Impacting NCD Public Health Actions and Policies
Collaborate Innovate Inspire

National Centre for Disease Informatics and Research, Bengaluru

(Indian Council of Medical Research)

ANNUAL HIGHLIGHTS 2020 -2021

Nirmal Bhawan-ICMR Complex (II Floor), Poojanahalli, Off N.H–7, Kannamangala Post, Bengaluru–562 110 (India)

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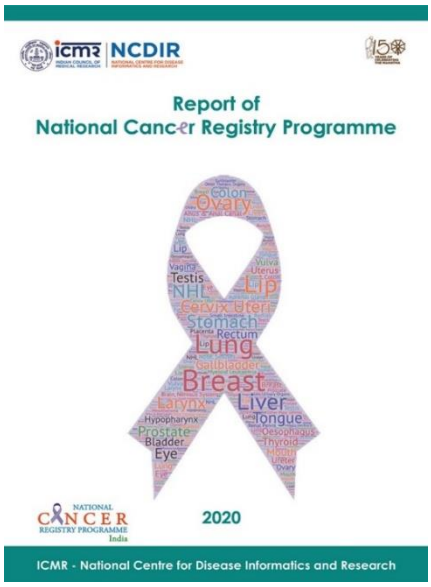
KEY ACHIEVEMENTS

1. ICMR – NCDIR is celebrating 40 years of setting up of the ICMR National Cancer Registry Programme (NCRP) which was set up on 11th December 1981. Over 40 years it has grown leaps and bounds. NCRP is the flagship program of ICMR and NCDIR, providing robust cancer statistics to guide its prevention and control efforts. The quality of data, coverage and its use has increased several folds over the past years.
2. ICMR Salutes Women Scientists for their Contribution in Fight against COVID-19: ICMR acknowledged the substantial contribution of Dr. Roli Mathur in the field of ethics during the pandemic.
3. The Report of "National Noncommunicable Disease Monitoring Survey 2017-18" was released by Dr Harsh Vardhan, Hon'ble Union Minister of Health and Family Welfare along with Prof Balram Bhargava, Secretary DHR and DG, ICMR and other dignitaries and online participants on 25th January 2021 to mark the 10th Foundation Day of ICMR-NCDIR, Bengaluru. It is the largest NCD survey in the country to measure progress of the country towards achieving the national NCD targets.
4. The Report of National Cancer Registry Programme, 2020 with five-year data (2012-2016) from 28 PBCRs and 58 HBCRs was released on 18th August 2020.
5. The Report of Profile of Cancer and Related Health Indicators in the Northeast Region of India – 2021 has been released on World Cancer Day i.e., on 4th February 2021.
6. Framework for Telemedicine use in Management of Cancer, Diabetes, Cardiovascular Diseases, and Stroke in India was released on 25th January 2021 by Dr Harsh Vardhan, Hon'ble Union Minister of Health and Family Welfare along with Prof Balram Bhargava, Secretary DHR and DG, ICMR and other dignitaries and online participants to mark the 10th Foundation Day of ICMR-NCDIR, Bengaluru.
7. Guidance document for appropriate recording of COVID-19 related deaths in India was developed to ensure the correct reporting of deaths due to COVID-19 in May 2020.
8. National Guidelines for Ethics Committees Reviewing Biomedical & Health Research during Covid-19 Pandemic was released in April 2020. It was one of the first such guideline across the world.
9. SOP Template for Emergency EC meeting during COVID-19 Pandemic, April 2020 for the conduct of ethics review in an emergency situation was released in April 2020.
10. The ICMR Consensus Guideline on Do Not Attempt Resuscitation (DNAR) prepared by ICMR Bioethics Unit has been published as Policy Document in Indian Journal of Medical Research (IJMR) and The National Medical Journal of India (NMJI) during 2020-21.

CANCER

COMPLETED ACTIVITIES

1. Report on National Cancer Registry Programme, 2020



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The Report of National Cancer Registry Programme, 2020 was released on 18th August 2020 by Director General, ICMR.

