

Collaborate Innovate Inspire



ANNUAL HIGHLIGHTS

2022 - 23



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KEY ACHIEVEMENTS

- 1. Report on Monitoring Survey of Cancer Risk Factors and Health System Response in North East Region (NER) was released on 4 February 2022. Accordingly, the reports of individual states of the Northeast region were released by the officials of the respective States during 2022-23.
- 2. ICMR-NCDIR in collaboration with the National Health Authority (NHA) released a working paper "Patterns of Stroke Care in AB PM-JAY beneficiaries in empaneled hospitals of PM-JAY Scheme" on 20 June 2022 on the patterns of stroke, stroke care and outcomes in beneficiaries treated in empaneled hospitals of the Ayushman Bharat Pradhan Mantri Jan Aarogya Yojana (AB PM-JAY) scheme. The paper has provided insights for strengthening data inputs in the AB transaction system by the addition of standard variables from the Hospital based Stroke registry of ICMR-NCDIR.
- 3. ICMR NCDIR and International Agency of Research on Cancer (IARC), Lyon have signed an MOU on 2 September 2022 for mutual goal to promote and conduct high-quality research to strengthen the cancer registry program and build evidence-base towards cancer prevention and control.
- 4. The 'Framework for audit of medical certification of cause of death at health facility' developed in collaboration with the World Health Organization (WHO, India), and the Central Bureau of Health Intelligence, Ministry of Health and Family Welfare was released on 15 September 2022. The framework facilitates process of review of MCCD forms to reduce errors in MCCD certification and build MCCD audit system at health facility.
- 5. Report on "A Situational Analysis of Childhood Cancer Care Services in India" prepared by ICMR-NCDIR in collaboration with the Directorate General of Health Services, Ministry of Health & Family Welfare and the World Health Organization, India was released on 27 September 2022. The findings of the report emphasize the need to formulate a childhood cancer policy that will enable timely diagnosis, treatment, supportive care, and follow-up through well-defined care pathways.
- 6. Monograph of "ICMR-NCDIR: A decade of research: impacting NCD public health actions" was released on 27 September 2022. The report depicts the work done and the achievements of the Institute during the last decade.
- 7. ICMR Bioethics Unit's capacity building interactives such as FAQs, animated videos and educational movies were released on 27 September 2022.
- 8. ICMR NCDIR has signed MOU with the State of Andhra Pradesh in December 2022 to set up cancer registry in the state to strengthen evidence base for cancer prevention and control.
- 9. International prize: Mrs. Thilagavathi R, Scientist B, ICMR-NCDIR won the Sharon Whelan Prize in the IACR International Scientific Conference 2022 for the paper titled, 'Utilization and adherence to clinical treatment guidelines in cancer care during COVID-19 pandemic in India'.

CANCER

COMPLETED PROJECTS / ACTIVITIES

1. A Situational Analysis of Childhood Cancer Care Services in India – 2022

Childhood cancers contribute substantially to the total cancer burden. Evidence of the status of childhood cancer care services in India is necessary for planning of health services. The report on 'A Situation analysis of childhood cancer care services in India' prepared by ICMR - NCDIR in collaboration with the Directorate General of Health Services, Ministry of Health & Family Welfare and the World Health Organization (India office) was released on 27th September 2022 by Dr Bharati Pravin Pawar, Honourable Minister of State for Health & Family Welfare.

Fig 1: Release of Report on 1.A Situational Analysis of Childhood Cancer Care Services in India-2022



The situational analysis was conducted using a cross-sectional survey of 137 tertiary-level hospitals, 92 secondary-level hospitals, 16 State Nodal Officers/NPCDCS officers and 9 Civil Society Organizations/Non-Governmental Organizations (CSOs/NGOs) in 26 states and 4 union territories (UT). The report highlights the need of the hour for formulating a childhood cancer policy to enable timely diagnosis, treatment, supportive care, and follow-up through well-defined care pathways. Integration of childhood cancer as a part of the national cancer control response is to be taken up as a matter of priority.

The report is available at:

https://www.ncdirindia.org/All Reports/Childhood Cancer/Default.aspx

2. Release of State wise reports on 'Monitoring survey of cancer risk factors and health system response'n the Northeast Region (NER)

The reports on 'Monitoring survey of cancer risk factors and health system response', were released in the eight states of Northeastern region in coordination with State Government authorities. The reports provided a descriptive profile of the prevalence of cancer and other NCD-related risk factors such as tobacco use, alcohol use, diet, physical activity, overweight / obesity, diabetes, hypertension, care-seeking behaviour, access to care and health system preparedness to address all NCDs' including cancer.

State	Released by	
Manipur	Dr. Ningombam Somorjit, State Mission Director, State Health Society, NHM, Govt. of Manipur	Release of Report on Monitoring Survey of Cancer Risk Factors and Health System Response in North East Region (NER) Mariner
Arunachal Pradesh	Dr. Sharat Chauhan, Principal Secretary, Dept. of Health & Family Welfare, Govt. of Arunachal Pradesh	SALES CONTROLLED TO THE PARTY OF THE PARTY O
Mizoram	Dr. R. Lalthangliana, Hon'ble Health Minister, Govt. of Mizoram	
Meghalaya	Shri Sampath Kumar, Principal Secretary, Dept. of Health & Family Welfare, Govt. of Meghalaya	
Tripura	Sri Pranab Sarkar, Secretary, Agartala Press Club	Cartur Rish y actors at Topon PNESS RE EASE Lest Of All Control of
Nagaland	Shri S Pangnyu Phom, Hon'ble Health Minister, Govt. of Nagaland	AGALAND HEREN LL. SCHOOL OF THE SECOND CONTROL OF THE SECOND CONTR
Sikkim	Dr M.K.Sharma, Hon'ble Health Minister, Govt. of Sikkim	
Assam	Dr Nilmadhab Das, Director of Health Services, Assam	

Fig 2: Release of State wise report on 'Monitoring survey of cancer risk factors and health system response'

The Reports can be accessed at: https://ncdirindia.org/All_Reports/ner2022/Default.aspx

The evidence shall support the planning of awareness, health protection, prevention of NCD risk factors and strengthen capacity building.

3. CaRes NER - A Multidisciplinary Research Programme for prevention and Control of Cancer in the North Eastern States in India - Call for proposals 2022

The CaRes NER programme aims to address the rising incidence of cancer in the Northeast Region (NER) by encouraging the submission of proposals which focus on research with implications for strengthening health systems, programmes and policies concerning cancer control. Two studies were approved for funding in 2022.

- Pattern of health expenditure by cancer patient at different stages of cancer care & economic burden on household and the local economy - A study among the patients with breast cancer, cervical cancer, and lung cancer in the NER.
- Effectiveness of self-help groups for breast and tobacco-related cancer prevention in Meghalaya: a quasi-experimental study.

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

The study was conducted between 1st March 2017- 31st March 2023.

The objectives of the study included (i) to estimate demographic and disease-free survival for Childhood, Haematolymphoid and Gynecological malignancies (except cervix uteri). (ii) to assess the epidemiological and clinical determinants of survival for these three cancers.

This study was conducted in the following eight hospitals of the cancer registry network in Delhi, Mumbai, Bangalore, Chennai and Thiruvananthapuram where cancer patients were diagnosed and treated.

No	Centre Name
1.	Cancer Institute (WIA), Chennai
2.	Dr B R Ambedkar Institute Rotary Cancer Hospital, New Delhi
3.	Kidwai Memorial Institute of Oncology, Bengaluru
4.	Medanta Cancer Centre, Gurugram
5.	Rajiv Gandhi Cancer Institute and Research Centre, New Delhi
6.	Vydehi Institute of Medical Sciences, Bengaluru
7.	Regional Cancer Centre, Thiruvananthapuram
8.	Tata Memorial Hospital, Mumbai

(i) Key findings from analysis of POCSS Haematolymphoid cancer:

- Out of the 3408 cases included in the study, 31.7% belonged to 0-19 age group, and 68.3% were above 20 years.
- Lymphoid leukemia (52.8%) was the most common in age group 0-19 years and Myeloid leukaemia was the most common (30.2%) haematolymphoid cancer in age group > 20 years.
- Among males, approximately 22.7% in the age group of 0-19 years, and 36.5% of cases in the age group of >20 years were diagnosed at stage IV. In females, 20.8% in the age group of 0-19 years and 36.9% in the age group of >20 years were diagnosed at stage IV.
- The 3-year cumulative survival is 96% for lymphoma and 82% for leukaemia among males, 94% for leukaemia among females.

(ii) Key findings form analysis of POCSS Gynaecologic cancer cases:

- A total of 1815 gynecologic cancers were included in the study. The cancer types were ovarian (73.8%), uterine (22.2%) and vaginal (2.2%) cancers.
- Histologically endometrioid carcinoma (39.6%) and chorioepithelioma (22.4%) were the commonly detected uterine cancers.
- Serous carcinoma (42.7%), adenocarcinoma (24.1%) and carcinoma (3.7%) were the most common ovarian tumor types.
- Among uterine cancer cases, 46.6% were in Stage I and 10.3% detected in stage III. In ovarian cancers, 57.1% were in stage III and 23.9% of the cases were detected in stage IV.
- Median survival rate for corpus uteri cancer was 15 months and for ovarian cancer was 20 months.

