanced duplicate identification tool was developed for the Cancer Registry, incorporating fuzzy matching and a scoring algorithm to enhance accuracy in detecting duplicate records. The tool demonstrated significantly higher efficiency compared to the previous system, achieving better improvement in duplicate identification. The tool is equipped with a user-friendly graphical interface (GUI) and is currently being utilized.

PBCR Data Review meeting of PBCRs with the PI/Co-PI was conducted from 6-7 June 2024 and on 26 July 2024. Residential training of cancer registry staff at ICMR-NCDIR in registry data processing and software usage was conducted for 16 PBCRs between November 2024 and March 2025.

Access to the PBCR e-Notification software has been provided to the PBCRs. Module to capture District, Sub District, PHC and CHC from PBCRs to standardize demographics data has been developed and implemented. Prototype of a software tool to convert ICD-10 to ICD-11 for use in cancer registry is in place.

2. Hospital Based Cancer Registries in India

HBCRs are concerned with recording patient identifying information, diagnosis details, clinical stage, and treatment for all the proven malignant cases registered/diagnosed in a particular hospital. The HBCRs registered with NCDIR include 279 cancer treating hospitals (public & private), and 44 Regional Cancer Centres (RCC)/ Tertiary Care Cancer Centre (TCCC)/State Cancer Institute (SCI) hospitals. Data collection is done by standardized common core form for all the registries, and National Cancer Registry Programme (NCDIR-NCRP) is a repository of data from all the HBCRs. A short HBCR form was developed for non-funded centres to provide minimum set of data. An API was also developed for transmission of data for the Armed Forces Medical Services hospitals.

Collaborations to expand HBCR network:

- a) **National Medical Commission:** 168 medical colleges have registered
- b) **National Health Authority:** Data on AB-PMJAY beneficiaries who had availed cancer diagnosis and treatment in empanelled hospitals is being included.
- c) **National Board of Examinations (NBE):** Fifty hospitals offering DNB courses on cancer care have registered to establish a cancer registry.

Network of Hospital Based Cancer Registries



HBCR Data Review meetings were conducted region wise (below table).

| Sl. No. | Hosted at | Date |
|---------|-----------------------------|--------------------------------|
| 1 | SGPGI, Lucknow | 16 th November 2024 |
| 2 | Cancer Institute, Chennai | 9 th January 2025 |
| 3 | GMC, Bhopal | 16 th January 2025 |
| 4 | BBCI, Guwahati | 4 th February 2025 |
| 5 | RCC, Thiruvananthapuram | 21 st February 2025 |
| 6 | RST Cancer Hospital, Nagpur | 28 th February 2025 |
| 7 | ICMR-NCDIR, Bengaluru | 10 th March 2025 |

3. Patterns of Care and Survival Studies (POCSS) for Cancer Breast, Cervix and Head & Neck cancers

The specific objectives of this study are to determine hospital-based patterns of care in terms of diagnosis and treatment, estimate overall and disease-free survival of patients with these cancers. The results from

this study will aid clinicians and public health experts in evidence-based decision-making and contribute to prevention, early detection and control policies and programmes. It will enable hospitals to monitor and evaluate their performance in providing care to patients with these cancers.

- Twenty Hospitals and 40 TCCCs/SCIs/RCCs are contributing data for three main sites of cancer.
- ICMR-NCDIR received around 39000 cases of breast cancer, 20000 cases of cervical cancer and 55000 cases of head & neck cancers under this project for the year 2021 to 2023.
- It was observed that more than 70% of breast cancers are diagnosed in locally advanced stage.
- Majority of tongue and mouth cancers were observed in 35 – 64 years, and hypopharynx, oropharynx and laryngeal cancers were common in age 45-69 years.
- More than 50% of the head and neck cancers except larynx were reported in advanced stage.

4. Rajasthan Cancer Atlas

The project created a state-wide cancer registration system to assess the district wise patterns of cancer in Rajasthan with use of software and electronic data transmission to ICMR-NCDIR. Understanding the epidemiology and distribution of cancer in the state would provide essential leads in undertaking etiological research, targeting cancer control measures and examining clinical outcomes. Cancer was declared as the notifiable disease in the state of Rajasthan in July 2019. A state-wide cancer registration system is a health systems approach monitored by the State Health and Family Welfare Department. ICMR NCDIR provided technical support in implementing the state cancer registry.

State nodal officer (SNO) and district nodal officers (DNOs) were identified and trained. The DNOs ensured that all the cancer-treating hospitals in their district were transmitting data to ICMR-NCDIR. A total of 109 registered hospital staff were trained and provided access to transmit the data. Over 72,000 cases were registered for the years 2022-24.

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

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. This study has been initiated for lung and breast cancers in ten leading cancer hospitals, wherein the biomarkers were available for these cancer patients. ICMR-NCDIR serves as Data Management Centre for the DIAMOnDS Centres to manage the data submission, quality, data analysis and feedback to the centres

Twenty-Three institutions are part of this project. Around 21842 cases have been received (14236-Breast; 7606-Lung) from the inception of the project.

6. Andhra Pradesh Cancer Atlas

Cancer was declared a notifiable disease in the state in May 2022, and through this project, a state-wide cancer registration system has been developed to learn the patterns of cancer across Andhra Pradesh. Understanding the epidemiology and distribution of cancer in the state would provide essential leads in undertaking etiological research, targeting cancer control measures and examining clinical outcomes.

A total of 82 hospitals were registered to transmit data under AP cancer atlas. A virtual refresher training session for all the hospitals was conducted on 25th June 2024.