The Key elements of the report are as follows:

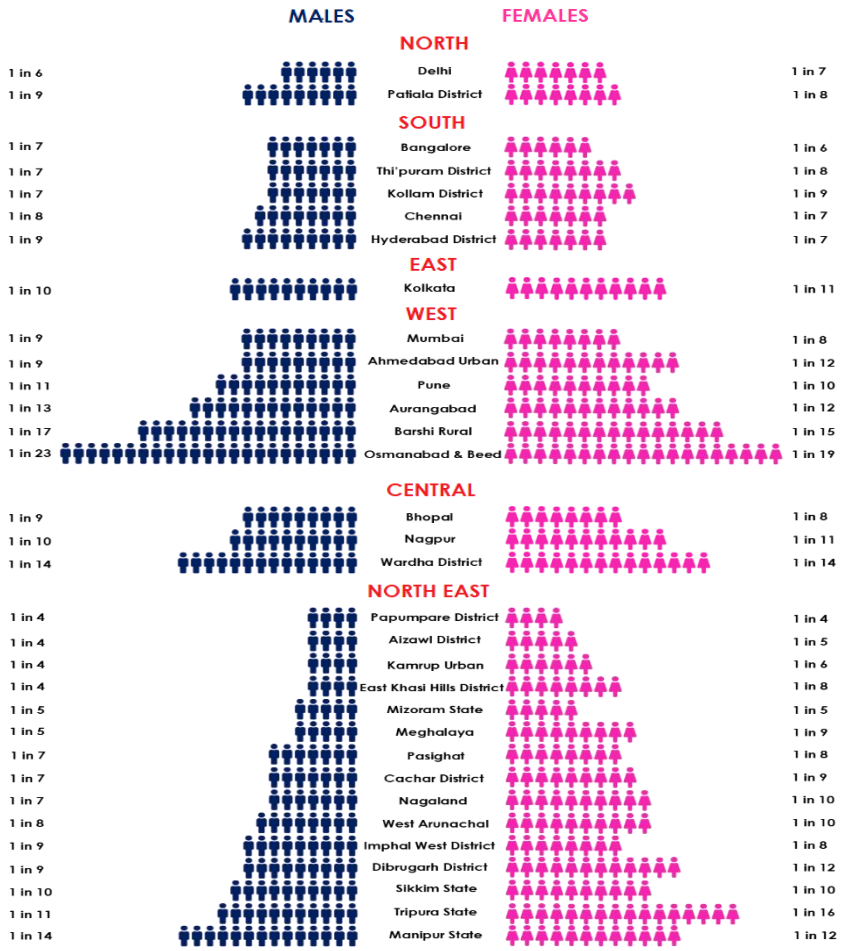
- Covers a five-year data (2012-2016) from 28 PBCRs and 58 HBCRs.
- The data is represented zone wise for six zones: North, South, East, West, Central and North East.
- Besides data on cancer incidence, mortality, leading sites and clinical data, the report also includes detailed anatomic site-specific data for some leading cancers- breast cancer, cervical cancer, head and neck cancer, cancer of the lung and stomach and projected number of cancer cases till 2025.