ONGOING PROJECTS / ACTIVITIES

1. Population Based Cancer Registries (PBCR)

PBCRs collect data on cancer incidence and mortality in their respective geographic areas on a continuous basis. They provide information on burden and trends of cancer in the population over time and projected future estimates of incident number of cases. There are 38 PBCRs functioning under NCRP (Fig 3). The activities coordinated by ICMR - NCDIR are depicted in Fig 3.



Fig 3: Activities of PBCR

Submission of data of 28 Population based cancer registries for the Cancer Incidence in Five continents (CI5) Vol. 12 - International Agency for Research Against Cancer (IARC) - WHO

Submission of data by PBCRs under NCRP to the CI5 data is done periodically which eventually becomes part of GLOBOCAN data from India. Data of years 2013-2017 was scrutinised in detail and submitted to IARC. Questionnaires and introductory text submitted by registries were reviewed/redesigned for the sake of uniformity under the umbrella of NCRP in consultation with the registries. A write up on NCRP and its contributions was submitted for inclusion in the upcoming volume of 'Cancer incidence in five continents'.



Fig 4: PBCR Network

PBCR Data status (31 March 2023):

Year	No of PBCRs	Under Process	Partial Submission	Data Finalized
2015	30	0	1	29
2016	32	4	1	27
2017	33	20	4	07
2018	35	17	9	01
2019	35	6	8	-
2020	38	-	4	-
2021	38	-	4	-

2. Hospital Based Cancer Registries

Cancer surveillance is an essential part of cancer prevention and control efforts. The specific objectives of this project include describing the cancer patterns in the hospital, clinical, pathological, and treatment-related details of cancer patients, contributing to active follow-up of the cancer patient; describing survival by anatomical site, clinical stage and types of treatment and to help assess the quality of hospital cancer care. HBCRs contribute to the Population-Based Cancer Registries in the given area. 213 HBCRs are functioning across the country as of March 2023.

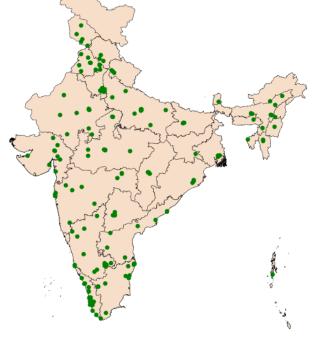


Fig 5: Network of HBCRs

Activities under HBCRs

- 1. Online trainings were conducted for the new HBCRs on 19th May 2022, 15th Dec 2022 and 20th Feb 2023.
- 2. Data review meeting was conducted on 16th and 17th March 2023 for Regional Cancer Centres / Tertiary Cancer Care Centres / State Cancer Institutes.
- 3. A study on patterns of care and survival of head and neck, breast and cervical cancers in India under the Hospital Based Cancer Registries of National Cancer Registry Programme.

Background:

Cancers of the head and neck, breast and cervical cancers are the most commonly occurring cancers in India. The Patterns of Care and Survival Studies (POCSS) for the three cancers were initiated by ICMR - NCDIR in 2006, and currently 93 centres are transmitting data. The study is approved at the centres which have been transmitting good quality data with ongoing recruitment of cases and follow up. The specific objectives are to determine hospital-based patterns of care in terms of diagnosis and treatment and estimate overall and disease-free survival of patients with these cancers. The findings will aid clinicians and public health experts in evidence-based decision making and contribute towards 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.



Fig 6: Participating centres for POCSS (Breast, Cervix & Head & Neck cancers)

Training activities under POCSS Breast, Cervix and Head and Neck

• Data review meeting was conducted on 16th and 17th March 2023 for Regional Cancer Centres / Tertiary Cancer Care Centres / State Cancer Institutes.

4. Rajasthan Cancer Atlas (RCA)

Cancer was declared as notifiable disease in the state of Rajasthan in July 2019. Knowing patterns of cancer would provide important leads in undertaking etiological research, in targeting cancer control measures and in examining clinical outcomes. A health systems approach is necessary for cancer prevention and control. The Dept. of Health and Family Welfare, Govt. of Rajasthan in collaboration with ICMR-NCDIR has initiated this project to create a statewide cancer describe registration system to similarities and differences in patterns of cancer across the state. This would be done with optimum use of software and electronic transmission of data to NCDIR. Through this project, participating centres can add to cancer prevention, referral and timely treatment initiation which will ultimately reduce cancer burden. A total of 80 hospitals have registered.



Fig 7: District map of Rajasthan

Trainings:

- 1. Online training for the District Nodal Officers of Rajasthan State on 23rd August 2022.
- 2. Sensitization training on the concept of cancer registry to District Nodal Officers and the registered hospitals in Rajasthan State on 20th September 2022.

5. Population Based Cancer Registry-Population Based Cancer Survival on Cancers of Breast, Cervix and Head & Neck

The project was initiated in 2017 to generate reliable data on population-based cancer survival in cancers of the breast, cervix and head and 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 to record the overall survival.

- Data for the years 2012-2015 of 11 PBCRs has been submitted to IARC-SURVCAN-Vol IV.
- Manuscript on cervical cancer survival has been submitted to The Lancet Regional Health Southeast Asia.
- Analysis and draft manuscript on Breast and Head & Neck cancer survival is under preparation.

Key findings include:

In India, the five-year Age specified rates (ASRS) (95% CI) of cervical cancer was 51.7 (50.2-53.3). Ahmedabad urban (61.5; 57.4-65.4) had a higher survival followed by Thiruvananthapuram (58.8; 53.1-64.3) and Kollam (56.1; 50.7-61.3).

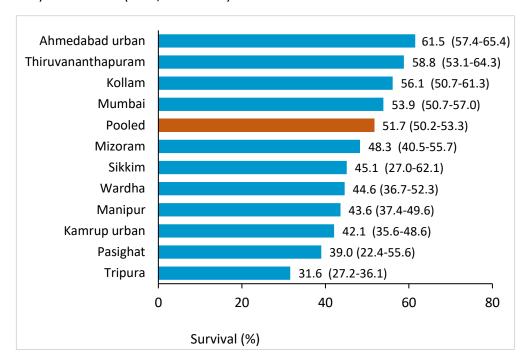


Fig 8: Five-year Age Standardized Relative Survival (ASRS) with Confidence Interval (95% CI) for Cervix cancer across the 11 PBCRs for the years 2012-2015.

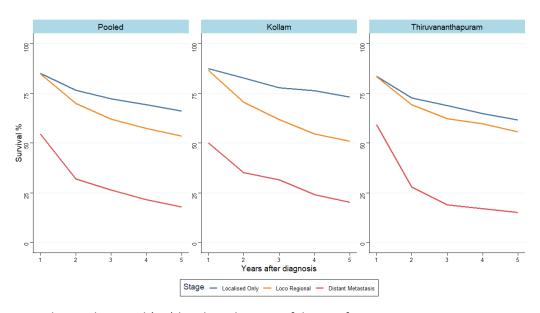


Fig 9: Observed survival (OS) by Clinical extent of disease for Cervix cancer across PBCRs

The five-year overall survival % for pooled PBCRs was (65.9, 53.5, 18.0) for localized, regional, and distant metastasis respectively.

6. Memorandum of Understanding(MoU) with the International Agency for Research on Cancer (IARC), Lyon, France

ICMR-NCDIR and IARC signed an MoU in September 2022 with a mutual goal to promote and conduct high-quality research to strengthen the evidence base towards cancer prevention and control.

Dr. Freddie Bray and Dr. Isabelle Soerjomataram from IARC visited ICMR-NCDIR on 27th February 2023 to further discuss the scope of research activities under this collaboration.



Fig 10: Visit of IARC team to ICMR-NCDIR on 27/02/2023

7. Setting up Cancer Atlas in Andhra Pradesh

The Government of Andhra Pradesh has signed an MoU with ICMR-NCDIR, from December 2022 seeking technical support for developing Andhra Pradesh cancer atlas, which would help pave the way for establishing a fully functional cancer registry.

Atlas Core form is being prepared for data collection and the dashboard for monitoring progress and software for data transmission is under development.

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

This multicentric longitudinal study was initiated in ten hospitals in northern & eastern regions of India. The primary objectives include obtaining a detailed pattern of care (diagnosis and management) for GBCs, estimating demographic (overall) survival for GBCs, identifying the epidemiological and clinical determinants of survival, and estimating their effect.

Ten hospitals contributed data on a total no of 2262 gallbladder cancer patients.