7. CaResNER: A Multidisciplinary Research Programme for Prevention and Control of Cancer in the North Eastern States in India

The CaRes NER Programme aims to address cancer incidence and mortality in the Northeast by encouraging research focused on cancer control and improved survival rates for cancer patients in the region. Call for proposals was implemented from 2019-2020. These projects aim to the use of research to inform health policy and practice. The status of studies that were funded under the CaResNER call for proposals is as follows.

| S. No | Title of the project | PI (Name and institution) |
|-----------------------------|---|--|
| Completed during FY 2024-25 | | |
| 1 | Knowledge, Attitudes, Barriers and Facilitators to Screening for cervical cancer among women in North East India | Dr Wansalan Shullai, NEIGRIHMS, Shillong |
| 2 | Epidemiological assessment of oral hygiene practices, screening of oral cancer and technological intervention for development of Behavioural change communication in Sikkim, North East India | Dr Sathish Chandra, SRMU, Sikkim |
| Ongoing | | |
| 1 | Effectiveness of self-help groups for Breast and Tobacco-related Cancer Prevention in Meghalaya: A quasi-experimental study | Dr Melari Nongrum, IIPH, Shillong |
| 2 | Source of spending for cancer treatment & the Economic burden on households (and local economy) - A study of health expenditure pattern of cancer patients in the Top 10 cancers in the North East India. | Dr. Toms K Thomas Shri Ramasamy Memorial University, Sikkim |
| 3 | A Pilot Model for Multi Sectoral Collaboration to Deliver Integrated Messaging and Create Awareness for Promoting Early Detection of Cancers at the grassroot level | Dr Ravi Kannan Cachar Cancer Hospital and Research Institute, Silchar |
| 4 | 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 North Eastern Indira Gandhi Regional Institute of Health & Medical Sciences, Shillong, Meghalaya |
| 5 | Prevention & early identification of cancer among women (breast & cervix Cancer) through behavior targeting model for early signs along with virtual library of cancer survivors (Health Coach) in the North East | Dr. Toms K Thomas Shri Ramasamy Memorial University, Sikkim |

8. Situational analysis of cancer care services in India

The primary objective of this study is to assess the availability and distribution of cancer care services across geographic areas. The study aims to cover cancer treatment facilities at all levels of health care at the district level in all the States/UTs of the country.

The study has been initiated in 8 states and 2 UTs through 28 nodal institutions, which will act as ‘hub’ centres for collating data from a specified number of districts. The nodal centres have been provided with login credentials for entering data through an online portal.

9. Collaboration with CONCORD study: Extending the global surveillance of trends in cancer survival: the CONCORD programme

CONCORD is a global surveillance programme since 1990 for monitoring cancer survival trends led by the London School of Hygiene & Tropical Medicine (LSHTM). The objective of the study is to provide world-wide trends and inequalities in cancer survival, to inform strategies for cancer control at national, regional and global level. PBCR survival data was shared with LSHTM as per formats of the CONCORD study.

10. Collaboration of ICMR-NCDIR with Rajiv Gandhi Centre for Biotechnology (RGCB), Thiruvananthapuram, India: Human papillomavirus (HPV)-related oropharyngeal cancer burden and the natural history of oral HPV infections

The objectives of the study are

- To compare the incidence and time trends of oropharyngeal cancer with that of oral cavity, lung and cervical cancer
- To estimate overall survival of HPV positive and HPV negative oropharyngeal cancer patients

Oropharyngeal cancer (OPC) burden will be estimated from the Population Based Cancer Registry (PBCR) data from 1982 to 2019 under National Cancer Registry Programme (NCRP). This data will be used to generate cancer incidence rate and trend analysis.

RGCB is conducting HPV analysis of tumour blocks of OPC from 15 Hospital Based Cancer Registries under the National Cancer Registry Programme. The HPV related OPC data will be linked with existing National Cancer Registry Programme (NCRP) datasets for epidemiological and clinical details such as stage and treatment.

11. Collaboration with IIT Bombay's National Disease Modelling Consortium on HPV and Cervical Cancer Burden

Indian Institute of Technology (IIT) Bombay, recognized as an Institute of Eminence by the Government of India, leads the National Disease Modelling Consortium (NDMC). This multi-institutional consortium drives programmatic and policy decisions for infectious diseases through transmission and system modelling, focusing initially on tuberculosis, malaria, vaccine-preventable diseases (including HPV), and neglected tropical diseases.

ICMR-NCDIR is collaborating with the NDMC to support evidence-based policymaking for cervical cancer elimination in India. The cervical cancer data of the National Cancer Registry Programme will be utilized for disease modelling.

12. Development and evaluation of quality indicators as benchmarking tools to improve cervical cancer care practices in India

Standardizing care using Quality indicators (QI) will help ensure better treatment outcomes and reduce disparity in survival from cervical cancer. Quality indicators that are relevant to the Indian context is required to evaluate Cervical Cancer care practices in India.

Objectives:

- To develop quality indicators to benchmark diagnostic and treatment practices in cervical cancer management in India.
- To evaluate the quality of care in cervical cancer using the developed quality indicators in participating hospitals that are part of the Hospital-Based Cancer Registry (HBCR) of the National Cancer Registry Programme network in India

- To assess change in care practice after feedback sessions in improving the Quality of care for CC management one year after the initial assessment of QIs in the participating hospitals

The quality indicators used to assess cervical cancer care were identified through a systematic review. The modified Delphi technique was used to finalise the QIs relevant in the Indian setting. The data collection tool was finalised to collect data on the identified quality indicators.

13. Building blocks of a registry: online training for clinicians / medical doctors

This project is part of ‘Support to Institutions for conduct of training’ funded by the Department of Health Research.