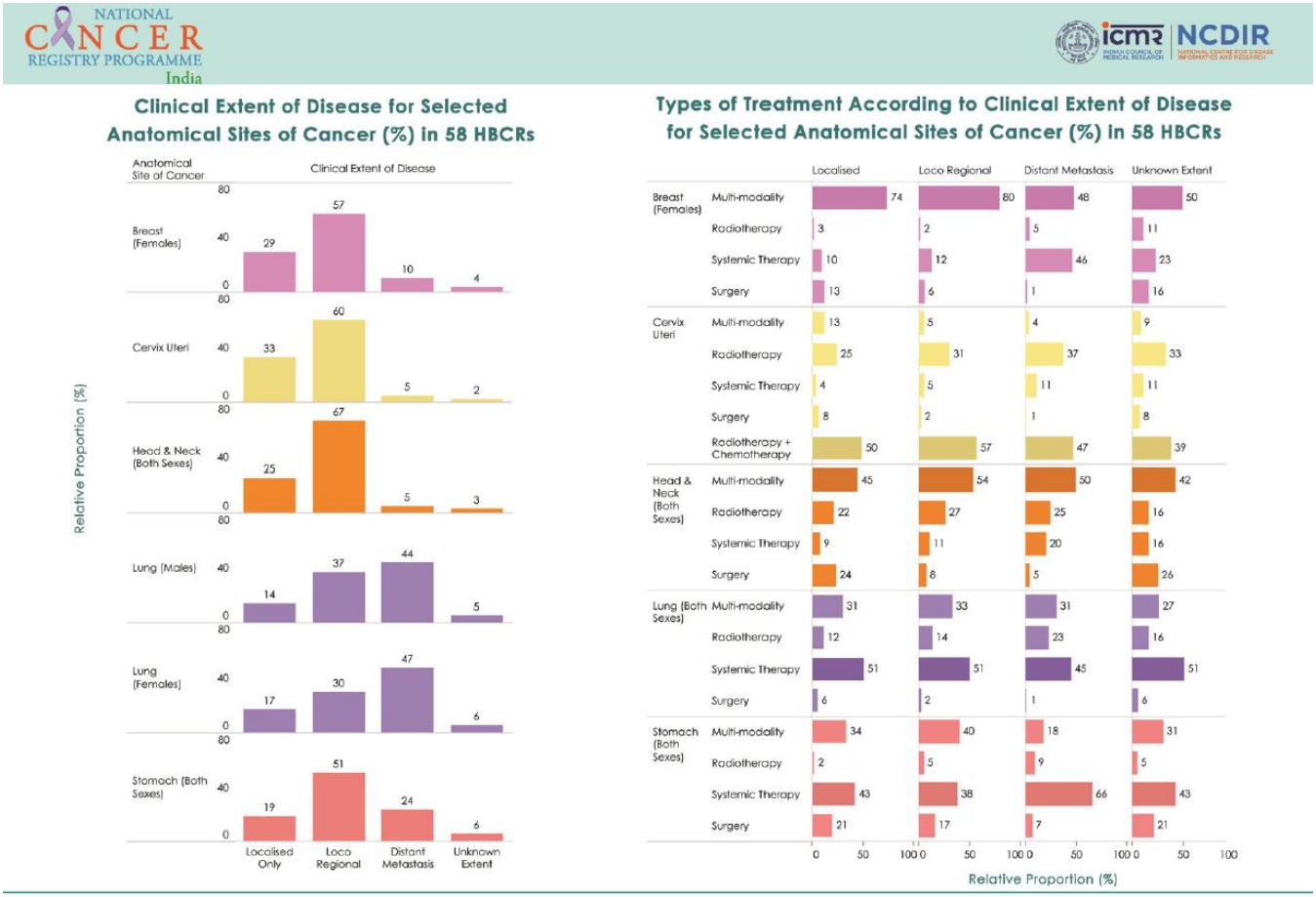
Summary of Report Findings:

- The highest incidence of cancer in India was observed in the north eastern region.
- Cancer of lung, mouth, stomach and oesophagus were the most common cancers in men.
- Cancer of breast and cervix uteri were the most common cancers in women.
- The highest burden of cancer breast was observed in metro cities.
- The highest burden of cancer in the north east were seen in the cancers of the oropharynx, nasopharynx, hypopharynx, oesophagus, stomach, liver, gall bladder, larynx, lung and cervix uteri.
- Cancer thyroid incidence rate is on the rise and it was most common in the districts of Thiruvananthapuram and Kollam in Kerala.

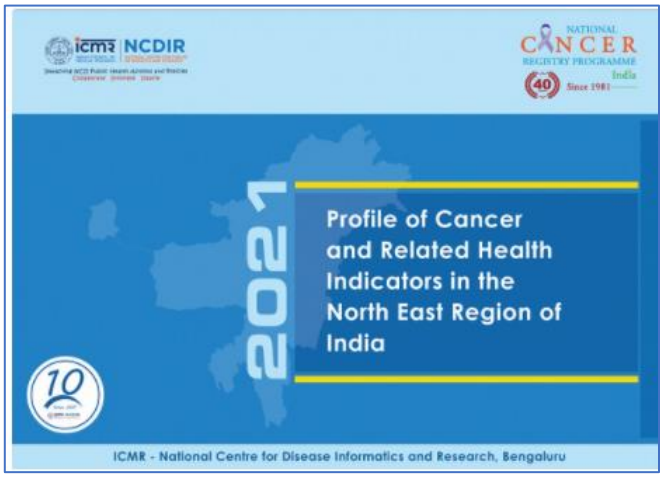
- The highest incidence rate of childhood cancer was seen in Delhi.
- Leukaemias and Lymphomas were the most common types of childhood cancers.
- Mouth cancer incidence rate was high in the PBCRs in western and central India.
- There is a rise in the trend of incidence of cancer breast, while cancer cervix uteri is on the decline.
- Majority of cancer breast and cervix uteri were diagnosed at locoregional stage.
- Chemo radiation was the most common type of treatment for cancer cervix uteri.
- Multimodality was the most common treatment given for cancer breast and head & neck cancers.
- Majority of lung and stomach cancers were diagnosed in advanced stage.
- Systemic therapy was the most common type of treatment given for cancer lung and stomach.
- Aizawl district in males and Papumpare district in females had the highest incidence rate of cancer stomach when compared with Non-Asian countries.
- In Asia, Aizawl district had the highest incidence rate of cancer lung in females.
- Cancer burden is estimated to increase to 1.57 million by 2025 in India from 1.39 in 2020.
- Tobacco related cancers are estimated to constitute 27% of all cancers in India.