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

Key findings:

- The occurrence of GB cancer was highest in the age group of 55-59 years among males and 45-49 years among females.
- Adenocarcinoma, NOS was the most common histologic type (91.2%).
- Liver was the most common secondary site of GBC (76.8%).
- Majority of the Gallbladder cancer cases presented at Stage IV (56.8%) followed by Stage III (23.8%).
- Surgery was the most common treatment modality (54.2%) followed by surgery and chemotherapy (29.2%) in stage I cases. Chemotherapy was the most common treatment modality for stage II (45.2%), stage III (59.4%), and stage IV (82.1%) gallbladder cancer cases.
- Follow up information was available for 94.6% of the GBC cases. Mortality was highest in stage IV (40.3%) followed by stage III (26.5%) cases.
- Stage I (76.5%) had significantly better survival than stage IV (12.1 %) at 2 years.

Activities:

- Data abstraction and entry by the participating hospitals.
- Regular trainings and workshops for the registry staff and interaction with PIs to complete data collection and data quality correction
- Meetings with the centers periodically regarding abstraction and follow-up.

This study will help the clinician and public health experts develop an evidence based decision making algorithm translated into GBC prevention, early detection, and control policies and programmes.

Meetings:

- Preview meeting (virtual) was held by the Expert Group of Task force projects on Gall Bladder Cancer on 10th January 2022.
- Data review meeting of the hospitals was conducted on 10th February 2023

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

This study aims to examine cholecystectomy specimen removed for any preoperative conditions and analyse the prevalence and factors associated with IGBC and other premalignant condition so that an algorithm can be developed for early detection of GBC in India. This multicentric cross-sectional study has been initiated in the following five hospitals having HBCRs in India.

A total of 4739 patients with cholecystectomy have been enrolled into the study from the following hospitals.

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

Key findings:

- Abdominal pain was the commonest presenting feature (94.3%) followed by vomiting (24.1%) among the patients (males – 30.4%, females - 69.6%)
- Calculus of gallbladder with other cholecystitis (ICD10-K80.2) (48.6%) was the commonest pre-op and post-op diagnosis followed by Chronic cholecystitis (ICD10- K81.1).
- Among the 4739 cases included in the analysis, 31 patients had IGBC (0.7%).

The common histology types of cholecystectomy specimens were- Adenocarcinoma was the commonest histologic type (80.6%) among the IGBC cases.

Activities:

- Regular trainings and workshops for the registry staff and interaction with PIs to complete data collection
- Quality assurance activities were carried out by a) review of histopathology slides from all centres by the team from AIIMS, Delhi and b) training workshops organised for pathologists and registry staff of all centres.

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

There are disparities in access to diagnostic and prognostic tests for cancer in India. This study aims to set up zonal molecular oncopathology labs to provide basic, 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.

NCDIR serves as a Data Management Centre for the DIAMOnDS centres with the objectives (i) to facilitate data management for the project (iii) To link the biomarkers in breast and lung cancer test results to the NCRP registry data to facilitate patient management and research.

The following nine tertiary medical institutions have enrolled a total of 3350 cases with breast (56.3%) and lung (43.6%).

Zone	Centre Name		
North	All India Institute of Medical Sciences, New Delhi		
NOTUI	Super specialty Cancer Institute, Lucknow		
	Christian Medical College, Vellore		
South	Jawaharlal Institute of Postgraduate Medical Education & Research,		
	Puducherry		
	Cachar Cancer Hospital and Research Centre, Silchar, Assam		
East	Regional Institute of Medical Sciences, Imphal		
	Tata Medical Center, Kolkata		
West	All India Institute of Medical Sciences, Jodhpur		
VV C3L	Tata Memorial Hospital, Mumbai		

Key findings:

The significant findings from the preliminary analysis of data (1887 cases of breast cancer and 1463 cases of lung cancer) is as follows:

Breast cancer:

- 97.9% were females and 2.1% males.
- Common in the age interval between 45-49 years in females and 50-54 years in males.
- Locoregional (46.5%) was the commonest presentation, followed by localized presentation (21.7%).
- The biomarkers included Estrogen receptor (ER), Progesterone (PR), Her2 and Ki-67/Mb1

Lung Cancer:

- 67.1% were males, 32.8% women and 0.1% belonged to others category
- Common in the age group between 60-64 years in males and 55-59 years in females.
- Distant metastasis (56.5%) was the commonest presentation, followed by locoregional presentation (18.7%).
- The biomarkers included EGFR Mutation positive, ALK Rearrangement positive, ROS1 Re arrangement positive and PDL1 positive.

11. Cancer Epidemiology and Surveillance Training Programme (CanEST)

This training programme was launched in October 2021 with the objective to train research scientists working in population and hospital-based cancer registries to (a) Develop skills to analyse, monitor and infer current registry data more efficiently and initiate and develop a strengthened surveillance system for cancer in a defined geographical area. (b) Develop research protocol for undertaking epidemiological research, both hospital-based and population-based; initiate and oversee all phases of research activity. (c) Comprehend current policies, programmes, and practices and help strengthen Cancer Prevention and Control. (d) Network with the Government Health system, the Private sector, and NGOs in Cancer Prevention and Control.

Key Progress:

Training was conducted at ICMR - NCDIR, and 26 Research Scientists from Population and hospital-based cancer registries were trained in 3 batches. It was a six-day training session with theory and practical hands-on exercises. The modules covered the basic concepts of epidemiology and biostatistics, cancer epidemiology and surveillance, and action plan development. The following guest lectures were delivered by experts in the field through online mode during the training to enable the participants to understand applied aspects of cancer epidemiology, cancer prevention and control.





Batch 5: 31 October – 5 November 2022

Fig 11: Cancer Epidemiology and Surveillance Training Programme (CanEST)

STROKE

ONGOING PROJECTS / ACTIVITIES

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

The objectives of PBCRs are to generate reliable data on the magnitude and incidence of first-ever stroke events in defined population-based stroke registry (PBSR) in India.

- The data collection and quality check for the period of 2020-21 is completed and the data is finalized.
- The quality check process for the data of year 2022 is in progress

PBSR Site visits:

Site visits were conducted by ICMR-NCDIR staff to the following four PBSRs to review the process of data collation and verification of data quality.



Fig 12: Site visit to PBSRs

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

Objectives of HBSR:

- 49 centres have registered for HBSR and out of which 47 centres have started submitting the data.
- The data for the years 2020-21 submitted by 20 HBSRs is finalized after verification of data quality
- The data quality of 30 HBSRs for the year 2022 is under review
- Standard format for recording imaging findings of stroke is rolled out and data collection has started at HBSRs.

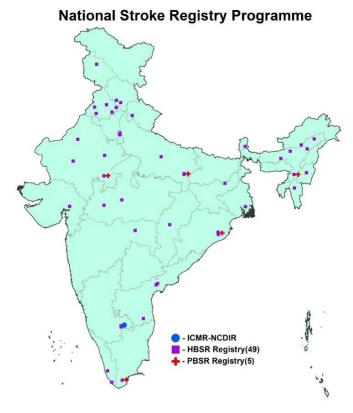


Fig 13: Participating Centres

Online sensitization and training programme on implementation of HBSR was conducted to AB-PMJAY empaneled hospital from different regions of India.

DIABETES

ONGOING PROJECTS

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

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

The objectives of the study are:

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

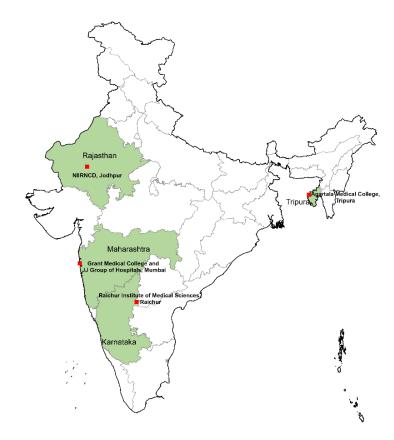


Fig 14: Participating centres of DNMS

Key Activities:

- Three study sites (Karnataka, Maharashtra, Tripura) have completed the baseline survey and commenced with the 1st year follow up survey. The follow up protocol document was prepared and shared with C- PIs.
- Monthly quality check reports are shared with centres to improve data quality. Regular
 monthly meetings are being conducted with each centre to monitor the progress in survey
 coverage and resolve project implementation issues. The C- PIs share the progress report and
 micro plan on a monthly basis.
 - The supportive supervision visits were carried out by NCDIR scientists and Research Area Panel members in the month of June July 2022, in the three study sites, site wise findings were shared with respective C- PIs for necessary action.

- Study site in Rajasthan is mentored by NIIRNCD, Jodhpur. Pilot study in one village in MRHRU area was completed in Nov. 2022 and the baseline survey is underway.
- The DNMS external quality assurance system (EQAS) strategy document has been developed. All identified laboratories by participating centres will be sending 5% samples to central laboratory, during the fixed week of each quarter (1st week of Jan, April, July and Oct) as per plan to central laboratory (Cardiac Biochemistry-AIIMS Delhi) for conducting EQAS.
- An annual review meeting of C -PI and Co-PIs was conducted on 24th March 2023, by involving few expert group members. Members advised data analysis based on diagnostic definitions of diabetes using different blood glucose values (FBS/ OGTT and HbA1c).