Objectives:

- To build the capacity of medical professionals of medical colleges to establish a registry in their Medical colleges
- To improve the capacity of medical professionals to use the registry as a tool of research
- To gain skills in data analysis, and interpretation of registry data for health planning and policy to improve patient outcomes

This training has been planned as an online training program for clinicians/medical doctors of medical colleges, tertiary and secondary care institutions. The focus of the training would be to develop knowledge and skills on the steps to establish a registry and develop scientific rigor in the analysis of data generated, including sessions on research methodology and health communication to scientific audience and lay public.

STROKE ONGOING PROJECTS / ACTIVITIES

1. Population based Stroke Registries (PBSR) in India

PBSR was established in 2018 in 5 centres: Cuttack, Cachar, Varanasi, Tirunelveli and Kota, with an objective to provide reliable estimates on stroke incidence and mortality.

To strengthen the data completeness and quality, site visits to PBSR Varanasi, Tirunelveli, Kota and Cuttack were completed for the year 2024-25. Recommendations were given to the PBSRs to improve the coverage and data completeness. Data verification exercises were conducted to improve the data quality.

Data collection and data quality exercises for the period of 2018-2022 was completed.

Estimated population and the number of first-ever stroke cases registered at PBSRs for 2018-22:

| Registry | Total Area covered (sq.km.) | Total Population of the PBSR | Total cases of First-ever stroke registered |
|-------------|-----------------------------|------------------------------|---|
| Cuttack | 884.5 | 5885233 | 8108 |
| Cachar | 3786.0 | 10453790 | 6979 |
| Tirunelveli | 2357.6 | 7676543 | 10214 |
| Kota | 548.4 | 7296582 | 6073 |
| Varanasi | 82.1 | 6470776 | 3955 |

2. Hospital Based Stroke Registries in the India

The Hospital Based Stroke Registry (HBSR) started in 2019, collect 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 and Rehabilitation) and wards of the hospitals will be included in the study. All registered cases are followed up at 28 days & 3 months. Online data entry software which has in-built quality checks like consistency, duplicity and range checks is being used.



The HBSR proforma have been revised with detailed section on “Diagnostic Procedure” variables to collect objective details. HBSR training workshop was conducted in September 2024 to review the data abstraction and transmission by the HBSRs.

DIABETES

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

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

Methodology:

A mixed methods study design of cross-sectional survey, cluster randomized control trial (cRCT) and focus group discussion is implemented. The study participants are primary care physicians managing diabetes and hypertension in private and public sectors. In the cRCT component, the interventions for medical officers and community health officers are focused on capacity building (latest treatment protocols and CVD risk assessment protocols, Behavioural Change Communication (BCC) for risk factor reduction), practice of redesigning (appointment, team base care, appropriate referral and follow up) care and appropriate record keeping.

The study sites include 2 districts each from the state of Haryana, Karnataka, Maharashtra, Tripura and Uttar Pradesh as depicted in the following table.

Study sites in India

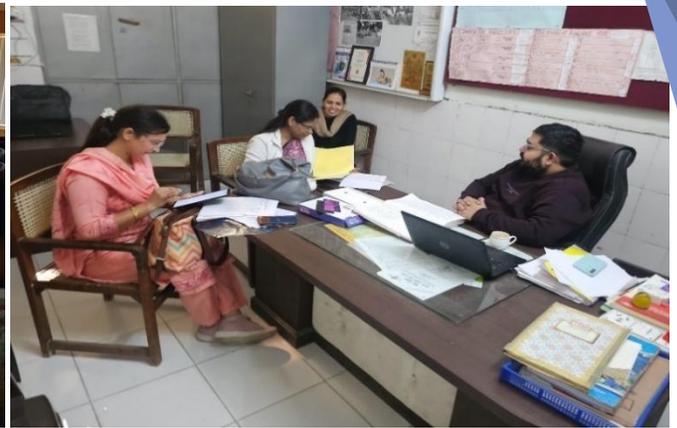
| State | District with the highest prevalence of raised blood sugar (%) | District with the lowest prevalence of raised blood sugar (%) |
|---------------|--|---|
| Haryana | Hisar (12.7) | Charkhi Dadri (0.6) |
| Karnataka | Bangalore (17.5) | Yadgir (0.8) |
| Maharashtra | Pune (19.5) | Gadchiroli (0.5) |
| Tripura | West Tripura (18.4) | North Tripura (4.1) |
| Uttar Pradesh | Jaunpur (6.6) | Kashiram Nagar/ Kasganj (0.2) |

A training package has been developed for Medical Officers and Community Health Workers and other paramedical staff in primary care settings. The training focuses on chronic care, team care, and use of treatment card for documenting the clinical and lifestyle modifications counselling provided to patients enrolled in the study and to monitor disease control status of patients put on treatment.

The training packages and training of trainers for 8 study sites in India has been conducted. In addition, the training of providers of the intervention block in 7 districts in India has been completed. After successful implementation of the project the training package will be handed over to the state and district officials for training of providers. Consultation meeting with state NCD officers was held and an expert group meeting was completed for finalization of study tools and sample size for intervention component.



Stakeholder meeting - State NCD officers, May 2024



Baseline data collection in Hisar District, Haryana



Session for Training of Trainers (TOT), NCDIR, Feb 2025



Training of MOs and CHOs in North Tripura District, Tripura



Trainina of MOs and CHOs in Yadair district, Karnataka

NON-COMMUNICABLE DISEASES

ONGOING PROJECTS / ACTIVITIES

1. Health Technology Assessment in India

Background:

Health Technology Assessment in India (HTAI) is a sub-scheme under the umbrella scheme of Human Resource and Capacity Building under the Department of Health Research (DHR), Ministry of Health & Family Welfare (MoHFW), Government of India to facilitate the process of transparent and evidence-informed decision making in the field of healthcare. The HTAI Resource Centre at ICMR-NDCIR has been entrusted with the responsibility to analyse health technologies viz. medicines, devices and health programmes for its cost-effectiveness, clinical-effectiveness and equity issues by means of Health Technology Assessment (HTA), and in turn help in decision making for an efficient use of the limited health budget and provide people access to the quality health care reducing their out of pocket expenditures (OOPs) on health.