Cumulative Risk of developing Cancer of any site in 0-74 years of Age in 28 PBCRs under NCRP





2. Profile of Cancer and Related Health Indicators in the North East Region of India – 2021



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The report has been released on World Cancer Day i.e., on 4th February 2021. The Report includes cancer data compiled by eleven PBCRs in all the eight states, and six HBCRs in four states (Assam, Manipur, Mizoram and Tripura) for 2012-2016. The Report presents a state wide cancer profile based on a pooled analysis of PBCR and HBCR data, and a state-wise cancer profile estimated from PBCR data. The state wide Report of pooled data also includes analysis of cancer incidence for specified districts-Imphal

West (Manipur), Aizawl (Mizoram), East Khasi Hills (Meghalaya)and Papumpare (Arunachal Pradesh).

The state wise presentation of cancer data is supported by a preceding description of relevant health indicators obtained from reliable data sources. The health indicators include socio-demographic profile, behavioural and metabolic risk factors, health seeking behaviour and health system status in terms of infrastructure and medical certification of cause of death.

Summary of Report findings:

- Northeast part of India have high burden of cancer compared to other region in India
- Highest cancer incidence: Males –Aizawl district, Mizoram (269.4 cases per 100,000) and Females - Papumpare district, Arunachal Pradesh (219.8 per 100,000).
- Less than one-third of breast, cervix, head and neck, stomach and lung cancer are in localized stage at the time of diagnosis.
- The proportion of cancer patients seeking treatment outside NER is highest for Sikkim (95.3%) followed by Nagaland (58.1%)
- Projected no of cases - 57,131 cancer cases in the region in 2025.
- Report will find wide use among stakeholders, from policymakers to laypersons, in understanding cancer profile in the northeast region and framing control measures.

3. Exploratory study to Standardize PCR Tests on Paraffin Sections to Detect *Helicobacter Pylori* and Compare with other Detection Tests

This is a collaborative project of NCDIR, Bengaluru and National Institute of Cholera and Enteric Diseases (NICED), Kolkata. The objective was to assess validity of PCR tests in identification of Helicobacter pylori in gastric biopsy samples as compared to other diagnostic tests (Rapid Urease Test and Serology) in patients with gastro -duodenal diseases (Nonulcer dyspepsia, peptic ulcer, gastroesophageal reflux disease, gastric cancer). The methodology of extraction of H.pylori from paraffin sections of gastric tissues was established.

Key Findings:

The study found that Rapid Urease test was positive in 38% of biopsy samples (n=68/178). Similarly, UreB gene positivity was detected by multiplex PCR test in culture (37.6%) and paraffin sections (38%) of the samples. Sensitivity and the specificity of PCR - paraffin section (UreB-F / UreB-R) as compared to the Rapid Urease test as gold standard were 88.23% and 92.7% respectively. Virulence factors VacA alleles (s1m1, s2m2, s1m2) (85%) and CagA (61%) were detected in the paraffin section samples positive for UreB gene(n=68) by multiplex PCR. The feasibility of DNA extraction for PCR tests to detect primers UreB, CagA and vac A (s and m region) by multiplex PCR was demonstrated.

Any future nationwide studies to understand H pylori infection in gastric cancer and lymphomas may be planned using multiplex PCR on paraffin sections of biopsy samples.