Fig 15: DNMS Annual review meeting held on 24th March 2022

CARDIOVASCULAR DISEASES

COMPLETED PROJECT

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

The study was a multi-centric, prospective study in five centres in small to medium sized towns in North, South, East, Northwest and South West regions of India.

The objectives of the study were:

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



Fig 16: Participating centres

Key Findings:

- A total of 10,059 cases were registered across 5 centres and most of the patients were from rural areas (60.5%). Majority were male (67.5%) patients.
- About 60% were in-patients and 40% were treated in OPDs.
- Almost half of the cases were in age group of 30-59 years of age.
- More than 90% of the cases presented with dyspnea on admission. Almost 75% of the admitted patients belonged to NYHA III & IV, and 85% of OP cases had NYHA II & III.
- Ischemic heart disease (73.4%) was the most common cause of heart failure followed by Cardiomyopathies (30%) and Rheumatic Heart Disease (7%).
- Diabetes, hypertension & anemia were the leading co-morbidities.
- Beta blockers were the most commonly prescribed drugs followed by loop diuretics, Angiotensin Receptor Blockers (ACEIs) and Mineralocorticoid Receptor Antagonists.
- The reported mortality among diagnosed heart failure cases at the end of 180 days was 14.1%.

Study outcomes

- Ischemic heart disease is the most common cause of HF in India and beta blockers were the most common first line drugs for HF patients.
- This study demonstrated that it was feasible to establish hospital-based heart failure registry in small to medium town hospitals by intense training of human resource and continued monitoring of data.
- The study has also demonstrated that data collection in outpatient settings was difficult and there were challenges in availability of information on investigations depending on the type of health facility and care settings (OP/IP).
- Follow up of the study participants was also challenging during COVID -19 pandemic.

ONGOING PROJECTS

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

The registry was established to understand about the pattern of clinical presentation, availability of diagnostic services for CVD and Heart failure, and treatment patterns for heart failure in northeast 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).

Sl. No	Centre Name	
1.	Christian Institute of Health Sciences & Research, Dimapur, Nagaland	
2.	Gauhati Medical College & Hospital, Indrapur, Guwahati, Assam	
3.	North Eastern 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	

Activities:

- The project staff from 8 centres were trained on HBCVDR and software for data abstraction.
- Internal data validation tool was developed and introduced to project staff to monitor the data quality and registry indicators. Meetings were held to review the data quality. Quality check reports were shared with centres to improve the data quality
- Action points were given to C- PIs for improving the reporting of cases to registry.
- The five potential participating centres for second year (2022-2023) of HBCVDR-NE were identified and invitation letters were sent. Three centres have accepted the invitation.

Software development:

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



Fig 17: Meeting of project staff of HBCVDR-NE sites at ICMR-NCDIR on 13 and 14 Oct. 2022



Fig 18: Meeting of C- Pls / Co- Pls of HBCVDR-NE site on 2-3 March 2023

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

Background:

Strengthening the continuum of NCD care requires identifying barriers of integrated service delivery and employing interventions to improve access to quality NCD care with a focus on diabetes, hypertension, and their complications, at primary, secondary and tertiary levels of care. A rapid health facility and NCD services assessment in focused geographical locations will help to understand the current roll - out status and scope for improving the continuum of care for diabetes and hypertension within the existing government framework / guidelines.

Objectives:

- To assess the availability of NCD services and system readiness for the prevention and management of diabetes, hypertension and their complications at both public and private sectors.
- To identify the gaps in skills, referral and care coordination at various levels for delivering essential NCD services and providing effective NCD care.
- To assess the health seeking behavior and user satisfaction for availing services at different levels.
- To examine the progress made for empowering communities-health promotion, advocacy, communication and collaboration with other stakeholders.
- To review progress and challenges (barriers and gaps) in implementation of key NCD interventions with reference to six building blocks of health systems strengthening.

Methodology:

Study design:

Mixed method approach (quantitative and qualitative methods) was used.

- Quantitative method: Cross-sectional survey of the health facilities and patient exit interviews.
- Qualitative method: In-depth interviews of government officials (state / district NCD program managers/state/ district program officers) will be conducted.
- Desk review of available records: Available secondary data will be reviewed at health facilities. (Out Patient records, NCD program Registers, HMIS report, HMIS data, NCD app, family folders (at Sub centre), and community activity records (at Sub centre).

Study sites:

The study was conducted in 9 districts of 4 states (Odisha, Madhya Pradesh, Meghalaya and Chhattisgarh). The states are selected from the different geographic regions of India by NCD division of Ministry of Health and Family Welfare, Government of India.

NCDIR is the central coordinating agency and 4 state implementing partners were identified for collecting the data.

Key activities completed:

- An expert group meeting was conducted, and questionnaires were finalized.
- The state and district officials have been oriented on study methodology.

MORTALITY COMPLETED PROJECTS

- 1. Implementation of NCDIR electronic Mortality software (NCDIR e-Mor) in hospitals of the National Cancer Registry Programme (NCRP) network in North East India
- 2. Implementation of NCDIR electronic Mortality software (NCDIR e-Mor) strengthen Medical Certification of Cause of Death

Background & Rationale:

In India, the medical certificate of cause of death is unavailable or incomplete and inadequate, making it difficult to estimate cause specific mortality. It is largely observed that mode of dying or immediate cause is recorded as underlying cause of death. To improve the cause of death information and reporting in hospitals, NCDIR electronic mortality (NCDIR e-Mor) software was developed and implemented to strengthen Medical Certification of Cause of Death (MCCD) recording in hospitals.

Objectives:

- To implement the NCDIR e-Mortality software to record deaths and capture cause of death information of all deaths occurring in the hospitals
- To aid the hospitals by facilitating outputs (MCCD-Form 4 and Death Report-Form 2) for the purpose of death registration.

Methodology:

The NCDIR e-Mor software was implemented in hospitals to record causes of deaths and provide ICD codes to the underlying cause of death as per National list of Office of Registrar General of India. The centres were trained in MCCD and use of software to record all details. The quality checks included avoiding mode of dying, guiding in recording the underlying cause of death, and avoiding errors in reporting of deaths. Few hospitals generated MCCD and Death report (Form 4 and 2 respectively) using the software to facilitate death registration.

Mortality data from the emergency department, ICUs, Wards, and all other departments of the hospital was entered into the software. Data were encrypted, and data security and confidentiality were maintained. Data was subjected to quality verification and finalized by each centre.

The coordinating unit collated and analyzed the data and prepared tables for the consolidated report of that year. Review meetings were held with the Principal Investigators and staff to discuss the aspects of e-Mor implementation and data quality. Data analysis reports were prepared based on quality and specific causes of mortality by the coordinating centre. These reports were sent as feedback to participating centres.

Participating Centres:

Project - 1

SI. No	Centre	
1.	STNM Hospital, Sikkim	
2.	NAGA Hospital, Nagaland	
3.	Bakin Pertin General Hospital, Pasighat, Arunachal Pradesh	
4.	Tomo Riba State Hospital, Naharlagun	
5.	Silchar Medical College, Cachar	
6.	Civil Hospital, Aizawl, (Mizoram)	
7.	Mizoram State Cancer Institute, Aizawl, Mizoram	
8.	Civil Hospital, Shillong	
9.	Zoram Medical College, Falkawn, Mizoram	
10.	District Hospital, Dimapur	
11.	Gauhati Medical College, Guwahati	
12.	Jorhat Medical College and Hospital, Jorhat Assam	
13.	Cachar Cancer Centre-Cachar, Silchar	
14.	Dr.B. Borooah Cancer Institute, Kamrup	
15.	Regional Institute of Medical Sciences (RIMS), Imphal	
16.	Christian Institute of Health Sciences & Research, Dimapur	
17.	Zion Hospital and Research Centre, Dimapur	
18.	Eden Medical Centre, Dimapur	

Project - 2

SI. No	Participating centre		
1.	AIIMS Raipur		
2.	AIIMS Rishikesh		
3.	Andhra Medical College, Visakhapatnam		
4.	B J Government Medical College, Pune		
5.	Bhagat Phool Singh Government Medical College for Women, Haryana		
6.	Cancer Hospital & Research Institute, Gwalior		
7.	GMC Kota		
8.	Government Medical College & Rajendra Hospital, Patiala		
9.	JIPMER, Puducherry		
10.	Kamala Nehru Memorial Hospital, Prayagraj		
11.	M.S Ramaiah Medical College and Hospital, Bangalore		
12.	Malabar Cancer Centre, Kannur		
13.	NIMHANS, Bengaluru		
14.	Rajendra Institute of Medical Sciences (RIMS), Ranchi		
15.	Sher-i-Kashmir Institute of Medical Sciences, Srinagar		

Outcomes:

The software has facilitated development of mortality databases in hospital. More than three-fourth of hospitals linked e-Mor to the death registration process of hospital. More-than half (57%) utilized e-MoR to improve the MCCD reporting. Two thirds of the hospitals had conducted training on MCCD for their doctors. The e-MoR software has been used for recording MCCD (80%), reporting MCCD (66.7%), and mortality audits (33%).