Progress: The following studies have been completed during 2024-25.

| S. No | Title |
|-------|---|
| 1. | A comparison of the cost-effectiveness of HPV (self-sampling and health care provider sampling) versus VIA for cervical cancer screening in India |
| 2 | A systematic review and meta-analysis of clinical performance of urine self-sampling for human papillomavirus (HPV) for cervical cancer screening |
| 3 | Cost Effectiveness of LDCT (Low Dose Computed Tomography) for Lung cancer screening in India: A Markov Modelling study |
| 4 | An umbrella review of systematic reviews on the Low Dose Computed Tomography (LDCT) for lung cancer screening |

1. DHR- 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.

The project has been initiated, and two articles have been published as preliminary work.

Publication details:

1. Kulothungan V, Mascarenhas L, Das P, Mathur P. District-level Epidemiology and Sociodemographic Determinants of Noncommunicable Diseases (NCDs)-Results the National Family Health Survey-5 (2019-21). *Diabetes & Metabolic Syndrome: Clinical Research & Reviews*.2024 Jul 31;18 (7): 103085
2. 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

COMPLETED PROJECTS / ACTIVITIES

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

Project Duration: 01 March 2022 to 31 August 2024

The study focussed to improve the reliability and completeness of mortality data, which is crucial for public health planning, policymaking, and resource allocation. ICMR-NCDIR in collaboration with AIIMS, New Delhi and PHFI, Gurgaon conducted an Implementation Research Study in 6 states (Tripura, Karnataka, Andhra Pradesh, Rajasthan, Delhi and Punjab) between 2022 to 2024.

The main findings of the completeness and quality of MCCD in the six states is presented in below table:

| Variables | Andhra Pradesh | Karnataka | Tripura | Rajasthan | Punjab | Delhi |
|---------------------------------|--|-----------|---------|-----------|--------|-------|
| Nodal Dept for MCCD | Health | DES | Health | DES | Health | DES |
| MCCD Coverage (2020) (%) | 22.3 | 28.7 | 35.3 | 16.3 | 17.2 | 56.6 |
| Minor errors | Time intervals in part I missing (87 - 97% of forms) | | | | | |
| | Part II incomplete / incorrect | | | | | |
| | Use of abbreviations | | | | | |
| | Status of pregnancy or delivery details missing in case of females | | | | | |
| | Manner of death missing | | | | | |
| Major error | Mechanism of death written in any of the lines of part I | | | | | |
| | More than one causes or multiple causes written in any of the lines | | | | | |
| | Improper cause of death | | | | | |
| | Missing data on external causes of death and behaviour & morphology of neoplasms | | | | | |
| | At least one major error was observed in 67-96% of the forms | | | | | |
| Important challenges | Lack of regular training | | | | | |
| | Lack of monitoring and feedback both at the facility level and system level | | | | | |
| | Inadequate understanding of the importance of MCCD among the stakeholders | | | | | |

- Civil registration system (CRS)-MCCD system in the 6 states (Karnataka, Andhra Pradesh, Tripura, Delhi, Rajasthan and Punjab) was well- established but lacking in training and data validation for quality of MCCD.
- Health facilities (public and private) in 12 districts reported limited formal training on MCCD, no review or feedback to the treating doctors writing cause of death and poor internal quality assurance. Clerical and certification errors were common across all health facilities.
- Meetings with stakeholders were conducted in the states of Karnataka, Andhra Pradesh, Tripura and Rajasthan. The important recommendations were to improve capacity of doctors on writing MCCD and improving coverage of non-institutional deaths to strengthen MCCD.



Karnataka - Meeting with stakeholders was chaired by Director, Dept of Health and Family Welfare services, Karnataka, on 17-05-2024.



Tripura-Meeting of Stakeholders on MCCD in Tripura chaired by Director, Health Services and Chief Registrar of Births and Deaths and conducted at Agartala Government Medical College, held on 28-05-2024.



Andhra Pradesh - Meeting of the stakeholders chaired by Spl.Chief Secretary, Department of Health and Family Welfare was held on 20-06-2024



Tripura-Training of doctors on MCCD in Tripura, 26-07-2024 (Dept of Health, Medical Education)

Interventions that were implemented with collaboration with the States:

- a) Training of District Medical or Health Officers in Tripura & Rajasthan
- b) Improve coverage of institutional and non-institutional MCCD through government circulars and interventions: Karnataka, Rajasthan, Andhra Pradesh
- c) Improving and standardizing CRS software (e-Pehchan) in Rajasthan

ONGOING PROJECTS/ACTIVITIES

1. Setting up of a system for Medical Certification of Cause of Death for non-institutional deaths in a selected area of a Taluk of Kolar district, Karnataka: feasibility and validity

Background: This project has been conceptualized to develop a system for cause of death certification (PhyCoD) for non-institutional deaths and test the validity and feasibility of the approach.

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:

Doctors of selected major hospitals in Kolar taluk and PHC medical officers and private practitioners of two 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 study would facilitate

- 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

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

Tamil Nadu

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.

Quality checks, data analysis tables, statistical tables of MCCD report were discussed with the team members of the Directorate of Public Health. Software support to the Tamil Nadu to develop these will be provided. In addition, discussion to include the WHO Digital Open Rule Integrated Cause of death selection was held with the Tamil Nadu team.