The centres also used the software for providing ICD codes for the underlying cause of death. Less than 15 % of the records were not coded with a specific ICD code. Time interval of cause of death was missing in a majority of records.

There is need for developing a review system for verification of MCCD so that the quality of MCCD data improves without errors. Sensitization and training on framework for MCCD audit was conducted for the hospitals to further strengthen the system in the hospital. This shall help in conducting MCCD and mortality audits in the hospital.

Scope for future:

Capacity building at institution level was identified as the foremost need in all hospitals. The e-MoR software will be useful in providing the training and hands-on skills for writing the cause of death and ICD-10 codes for underlying cause of death.

3. Strengthening Medical certification of cause of death (MCCD) by development of mortality audit systems framework, online MCCD modules and standardize e - MoR application

Framework for audit of Medical Certification of Cause of Death (MCCD) at Health Facility was developed by ICMR - NCDIR in collaboration with Central Bureau of Health Intelligence - Director of Health Sciences, Govt. of India and World Health Organization. Implementation of this framework by hospitals would help minimize errors and ensure completeness of MCCD forms at the hospital. This shall facilitate periodic audit of MCCD forms to help in proper recording of cause of death information, provide timely cause of death statistics for evidence-based decision at the hospital. In addition, it will support the timely submission of MCCD forms by hospitals to the Civil Registration system (CRS). The Guidelines were released on 15 September 2022 by Secretary, Department of Health & Family Welfare, Government of India.

https://www.ncdirindia.org/All_Reports/MCCD_Frmwrk/Framework_MCCD_Audit.pdf



Fig 19: Release of Framework for audit of MCCD at Health Facility

ONGOING PROJECTS

1. NCDIR Collaborations in Setting up State wide e-Mor program for strengthening MCCD systems

Background and rationale:

ICMR- NCDIR works with the Chief Registration System (SRS) 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

ICMR-NCDIR e-Mor has been integrated in the Tamil Nadu CRS software and implemented state-wide for recording institutional and non-institutional deaths in hospitals and local registrar offices. ICMR-NCDIR is providing technical resources in capacity building and enhancements in software for proper recording of cause of death terms and in data analytics of MCCD reporting.

B. Karnataka

Proposals to provide technical inputs in improving the CRS 'e-janma' software for recording MCCD has been submitted to the Chief Registrar of births and deaths, Karnataka. Training of Medical officers on MCCD has been initiated in collaboration with the Regional Office of Health and Family Welfare. The Dept of Health and Family Welfare has issued a government order in 2020 for implementation of NCDIR e-Mor in all hospitals to streamline and standardize MCCD reporting. The Director of Health has nominated a nodal officer to implement e-Mor in two districts in Karnataka.

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

Background and Rationale:

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 rollout 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.

A baseline assessment of medical certification of cause of death (MCCD) system to understand the barriers and facilitators at system level; and in selected tertiary and secondary healthcare facilities by process mapping, interviews of stakeholders in hospitals and assessment of quality of cause of death assignment to understand the barriers at the health facility level is ongoing.

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.

Data collection (baseline assessment of CRS/MCCD system at facility and system level, identifying barriers and solutions) completed in Karnataka, Tripura and Andhra Pradesh.

Outcomes:

Identification of solutions that facilitate improvement in MCCD practices at health facility, MCCD system in the district and state level will be identified. A Framework for Strengthening MCCD shall be developed for the country. System level changes in improving MCCD will support the CRS and mortality reporting systems in India. In addition, MCCD system shall be strengthened to contribute to mortality surveillance in India.

Trainings conducted:

- DHR / ICMR Workshop on "Strengthening Medical Certification of Cause of Death in hospitals" was held on 02-02-2023 and 03-02-2023 for medical doctors from various hospitals across the country. Nearly 30 doctors participated in this training. This two-day workshop provided hand on skills in MCCD to 23 faculties from 17 medical colleges across India.
- An online workshop on "Strengthening Medical Certification of Cause of Death in Karnataka" was conducted by ICMR-NCDIR in collaboration with Regional Office of Health and Family Welfare, Bengaluru and State Bureau of Health Intelligence, Karnataka for District Health Officers, Medical College RMOs, District Surgeon, Taluk Health Officers, and

Taluk Medical Officers on 28-03-2023 and 29-03-2023. More than 200 participants participated in this training programme.



Fig 20: DHR / ICMR Workshop on "Strengthening Medical Certification of Cause of Death in hospitals" held on 02/02/2023

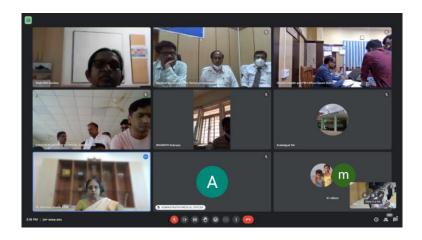


Fig 21: Online workshop on "Strengthening Medical Certification of Cause of Death in Karnataka held on 28-03-2023 and 29-03-2023

ICMR BIOETHICS UNIT

Report of ICMR Bioethics Unit activities from 1 April to 31 December 2022

COMPLETED ACTIVITIES

1. Finalization, Publication and Release of ICMR Reference book on "Biomedical Ethics Perspectives in the Indian Context" on 7th April 2022

ICMR Bioethics Unit, under the aegis of ICMR, has published a reference book on 'Biomedical Ethics Perspectives in the Indian Context' through Jaypee Medical Publishers. It is a first-of-its-kind book in India with a comprehensive and unique compilation of topics addressing ethical aspects in various kinds of biomedical and health research in the Indian context. National-level experts have contributed and shared their expertise and knowledge on specialized topics that have been articulated in a manner to understand the intrinsic ethical challenges faced by researchers, clinicians, students and ethics committee members involved in biomedical and health research in India. It was released on the occasion of World Health Day on 7th April 2022. The book is expected to serve as a tool for teaching and act as a guidance document for students, researchers and ethics committee members.

Reference: https://ethics.ncdirindia.org/Reference_books.aspx
ht



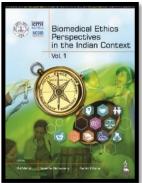




Fig 22: Release of ICMR Reference book on "Biomedical Ethics Perspectives in the Indian Context" on 07/04/2022 at ICMR Headquarters by DG ICMR and Secretary, DHR

2. "ICMR-DHR Biomedical & Research Ethics Update"- Training program for ethics committee members.

A webinar on "Biomedical & Research Ethics Update" was conducted on 18 May 2022 in hybrid mode. The program was tailored and customized for ethics committee members of ICMR network of institutions in consultation with DHR. Relevant updates with respect to the ICMR National Ethical Guidelines 2017 & 2020, Roles and Responsibilities of EC members, EC registration on DHR Naitik Portal, SOPs, Communications of EC, Training of EC members, Common Review of

Multicentre Research by ICMR network of institutions, etc., were discussed by speakers. More than 150 Researchers and Ethics Committee members from ICMR institutions and some Non - ICMR institutions participated in the event.



Fig 23: Training Program for Ethics Committee Members on "ICMR-DHR Biomedical & Research Ethics Update" held on 18/05/2022

3. Finalization and Release of FAQs for Ethics Committees & Researchers

ICMR Bioethics Unit routinely receives emails with a wide range of queries concerning ethical aspects of research studies, functions of ethics committees, regulatory requirements, etc. A total of more than 150 Frequently Asked Questions (FAQs) have been framed. The FAQs are available on the website and are arranged section-wise to ascertain easy access and navigation to these particular topics. This serve as a mine of information for young researchers and newly constituted ethics committees in various colleges/institutions across the country.

The FAQ's were released on 27th September 2022 by the Hon'ble Minister of State for Health, Ministry of Health & Family Welfare, Govt. of India, Dr. Bharati Pravin Pawar, at Bengaluru.



Fig 24: Release of FAQs for Ethics Committees & Researchers on 27/09/2022 by the Hon'ble Minister of State for Health, Ministry of Health & Family Welfare, Govt. of India, Dr. Bharati Pravin

4. Release of Animated videos and infographic posters based on ICMR National Ethical Guidelines 2017

ICMR Bioethics Unit has led initiatives to develop short animated videos based on current biomedical and health research topics in the country. In collaboration with the Global Health Strategies (GHS), Delhi, 6 animated videos were prepared based on National Ethical Guidelines, Ethics preparedness in outbreak and emergencies and other relevant regulatory requirements. The animated videos will be useful in ethics training programs for researchers and Ethics Committee members for a better understanding of the ICMR national ethical guidelines. The videos are approximately 2-4 minutes each and are made freely available online on ICMR Bioethics Unit website (https://ethics.ncdirindia.org/).



Fig 25: Release of Animated videos and infographic posters on 27/09/2022

5. Short Movies as an ethics teaching tool/resource material (Phase-1)

ICMR Bioethics Unit developed the first of its kind - short educational movies on research ethics in the country. The videos are based on case scenarios and are intended to aid young researchers, scientists, clinicians, EC members and the community at large for a better understanding of the ethical issues they frequently face while conducting research. These self-learning videos will also serve as a tool for addressing complex scenarios that deviate from the norms and assisting the stakeholders in taking appropriate action in such cases. 13 videos of approximately 2-5 minutes each were developed and released. It is freely available online on ICMR Bioethics Unit webpage for easy accessibility (https://ethics.ncdirindia.org/).



Fig 26: Release Short Movies as an ethics teaching tool/resource material (Phase-1) on 27/09/2022

6. Prepared new and updated existing ICMR CECHR Common Forms

ICMR Common Forms have been updated to reflect emerging requirements of Ethics Committees in the country. It was realized that a separate form was needed for seeking extensions for research approved by the ethics committee. A revised form has been prepared entitled "Annexure-14-Project Extension Form" and is added to the existing forms. This form addresses studies that require an extension over the initially granted approval period. A new form has been prepared entitled "Annexure 15- Initial review form of Multicenter research". The annual report form has also been amended to add a "brief summary of the study done in the past year" to get a better insight into the study. Both updated forms have been posted on the ICMR Bioethics Unit webpage. It is available for download in both Microsoft Word and PDF format and can be adopted by ethics committees across the country (https://ethics.ncdirindia.org/Common forms for Ethics Committee.aspx).

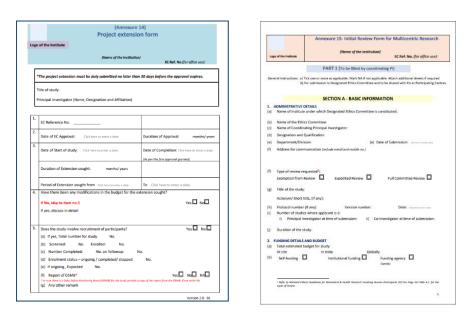


Fig 27: ICMR Common Forms for Ethics Committee Review

7. ICMR-DHR Outreach and Capacity Building Program for Ethics Committees

An outreach and capacity-building program has been initiated jointly by ICMR and DHR. This initiative provides members of ethics committees with guidance and assistance so as to strengthen the functioning of the ethics committee. The program provided insights into the grassroots-level problems faced by the ethics committees in the county. This helped in understanding the need for further enhancement of the currently existing regulatory framework for research ethics oversight in the country.

A total of 26 ethics committees have participated in the outreach program at Regional Medical Research Center (RMRC), Gorakhpur on 4 November 2022 and at Bengaluru on 6 December 2022.





Fig 29: ICMR-DHR Outreach and Capacity Building Program for Ethics Committees

SN	Place	Date	No of EC
1.	Gorakhpur	4 November 2022	3
2.	Bengaluru	6 December 2022	23
Total		26	

8. WHO workshop on Piloting the Tool for Benchmarking Ethics Oversight of Health - Related Research with Human Participants on 6-7 December, 2022.

WHO has developed a draft Benchmarking Tool, aiming to assist its Member States in reviewing their current capacity for ethical oversight of health-related research. As a WHO Collaborating Centre, the ICMR Bioethics Unit was approached by the WHO to pilot the Benchmarking Tool in India to understand the functionality and acceptability of the tool in an Indian setting. In this regard, the ICMR Bioethics Unit organized a workshop titled "WHO workshop on Piloting the Tool for Benchmarking Ethics Oversight of Health-Related Research with Human Participants" with support from WHO Headquarters on 6-7 December, 2022 in Bengaluru. The workshop was attended by members from about 23 ethics committees across the country and the program was facilitated by 8 national and international facilitators.



Fig 28: WHO workshop on Piloting the Tool for Benchmarking Ethics Oversight of Health - Related Research with Human Participants on 6-7 December 2022

OTHER PROJECTS / ACTIVITIES COMPLETED ACTIVITY

Cyber Jaagrookta Diwas

This is an initiative launched by the Ministry of Home Affairs that requires all government organizations to create an action plan to spread cybersecurity awareness. The purpose was to create awareness and sensitize the users on safeguarding against cyber fraud and cybercrimes.

ICMR -NCDIR observed Cyber Jaagrookta Diwas on first Wednesday of every month from May 2022 to March 2023 to create awareness for the prevention of cybercrimes through awareness workshops, seminars, interactive sessions, quiz competitions, best practices, case studies, etc.

First Cyber Jaagrookta Diwas was conducted on 5th May 2022 and Introduction to Cyber Crimes and Safety was explained to all the staff of ICMR-NCDIR. Sessions were held monthly on the following topics.

- Concept and use of Cyber Hygiene in daily life (08/06/2022)
- Introduction to Social Networks (06/07/22)
- Quiz 1 (03/08/22)
- Electronic payments and safeguards therein (07/09/22)
- Introduction to Information and Technology Act. 2000 (IT Act), The Indian Wireless Telegraphy Act and their use in Cyberspace (12/10/2022)
- Quiz 2 (02/11/2022)
- Financial Cybercrime and How to overcome (07/12/2022)
- Cyber Crime Awareness (04/01/2023)
- Quiz 3 (01/02/2023)
- Cyber Crime Awareness (For newly joined staff) (01/03/2023)

The concluding session was held on 21st March 2023. Sri S Badrinath, Deputy Commissioner of Police, Crime II, Bengaluru City gave a talk about "Cybercrime and its recognition" with live examples and how to protect ourselves from cybercrimes.



Fig 30: Concluding Session of Cyber Jaagrookta Diwas on 21/03/2023

During this awareness program, the following materials were shared with all staff of ICMR-NCDIR.

- 1. Cyber Security Guidelines for Government employees prepared by Meity
- 2. "Information Security Best Practices" to be followed by ICMR Institutions/Centres.

Additional training programmes conducted include:

No	Date	Title	Organized by	Who Attended
1	22 - 26 August	Management of Digital	C-DAC, Mohali	IT staff
	2022	Hygiene Staying Secure in Cyber Space		
2	6 October 2022	Awareness on Cyber & Data	Department of	All staff
		Security	Health Research	
3	11 January 2023	Training on Security posture		IT Staff

ONGOING PROJECT / ACTIVITY

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

This is an ICMR task force study conducted among the staff of the ICMR Institutes. The objectives of this study are

- to characterize SARS-CoV-2 specific humoral and cellular immune response after the homologous precautionary third dose of COVISHIELD/COVAXIN vaccine at different time points
- to estimate the incidence of SARS-CoV-2 symptomatic infections post the third dose of the COVID-19 vaccine.

The immune response was assessed at five time points namely, baseline before taking the third dose of the COVID vaccine, and at first, third, sixth, and 9 to 12 months after taking the vaccine. About 5 ml of blood was collected at each of these time points. ICMR-NIV, Pune is the nodal centre for the measurement of immune response. The data collection is ongoing and one year follow-up of completed with 99% follow up of enrolled participants.

2. Internship at ICMR NCDIR

ICMR NCDIR is offering internships in the disciplines of noncommunicable diseases epidemiology, medical statistics, information technology, and bioethics (till Dec 2022) for periods ranging from two to six months. Each intern works under the close supervision and guidance of a mentor with hands-on learning on registry, NCD epidemiology, data management and analytics. They complete the internship with a presentation and a written report of the work done at NCDIR.

For the period from 01 Apr 2022 to 31 Mar 2023, 18 students completed their internship: 14 (77%) were pursuing their Masters in Public Health, and others were pursuing Masters in Statistics(2), BTech in Computer Science(1), and Integrated MTech in Bioengineering(1). The students came from the following institutions:

- 1. SRM Institute of Science and Technology, Vellore
- 2. MIT, International University, Pune
- 3. Karnataka, State rural development and panchayat University, Gadag, Karnataka
- 4. Symbiosis International University, Pune
- 5. Jawaharlal Nehru Medical College, Belagavi
- 6. Indian Institute of Science, Ropar
- 7. MIT School of Bioengineering Science and Research, Pune
- 8. JSS Academy of Higher Education, Mysuru
- 9. Devi Ahilya, Vishwavidyalaya, Indore, MP
- 10. Prasanna School of Public Health, Manipal Academy
- 11. Rajiv Gandhi Institute of Public Health and Centre for Disease Control, Bengaluru, Karnataka
- 12. Indian Institute of Public Health, Gandhinagar
- 13. MS Ramaiah University of Applied Sciences, Bengaluru