Karnataka

In collaboration with the Regional Office of Health and Family Welfare, Bengaluru, training sessions on MCCD was conducted for medical officers and doctors of Department of Health & Family Welfare, Karnataka. Training on MCCD was provided to Medical Officers of Dept of Health (Belagavi and Kalaburagi Divisions), on importance of MCCD and the guidelines to complete MCCD for in-hospital deaths.

3. Conduct an implementation pilot of the MCCD audit framework in selected health facilities in India

The project objectives were to standardise the system of cause of death recording and reporting in health facility through the implementation of the MCCD audit framework in select hospitals, evaluate the performance and propose recommendations for scaling up MCCD audit.

Methods:

The implementation research study was conducted in three participating centres of AIIMS Raipur, JIPMER, Puducherry, and St. John's Medical College Hospital, Bengaluru. These hospitals implemented the MCCD audit system from October 2024 to April 2025 to assess the types of errors and understand the practices in different departments. Forms were reviewed to verify completeness and accuracy of cause of death by the audit committee. The MCCD e-audit-tool was used by the centres for monthly audits and generating the MCCD quality score. The process of implementation was assessed using the RE-AIM framework.

Results:

Overall quality of MCCD grading improved from 40% at baseline to 75% at end assessment. RE-AIM framework assessment described the penetration of the intervention. Most doctors shared that they are aware of the importance of writing accurate MCCD through this study. Long term sustainability of MCCD quality was envisaged through periodic training of post graduate doctors and conducting MCCD audit with death audit or review meetings.

The main recommendations to scale up the use of MCCD audit framework include:

1. Committed leadership to facilitate MCCD audit systems and assigning roles for nurses to conduct review for completeness, doctors to check accuracy of cause of death, and MRD staff in ICD coding.
2. Capacity building on MCCD to be integrated within the routine training programmes and departmental or hospital meetings like mortality audit or death review meetings.
3. Integration of monthly MCCD audit within existing periodic mortality/death review committees of departments or institutions. Institutional mortality audit systems shall evaluate MCCD along with the discussion of cause of mortality.
4. Standard formats for death summary and good clinical practices in writing death summary with sequence of events of cause of death that are consistent with MCCD need to be implemented.

OTHER PROJECTS / ACTIVITIES

COMPLETED PROJECTS /ACTIVITIES

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

Project duration: 03 March 2022 to 03 August 2024

Brief background: This is a multicentric study coordinated by ICMR Headquarter, conducted among fully vaccinated (i.e. who have received two doses of COVISHIELD/COVAXIN) individuals working in different ICMR institutes in India. The primary objective was to characterise SARS-CoV-2 specific humoral and cellular immune response after homologous precautionary third dose of COVISHIELD/COVAXIN vaccine at different time points (zero, one, three, six, twelve, fifteen, eighteen and twenty-four months) and to estimate the incidence of SARS -CoV-2 symptomatic infection post third dose of COVID-19 vaccine.

Progress: A total of 19 staff of ICMR NCDIR participated in the cohort study, with a follow-up rate of 17/19 (89.5%).

2. ICMR Capacity Building Programme for Disease Burden Estimation

Project duration: 1 September 2023 to 30 November 2024

This training programme is a collaborative effort between the ICMR, PHFI and IHME, aimed at enhancing the expertise of ICMR scientists in disease burden estimation in India. Through an intensive year-long programme, select ICMR scientists have undergone comprehensive training in disease burden estimation as relevant for India.

The mentees were trained to prepare high-quality scientific manuscripts for publication along with policy brief facilitating the practical utilization of research outcomes within India, and dissemination of findings to policymakers, media, and other stakeholders.

Mentees are now considered as Co investigators for the project under National Disease Modelling Consortium titled “Developing India-Specific Models to Estimate and Project Disease Burden for the Control and Elimination of Priority Diseases”

ONGOING ACTIVITIES

1. Internship

ICMR NCDIR is offering internships in the disciplines of epidemiology and public health system- non-communicable diseases, medical statistics, and data science for periods ranging from two to six months. Internship at ICMR NCDIR is very structured, each intern works under the close supervision and guidance of a mentor. The intern makes a presentation to the scientists and submits a written report of the work done at NCDIR at the end of the internship.

Key progress: For the period 01 Jan 2024 to 31 March 2025, a total of 23 students pursuing master’s degree in public health/ Biostatistics/ Data science/Information Technology/Computer Applications joined and benefitted from the internship program.

2. Communication, Outreach, Public Engagement (COPE) at ICMR-NCDIR

The unit was engaged in posting Social Media messages on important scientific and health awareness days, events and scientific publications on X, Instagram and Facebook. It also posted career opportunities and social media messages on the official LinkedIn account of ICMR-NCDIR.

The media outlets have quoted findings from ICMR-NCDIR studies on various noncommunicable diseases (NCDs). Coverage included cancer statistics in general, as well as specific cancers like oral, breast, cervical, bone and blood cancer, and childhood cancer. Studies on diabetes, hypertension and cardiovascular diseases have also been highlighted. Articles discussing tobacco use, obesity and physical inactivity as risk factor for cancer have cited the Institute’s work. In addition, local media reported on workshops and meetings conducted by our network partners in which ICMR-NCDIR participated.

Summary of social media posts for the year 2024-25

| Social Media | No. of Posts | Likes/ Views |
|--------------|--------------|--------------|
| X | 45 | 486/27983 |
| Instagram | 47 | 339 |
| Facebook | 32 | 122 |
| LinkedIn | 18 | 449 |

A video on Women Scientists of NCDIR which highlighted the essence of their journey as a Scientist was prepared and uploaded on the Institute's website on the occasion of International women's day. Another video on the activities carried out as a countdown to International Yoga day was posted on Instagram. ICMR NCDIR had about 31 media mentions during this period.