PUBLICATIONS / REPORTS/ GUIDELINES / BOOKS / POLICY 2022-23

- Nath A, Sathishkumar K, Das P, Sudarshan KL, Mathur P. A clinicoepidemiological profile of lung cancers in India - Results from the National Cancer Registry Programme [published correction appears in Indian J Med Res. 2022 Jan;156(1):168]. Indian J Med Res. 2022;155(2):264-272. doi:10.4103/ijmr.ijmr_1364_21 Erratum: A clinicoepidemiological profile of lung cancers in India – Results from the National Cancer Registry Programme. Indian Journal of Medical Research 156(1):p 168, July 2022. | DOI: 10.4103/0971-5916.362038 IF: 5.274
- 2. GBD 2019 Colorectal Cancer Collaborators. Global, regional, and national burden of colorectal cancer and its risk factors, 1990-2019: a systematic analysis for the Global Burden of Disease Study 2019. *Lancet Gastroenterol Hepatol*. July, 2022, 7(7):627-647. **IF: 45.042**
- 3. Sathishkumar K, Chaturvedi M, Das P, Stephen S, Mathur P. Cancer incidence estimates for 2022 & projection for 2025: Result from National Cancer Registry Programme, India. *Indian J Med Res.* October-November, 2022 ;156(4&5):598-607. **IF: 5.274**
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- 13. Nath A, Sudarshan KL, Rajput GK, Mathew S, Chandrika KRR, Mathur P. A rapid assessment of the impact of coronavirus disease (COVID- 19) pandemic on health care & service delivery for noncommunicable diseases in India. Diabetes and Metabolic Syndrome: Clinical Research and Reviews. October, 2022;16(10):102607. IF: N/A (Indexed in Web of Science & Scopus)
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Reports

- A Situational Analysis of Childhood Cancer Care Services in India 2022 https://ncdirindia.org/All Reports/Childhood Cancer/Default.aspx
- 2. Monograph of ICMR-NCDIR: A decade of research: impacting NCD public health actions
- 3. Frequently Asked Questions(FAQ) based on National Ethical Guidelines for Biomedical and Health Research Involving Human Participants, 2017
- 3. Report on Monitoring Survey of Cancer Risk Factors and Health System Response in North East Region (NER)
 - https://ncdirindia.org/All Reports/ner2022/Default.aspx
- Report of monitoring survey in Manipurhttps://ncdirindia.org/All Reports/ner2022/Manipur.aspx
- Report of monitoring survey in Arunachal Pradesh https://ncdirindia.org/All Reports/ner2022/Arunachalpradesh.aspx
- Report of monitoring survey in Mizoram
 https://ncdirindia.org/All Reports/ner2022/Mizoram.aspx
- 7. Report of monitoring survey in Meghalaya https://ncdirindia.org/All Reports/ner2022/Meghalaya.aspx
- 8. Report of monitoring survey in Tripura https://ncdirindia.org/All Reports/ner2022/Tripura.aspx
- Report of monitoring survey in Nagaland https://ncdirindia.org/All Reports/ner2022/Nagaland.aspx

- 10. Report of monitoring survey in Assam
 - https://ncdirindia.org/All Reports/ner2022/sikkim.aspx
- 11. Report of monitoring survey in Assam
 - https://ncdirindia.org/All Reports/ner2022/assam.aspx
- 12. <u>Patterns of Stroke Care in AB PM-JAY Beneficiaries in Empanelled Hospitals</u> https://ncdirindia.org/All Reports/Stroke/POSC ABPM JAY.pdf

Guidelines

Framework for Audit of Medical Certification of Cause of Death at Health Facility https://ncdirindia.org/All Reports/MCCD Frmwrk/Framework MCCD Audit.pdf

Contributions in International Guidelines / Reports

- 1. WHO Emergency use of unproven clinical interventions outside clinical trials: ethical considerations. 12 April 2022
- 2. COVID-19 and mandatory vaccination: Ethical considerations. Policy brief 30 May 2022.
- 3. <u>Global Network of WHO Collaborating Centres for Bioethics Progress Report 2019-2021</u> https://ncdirindia.org/All_Reports/Ethics/WHO_CC_Report.pdf

Reference Book

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

Policy Brief

1. A situational analysis of childhood cancer services in India, Policy brief
A situational analysis of childhood cancer services in India, Policy brief

Educational Materials

ICMR Bioethics Unit Capacity building interactives such as animated videos and educational movies.

Contributed the following chapters on books.

Published

- 1. Manoj Kalita, **Sathish kumar** K, Nizara Baishya and D Barman. Biostatistics in Oncology. Principles and Practice of Oncology, edited by AC Kataki, Dr.B.Borooah cancer Institute Academia, 2021, 17-30
- 2. **Prashant Mathur**, Narendra K Arora. Ethical Issues in Epidemiological Studies, Biomedical Ethics Perspectives in the Indian Context, edited by Roli Mathur, Vasantha Muthuswamy, Nandini K Kumar, 30-41.

- 3. Amal Chandra Kataki, Parmita Tiwari, **R. Thilagavthi**, Manigreeva Krishnatreya. Epidemiology of Gynecological Cancers, Fundamentals in Gynaecologic Oncology, edited by Amal Chandra Kataki, Debabrata Barmon, 2022, 1-8.
- 4. **Roli Mathur**. Towards Ethical Biomedical and Health Research During the Covid-19 Pandemic The Case of India. Tracking and Tackling Covid-19 Global Perspectives, edited by Ali Mehdi 2022, 40-52.

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

1.	Book Release Program on "Biomedical Ethics Perspectives in the Indian Context" on 7 Ap 2022		
2.	2. Research Area Panel on Cancer on 21 Apr 2022		
3.	Meeting of the Central Ethics Committee on Human Research (CECHR) on 21 Apr 2022		
4.	DIAMOnDS Project Review Meeting at DHR, New Delhi on 22 Apr 2022		
5.	National Training Program in Cancer Epidemiology and Surveillance (CanEST program) b ICMR-NCDIR, Bengaluru - third batch from 25- 30th April 2022 on 25 to 30 Apr 22		
6.	Research Area Panel on Stroke on 26 Apr 2022		
7.	Meeting to discuss feasibility of conducting population based COPD survey on 27 Apr 2022		
8.	Educational Visit of Postgraduate Residents of Dept of Community Medicine, AFMC Pune to ICMR-NCDIR on 27 Apr 2022		
9.	Ethics program under Cancer Epidemiology and Surveillance training (Can EST) on 28 Apr 202		
10.	Expert group meeting to discuss the draft tools and study protocols of state NCD monitorin survey 2022-23 on 29 Apr 2022		
11.	Cyber Jaagrookta (Awareness) Diwas (CJD) on 04 May 2022		
12.	Training programme for the Hospital-Based Stroke Registry centres on 05 May 2022		
13.	Training on Verbal Autopsy on 06 May 2022		
14.	State NNMS project - Second expert group meeting on 10 May 2022		
15.	Meeting regarding submission of multi- centric study proposal for assessing the feasibility conducting Population based lung health assessment in general population on 13 May 2022		
16.	Meeting to discuss study tools for study titled "Assessing the capacities of States and Unio Territories for prevention and control of NCDs in India on 13 May 2022		
17.	ICMR-DHR Biomedical & Research Ethics Update on 18 May 2022		
18.	Training workshop for Hospital Based Cancer Registry on 19 May 2022		
19.	Visit by Undergraduate students of DG Vaishnav college, Chennai on 25 May 2022		
20.	Online training for DHR-ICMR Advanced Medical Oncology Diagnostic Services (DIAMOnDS project on 24 May 2022		
21.	Discussion regarding Childhood Cancer registry on 27 May 2022		
22.	Technical review meeting for air pollution and meta-analysis study on 31 May 2022		
23.	Cancer cluster meeting on 03 Jun 2022		
24.	CanEST IV Batch Inauguration on 06 to 11 June 2022		
25.	Sensitization workshop on Hospital Based Stroke Registry (HBSR) for AB-PMJAY empanelle hospitals - NCDIR and NHA on 7 to 8 Jun 22		
26.	Web meeting for technical review of proposals submitted under Cancer Research North East (CaRes NER) Programme Call for Proposals on 09 Jun 2022		
27.	To discuss the draft study tools of the study titled Assessing the capacities of States and Union Territories for prevention and control of NCDs in India' on 09 Jun 2022		
28.	Ethics program under Cancer Epidemiology and Surveillance training (Can EST) on 9 Jun 202		