PUBLICATIONS / REPORTS/ GUIDELINES / BOOKS / POLICY

2024-25

1. Vijayakumar S, Narayan PK, Kumari S, Ranjan R, Kumar V, Kumar A, Alti D. A review of non-invasive samples and tools in kala-azar diagnosis and test of cure. *Exp Parasitol*. 2024 Apr;259:108713. doi: 10.1016/j.exppara.2024.108713. **(IF: 1.6)**
2. 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 May 15;130(10):1816-1825. **(IF: 5.1)**
3. Kulothungan V, Nongkynrih B, Krishnan A, Mathur P. Ten-year risk assessment for cardiovascular disease & associated factors among adult Indians (aged 40-69 yr): Insights from the National Noncommunicable Disease Monitoring Survey (NNMS). *Indian J Med Res*. 2024 May;159(5):429-440. **(IF: 2.5)**
4. 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 Jun;205(2):323-332. **(IF: 3.0)**
5. Vijayakumar S, Kumar LL, Borkotoky S, Murali A. The Application of MD Simulation to Lead Identification, Vaccine Design, and Structural Studies in Combat against Leishmaniasis - A Review. *Mini Rev Med Chem*. 2024;24(11):1089-1111. **(IF: 3.3)**
6. Stuart RM, Cohen JA, Kerr CC, Mathur P; National Disease Modelling Consortium of India; Abey Suriya RG, Zimmermann M, Rao DW, Boudreau MC, Lee S, Yang L, Klein DJ. HPVsim: An agent-based model of HPV transmission and cervical disease. *PLoS Comput Biol*. 2024 Jul 5;20(7):e1012181. doi: 10.1371/journal.pcbi.1012181. **(IF: 3.6)**
7. Ramamoorthy T, Kulothungan V, Mappillairaju B. Exploring stroke discourse on Twitter through content and network analysis among Indian users. *Sci Rep*. 2024 Jul 2;14(1):15204. doi: 10.1038/s41598-024-65858-9. **(IF: 3.9)**
8. Ramamoorthy T, Kulothungan V, Sathishkumar K, Tomy N, Mohan R, Balan S, Mathur P. Burden of cervical cancer in India: estimates of years of life lost, years lived with disability and disability adjusted life years at national and subnational levels using the National Cancer Registry Programme data. *Reprod Health*. 2024 Jul 29;21(1):111. doi: 10.1186/s12978-024-01837-7. **(IF: 3.4)**
9. Kulothungan V, Mascarenhas L, Das P, Mathur P. District-level epidemiology and sociodemographic determinants of noncommunicable diseases - results the National Family Health Survey -5 (2019-21). *Diabetes Metab Syndr*. 2024 Jul;18(7):103085. doi: 10.1016/j.dsx.2024.103085. **(IF: 3.4)**

10. Nath A, Mathew S, Pant A, Thadi Y. The clinical effectiveness of telemedicine for managing type 2 diabetes in India: a meta-analysis of the impact of telemedicine with clinic visits. *J Diabetes Metab Disord*. 2024 Jul 27;23(2):2095-2104. **(IF: 1.6)**
11. Sankarapillai J, Krishnan S, Ramamoorthy T, Sudarshan KL, Mathur P. Descriptive epidemiology of prostate cancer in India, 2012-2019: Insights from the National Cancer Registry Programme. *Indian J Urol*. 2024 Jul-Sep;40(3):167-173. **(IF: 0.9)**
12. Allemani C, Silva GAE, Mathur P, Coleman MP. The CONCORD-Lancet Global Commission on Cancer. *Lancet*. 2024 Jul 27;404(10450):320-322. **(IF: 88.5)**
13. Srinivas V, Jha P K, Singh S, Sanjay K. Prevalence and predictors of cancer among older adults in india, by place of residence: findings from longitudinal ageing study in india (lasi) wave -1. *International Journal of Medicine and Public Health*. 2024 Jul-Sep;14(3):1082-1091. **(IF: NIL)**
14. Mathur P, Ramamoorthy T, Lakshminarayana SK, Nath A, Mathew S, Rajput GK. Utilization of clinical practice guidelines for cancer care in routine practice and during the coronavirus disease 2019 pandemic in India. *Asia Pac J Clin Oncol*. 2024 Aug;20(4):507-514. **(IF: 1.6)**
15. Kulothungan V, Ramamoorthy T, Sarveswaran G, Jadhav SY, Mathur P. Association of Tobacco Use and Cancer Incidence in India: A Systematic Review and Meta-Analysis. *JCO Glob Oncol*. 2024 Aug;10:e2400152. doi: 10.1200/GO.24.00152. PMID: 39173081. **(IF: 3.0)**
16. Sarveswaran G, Kulothungan V, Rangamani S, Huliappa D, Sreekantaiah P. Assessment of burden of prediabetes and diabetes with oral glucose tolerance test in community-based settings of Bengaluru rural district. *J Family Med Prim Care*. 2024 Sep;13(9):3806-3814. **(IF: 1.0)**
17. Kumari S, Vijaykumar S, Kumar V, Ranjan R, Alti D, Singh V, Ahmed G, Sahoo GC, Pandey K, Kumar A. In silico and in vitro evaluation of the immunogenic potential of *Leishmania donovani* ascorbate peroxidase and its derived peptides. *Acta Trop*. 2024 Dec;260:107381. doi: 10.1016/j.actatropica.2024.107381. **(IF: 2.5)**
18. Nath A, Taneja R, Thadi YS, Sarveswaran G, Mathur P. A comparative study of incidence, mortality and disability adjusted life years (DALYs) for leading cancers in BRICS countries. *Ecancermedicalscience*. 2024 Sep 19;18:1773. doi: 10.3332/ecancer.2024.1773. **(IF: 1.3)**
19. NCD Risk Factor Collaboration (NCD-RisC). Worldwide trends in diabetes prevalence and treatment from 1990 to 2022: a pooled analysis of 1108 population-representative studies with 141 million participants. *Lancet*. 2024 Nov 23;404(10467):2077-2093. **(IF: 88.5)**
20. Bolio A, Waheed DE, Mugo N, Garland SM, Wanyoike S, Njambe Tondo Opute E, Singh K, Mathur P, Touray K, Bhatla N, Assad F, Zalalem M, Stanley M, Karafillakis E, Burdier FR, Kumar Das M, Arora NK, Limaye R, Vorsters A. Overview of CHIC symposia series: Summary of Africa and South Asia symposia. *Vaccine*. 2024 Jul 11;42 Suppl 2:S9-S15. doi: 10.1016/j.vaccine.2023.10.063. **(IF: 3.5)**
21. Malik A, Sudhir P, Prathyusha PV. Client factors influencing adherence to homework in psychotherapy: Findings from a tertiary care setting in India. *Journal of Rational-Emotive & Cognitive-Behavior Therapy*. 2025 Mar;43(1):9. **(IF: 1.4)**