29.	Guest talk by Mr Raghunandan - Impact of zoning regulations on public health through physical activity on 17 Jun 2022
30.	Virtual Data Review meeting on POCSS LHM, Childhood, and other Gynaec cancers - 4 centres on 23 Jun 2022
31.	Virtual Data Review meeting on POCSS LHM, Childhood, and other Gynaec cancers - 4 centres on 24 Jun 2022
32.	Training of HBSR - AB-PMJAY empaneled hospitals for North-east Zone & South Zone on 04 Jul 2022
33.	HBCVD software training of PI and project staff - TRIHMS, Arunachal Pradesh on 04 Jul 2022
34.	Cyber Jaagrookta (Awareness) Diwas (CJD) on 06 Jul 2022
35.	Discussion on secondary data analysis for lung health assessment at community level using BOLD study data on 13 Jul 2022
36.	Online expert meeting to discuss Diabetes in pregnancy registry proposal on 18 Jul 2022
37.	HBSR Sensitisation Workshop for PM-JAY empanelled hospitals in UTs F156 on 18 Jul 2022
38.	Release of Report on Monitoring Survey of Cancer Risk Factors and Health System Response in North East Region-Manipur on 19 Jul 2022
39.	Visit of Dr. Ved Yadav, National Professional Officer (Health Information) at World Health Organization, Delhi regarding MCCD discussion on 22 Jul 2022
40.	Release of Report on Monitoring Survey of Cancer Risk Factors and Health System Response in North East Region-Mizoram on 22 Jul 2022
41.	Release of the 'Report on monitoring survey of cancer risk factors and health system response in North East Region (NER)' for Meghalaya on 29 Jul 2022
42.	Review of HBCR Core form on 02 Aug 2022
43.	Working group meeting to discuss about POCSS on Cancer Breast data on 04 Aug 2022
44.	Release of survey report on "Monitoring Survey of Cancer Risk Factor and Health System Response in North East Region (Tripura)" on 05 Aug 2022
45.	Release of survey report on "Monitoring Survey of Cancer Risk Factor and Health System Response in North East Region, Nagaland Region on 8 August 2022 by Shri S. Pangnyu Phom, Hon'ble Minister of Health and Family Welfare, Govt of Nagaland on 08 Aug 2022
46.	HBCVDR-NE Software Training for Project Staff - RIMS, Imphal, Manipur on 10 Aug 2022
47.	Virtual meeting regarding initiating Hospital Based Cancer Registry (HBCR) at Apollo Cancer Centres on 17 Aug 2022
48.	Presentation of Spatial analysis findings on 18 Aug 2022
49.	Research Area Panel on Cardiovascular Diseases on 18 Aug 2022
50.	Meeting of the Central Ethics Committee on Human Research (CECHR) on 29 Aug 2022
51.	Cyber Jagrookta Diwas on 07 Sep 2022
52.	Mini SAC to discuss the proposal 'National Stroke registry programme in India: Development of Hospital Based Stroke Registries (HBSR) in different regions of India on 08 Sep 2022
53.	Expert group meeting on estimation of mortality statistics during COVID-19 pandemic on 19 Sep 2022
54.	Sensitization training on the concept of cancer registry on 20 Sep 2022
55.	Meeting regarding implementation research in health systems to improve NCD care in collaboration with NHSRC on 28 Sep 2022
56.	Training Workshop MCCD Implementation research study on 28 Sep 2022
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57.	Discussions on key findings of Continuum of Care study for DM and HT in India with WHO team on 06 Oct 2022
58.	Meeting of Expert Committee for evaluation of new proposals received under Grant-in-Aid (GIA) Scheme during call for online proposals for 2022-23. on 06 Oct 2022
59.	Cyber Jaagrookta Diwas (CJD)" on 06 Oct 2022
60.	Initial meeting regarding Setting up HBCR in Army HospitalR & R on 11 Oct 2022
61.	Visit of Director General, ICMR on 13 Oct 2022
62.	Hospital based cardiovascular disease(CVD) registry Training on 14 Oct 2022
63.	DNMS Jodhpur site training on 17 Oct 2022
64.	Release of Report Monitoring Survey of Cancer Risk Factors and Health System Response in North East Region for Sikkim on 20 Oct 2022
65.	Discussion with Dr Ved regarding MCCD training and MCCD audit on 20 Oct 2022
66.	Hindi Samaroh on 21 Oct 2022
67.	Academic club -Article review - Clinicopathological prognostic factors for gallbladder carcinoma: a retrospective study on 27 Oct 2022
68.	Can EST programme on 31 Oct to 5 Nov 2022
69.	Working group meeting to discuss about Patterns of Care and Survival on Head and Neck Cancers data on 31 Oct 2022
70.	Meeting - Initiating HBCR in PD Hinduja Hospital, Mumbai on 31 Oct 2022
71.	Karnataka Rajyotsava Celebration in NCDIR on 01 Nov 2022
72.	Cyber Jaagrookta Diwas - Online Quiz on 02 Nov 2022
73.	Release of Report on Monitoring Survey of Cancer Risk Factors and Health System Response of Assam in North East Region (NER) on 09 Nov 2022
74.	Review Meeting of e-Mor Centres on 15 Nov 2022
75.	Discussion on MCCD Implementation research study on 22 Nov 2022
76.	Training of Hospital based Stroke Registries on 23 Nov 2022
77.	Sensitization workshop on Prevention of Sexual Harassment of Women at Workplace on 25 Nov 2022
78.	Meeting with C- PIs / Co- PIs to review progress on HBCVD-NER registry on 01 Dec 2022
79.	Discussion on proposal for implementation of NCRP data in the public domain on 02 Dec 2022
80.	Discussion on Situational analysis of cancer care services - implementation tool on 05 Dec 2022
81.	Meeting of the Central Ethics Committee on Human Research (CECHR) on 6 Dec 2022
82.	WHO workshop on Piloting the Tool for Benchmarking Ethics Oversight of Health-Related
	Research with Human Participants from 6 – 7 Dec 2022
83.	Hospital based Cancer Registry Training on 15 Dec 2022
84.	HTAIn DIAMOnDS Meeting for Data Management on 16 Dec 2022
85.	Data review cum training for AIIMS Jodhpur DIAMOnDS Centre on 21 Dec 2022
86.	Data review cum training on 22 Dec 2022 for DIAMOnDS Centre Virtual Meeting RIMS Imphal, TMC Kolkata and JIPMER Puducherry
87.	Meeting on Proposal for oncology data analysis on 28 Dec 2022
88.	Cyber Jaagrookta(Awareness) Diwas (CJD) on 04 Jan 2023
89.	Online expert group meeting regarding NCDIR_PROP19 (Ca Res project) on 06 Jan 2023
90.	Meeting with NCDIR Scientists regarding 5 Scientific problems as per the minutes of the meeting held on 2 January 2023 on 19 Jan 2023

91.	HBCR Core proforma meeting with experts on 20 Jan 2023
92.	NCDIR Annual Day celebration on 24 Jan 2023 and 26 January 2023
93.	Workshop on Quality assurance and hands on training for pathologists for Incidental Gall Bladder Cancer and Other Pre-malignant Gall Bladder Condition in India towards early detection of Gall Bladder Cancer on 30th Jan 2023 on 30 Jan 2023
94.	Discussion on Publication by Registries on 31 Jan 2023
95.	MCCD workshop on 02 Feb 2023
96.	HBCR Core proforma meeting 16 HBCR Pis on 03 Feb 2023
97.	Meeting of experts on Cancer Research on 08 Feb 2023
98.	Online Data review meeting for Patterns of Care and Survival Studies (POCSS) on Gall Bladder Cancer (GBC) in Hospital Based Cancer Registries under ICMR- National Cancer Registry Programme (NCRP) on 10 Feb 2023
99.	Expert meeting to discuss IARC collaboration on 14 Feb 2023
100.	Meeting to discuss Problem Statements on 16 Feb 2023
101.	HBCR Training -10 new centres on 20 Feb 2023
102.	Visit of DG, ICMR for the meeting with Principal Health Secretary and Chief Secretary, Govt of Karnataka on 24 Feb 2023
103.	Visit of Dr. Freddie Bray , IARC Leon to ICMR-NCDIR on 27 Feb 2023
104.	HBSR Staff training on 28 Feb 2023
105.	CVDNER PIs meeting on 2 to 3 Mar 23
106.	HBCR Core form Discussion with 10 centres on 02 Mar 2023
107.	Expert meeting for COC Round II on 13 Mar 2023
108.	PBSR Data Review meeting on 14 Mar 2023
109.	Data Review Meeting of HBSRs on 15 Mar 2023
110.	Sensitization meeting with state and district NCD officials, site PIs / co investigators for study titled Assessment of continuum of care for Hypertension & Diabetes in India- 01 February 2023 - 31 May 2023 on 15 Mar 2023
111.	Data Review Meeting of Hospital Based Cancer Registries (Regional cancer centres) on 16 to 17 Mar 2023
112.	Cyber Jagrookta - Final Program on 21 Mar 2023
113.	Meeting with the officials of Govt of Andhra Pradesh to discuss development of cancer atlas on 21 Mar 2023
114.	Meeting called by National Health Authority regarding AB-PMJAY empanelled hospitals with National Cancer Registry Program on 22 Mar 2023
115.	IEC meeting on 23 Mar 2023
116.	Annual Review meeting for DNMS centres on 24 Mar 2023
117.	Review of Andhra Pradesh Cancer Atlas project on 28 Mar 2023
118.	Meeting on issues related to continuation of "Population Based Registries" on 30 Mar 2023



Impacting NCD Public Health Actions and Policies
Collaborate Innovate Inspire

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