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

| S. No | Description |
|-------|---|
| 1. | Working Group Meeting for Patterns of Care and Survival Studies, 02 April 2024 |
| 2. | Meeting with officials of Pondicherry Government regarding setting up of cancer atlas, 04 April 2024 |
| 3. | Workshop on Evidence synthesis for NCD control, 16 April 2024 |
| 4. | Meeting regarding data sharing between NCDIR and NDMC, 19 April 2024 |
| 5. | <p>a) State level Meeting with Stakeholders on strengthening Medical Certification of Cause of Death (MCCD) with Karnataka - 17 May 2024 ; Tripura - 28 May 2024; Rajasthan - 24 July 2024 and 25 October 2024</p> <p>b) Meeting of the Stakeholders on 'Strengthening the Medical Certification of Cause of Death (MCCD) Practices in Public and Private Healthcare Facilities in India' in collaboration with Government of Andhra Pradesh, 20 June 2024</p> <p>c) Meeting with collaborating institutes on MCCD study, 20 August 2024</p> <p>d) Meeting with NIC Rajasthan to discuss e-pehchan software for MCCD, 06 November 2024</p> <p>e) Technical Advisory committee meeting - Study on MCCD Audit, 04 September 2024 and 19 March 2025</p> <p>f) Training on Strengthening Medical certification of cause of death in collaboration with concerned state authorities / institutions</p> <ul style="list-style-type: none"> • Tripura on 26th July, 2024 • AIIMS, Raipur on 7th and 8th November 2024 • Jaipur on 28th and 29th November 2024 • St. Johns Medical College, Bengaluru, 2nd and 3rd December 2024 |
| 6. | Training Visit of Postgraduates of Community Medicine of Amrita Institute of Medical Sciences, Kochi to ICMR – NCDIR, Bengaluru, 27 May 2024 |
| 7. | Sensitization training on the Hospital Based Cancer Registries for the Staff under Armed Forces Medical Services, 29 May 2024 |
| 8. | Meetings with Koita Centre for Digital Oncology (KCDO) regarding <p>a) Cancer Registry, 29 May 2024</p> <p>b) API for data transfer, 17 December 2024</p> <p>c) Overview on NCDIR activities, 12 March 2025</p> |
| 9. | Expert meeting on estimation of radiotherapy machines for India, 03 June 2024 |
| 10. | PBCR Review meeting, 06 and 07 June 2024; 26 July 2024 |
| 11. | Meeting regarding Setting up a National Paediatric Stroke Registry on 12 June 2024 |
| 12. | Training for the staff of participating hospitals of Andhra Pradesh Cancer Atlas project, 25th June 2024, 12 November 2024, 23 October 2024 and 03 January 2025 |

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| 13. | Meeting with Program team of National Viral Hepatitis Control Program (NVHCP) regarding integration of NVHCP with NCRP, 28 June 2024 |
| 14. | Meetings on establishment of State Cancer Registry in Himachal Pradesh on 02 July 2024 and 06 February 2025; Training 06 March 2025 |
| 15. | Training on Implementation of e-Notification application for PBSR a) Tirunelveli, 02 July 2024 b) Kota, 10 July 2024 c) Cachar, 21 August 2024 |
| 16. | Training workshop for Hospital Based Stroke registry centres conducted on c) 19 June 2024, 3 July 2024, 26 to 27 September 2024, 04 October 2024, 12- 13 November 2024, 05 to 06 December 2024, 19 December 2024, 23 December 2024, and 28 February 2025 |
| 17. | Training of the centres on the revised DIAMOnDS Core form, 16 July 2024 |
| 18. | National Stroke Review Meeting, 18 July 2024 and 19 September 2024 |
| 19. | Workshop on Estimation of Healthy Life Expectancy in India, 05 and 06 September 2024 |
| 20. | Training for the Nodal Institutions on Situational Analysis of Cancer Care Services in India, 10 September 2024 |
| 21. | Swachhata Divas followed by felicitation of Safai Mitras/Sanitation Workers, 01 October 2024 |
| 22. | Meeting regarding Rajasthan Cancer Atlas, 01 October 2024 and 30 December 2024 |
| 23. | Cyber security webinar, 15 - 18 October 2024 |
| 24. | Week-long Residential Training of HCBR and PBCR staff at ICMR-NCDIR, Bengaluru from November 2024 till March 2025 – 12 HCBRs and 16 PBCRs in 7 batches |
| 25. | Hindi Pakhwada Samaroh, 06 November 2024 |
| 26. | Training of Government of Karnataka (GoK) Medical Officers regarding Health Technology Assessment (HTA), 08 November 2024 |
| 27. | HBCR Data Review Meetings a) SGPGI, Lucknow on 16 November 2024 b) Chennai on 09 January 2025 c) BBCL, Guwahati on 04 February 2025 d) Thiruvananthapuram on 21 February 2025 e) Nagpur on 28 February 2025 f) Bengaluru on 10 March 2025 |
| 28. | Meeting of the Scientific Advisory Committee (SAC) of ICMR-NCDIR, Bengaluru, 27th November 2024 |
| 29. | a) POSH - Internal Complaints Committee Meeting, 13 December 2024 Sensitization training for staff regarding prevention of sexual harassment, 29 January 2025 |
| 30. | b) Multi-Stakeholders workshop on Strengthening Civil Registration and Vital Statistics in Odisha, 27 December 2024 |
| 31. | Meeting regarding Real world Data and Real-world Evidence on 22 January 2025 |
| 32. | AcSIR orientation for students, 23 January 2025 |

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| 33. | Scientific Symposium - Annual Day of ICMR-NCDIR, on 24 January 2025 |
| 34. | <p>a) Orientation meeting for the project Implementation research to improve clinical outcomes of diabetes and hypertension</p> <ul style="list-style-type: none"> • State level stakeholders of Karnataka & Tripura state. - 03 April 2024 • Medical colleges - 04 April 2024 • NCD District program officers – 24 April 2024 • State program officers - 03 May 2024 • Medical colleges, 31 December 2024 and 01 January 2025 <p>b) Meeting with participating centres for the project Implementation research to improve clinical outcomes of diabetes and hypertension, 09 October 2024</p> <p>c) Expert group meetings for the project on Implementation research to improve clinical outcomes of diabetes and hypertension, 31 May 2024, 05, 11 and 13 December 2024</p> <p>d) Trainings for the project on Implementation Research project - Implementation research to improve clinical outcomes of diabetes and hypertension cases by empowering public and private sector primary care physicians in India</p> <ul style="list-style-type: none"> • Training on baseline data collection, 05 November 2024 • Team members and site investigators – 05 November 2024 to 06 November 2024 • Supportive supervision – 11 November 2024 • Discussion on baseline survey, 03 January 2025 • Discussion on baseline survey analysis, 07 January 2025 • Discussion on survey coverage (Gadchiroli), 17 January 2025 • Medical College faculty (TOT) - 31 January 2025 to 01 February 2025 • Training of baseline data collectors (IR Study), 07 February 2025 • Discussion on Training of Providers at Facility Level, 10 February 2025 • Medical Officers and CHOs of Hisar district, Haryana– 17 February 2025 to 18 February 2025 • Paramedical staff (ANM., MPW and staff nurses) of Hisar district, Haryana - 19 February 2025 • Medical Officers and CHOs Charki Dadri district, Haryana – 20 – 21 February 2025 • Paramedical staff (ANM., MPW and staff nurses) on lifestyle management to improve clinical outcomes of diabetes and hypertension, charki Dadri, Haryana - 22 February 2025 • Medical officers and CHOs of, North Tripura District, Tripura - 24 -25 February 2025 • Medical Officers and CHOs of Gadchiroli district, 06 March 2025 • Discussion on baseline survey coverage, 10 March 2025 <p>e) Meeting with State & District NCD officers and Site PI for the project on Implementation research to improve clinical outcomes of diabetes and hypertension on 30 January 2025</p> <p>f) Meeting with Voluntary Health Association, Tripura, 7 March 2025</p> |
| 35. | Institutional Ethics Committee meeting on 22 August 2024, 27 January 2025 and 18 February 2025 |
| 36. | Meeting with National Health Authority, 28 January 2025 and 20 February 2025 |
| 37. | Training programme on “Family of International classification (ICD-10 & ICF) on 30th, 31st Jan 2025, 25th and 27th Feb in collaboration with the Regional Office for Health and Family Welfare, Bengaluru for the medical and non-medical personnel involved in the work of medical records / health statistics |
| 38. | Technical committee meeting for cancer registry in Odisha, 04 February 2025 |

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| 39 | Meeting with Indian Cancer Society, Karnataka, 5 February 2025 |
| 40 | AcSIR Director & Coordinators meeting, 04 February 2025 |
| 41 | Cyber Security Awareness Session, 18 February 2025 |
| 42. | Discussion with TN-DPH on e-Mor software, 07 February 2025 |
| 43. | PBSR meeting and training workshop, 07 February 2025 and 06 March 2025 |
| 44 | AcSIR Academic Committee Meeting, 11 February 2025 |
| 45. | Meeting with Deputy Director and team, NPCDCS, Govt of Karnataka regarding the way forward for development of Cancer care plan and state based cancer atlas in Karnataka 17 February 2025 |
| 46. | Data review meeting for situational analysis of cancer care services in India from 25 February 2025 to 28 February 2025 04 March 2025 to 05 March 2025 and 07 March 2025 |
| 47. | Discussion with Bhagwan Mahaveer Cancer Hospital & Research Centre, Jaipur, 04 March 2025 |
| 48. | Discussion of the project on Development and evaluation of quality indicators as benchmarking tools to improve cervical cancer care practices in India Delphi Round 1 Results, 06 March 2025 |
| 49. | Meeting on Digital personal data protection Act, 11 March 2025 |
| 50. | Turnitin iThenticate onboarding Admin Training, 17 March 2025 |
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