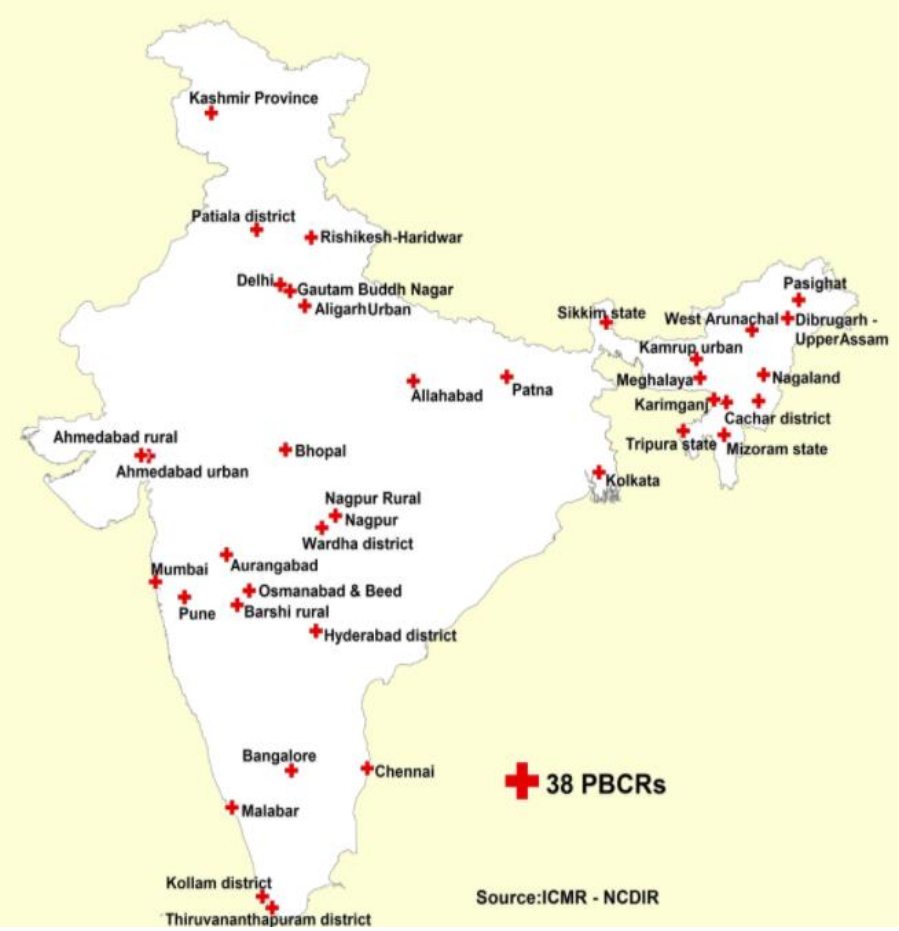
ONGOING PROJECTS / ACTIVITIES

1. Population Based Cancer Registries (PBCR)

The PBCRs collect data on the new occurrence of cancer and deaths in a defined geographical area for a specific time period. There are 38 Population Based Cancer Registries under the National Cancer Registry Programme (NCRP), the earliest being established in 1981. They cover 10% of the Indian population and are functioning at different cities and districts across the country. With the inclusion of Tamil Nadu Cancer Registry Programme (TNCRP), the coverage of PBCR's under NCRP increased to 15%. It covers 32 districts of Tamil Nadu (7.21 crores population as per census 2011).

These registries capture and process the data in the in-house developed software provided by ICMR - NCDIR. NCDIR monitors the data, evaluates it for quality, seeks clarifications and analyses the clean data to generate burden & distribution of cancer cases and changes over time.

A PBCR at R.S.T. Regional Cancer Hospital & Research Centre, Nagpur covering Nagpur rural has been initiated during 2020-21.



Network of PBCR

2. 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. The study is ongoing in 25 PBCRs across the country. Patients diagnosed from the year 2012 have been followed up regularly (at least five years from the date of first diagnosis of cancer). Registries have been submitting the follow-up data to NCDIR-NCRP. Quality checks have been done for the registries who have submitted complete data.

A photo of PBCR registry staff doing follow-up during home visit @ Meghalaya

- PBCRs have submitted updated five-year follow-up data for the years 2012-14 (diagnosed year) (24 out of 25 PBCRs) and for 2015 (15 out of 25 PBCRs)
- 13 PBCRs have follow-up of >70% (as on 31/12/2020) for the year 2012-2014
- 9 PBCRs have follow-up of >70% (as on 31/12/2020) for the year 2015

3. Hospital Based Cancer Registries (HBCRs)

The following 15 new centres have been registered for Hospital Based Cancer Registries under the network of NCDIR-NCRP during 2020-21.

Sl No.	Name of the Centre
1	A A Rahim Memorial Government District Hospital, Kollam
2	All India Institute of Medical Sciences, Bathinda
3	Andaman and Nicobar Islands Institute of Medical Science, Port Blair
4	Government Medical College, Kottayam
5	Government Medical College, Patiala
6	Institute of Post-Graduate Medical Education and Research (IPGMER) and Seth Sukhlal Karnani Memorial Hospital (SSKM) Hospital, Kolkata
7	Jawaharlal Nehru Institute of Medical Science, Imphal
8	Mahatma Gandhi Institute of Medical Sciences, Sevagram, Wardha
9	Mahatma Gandhi Medical College and Research Institute, Puducherry

10	Narayana Multispeciality Hospital, Ahmedabad
11	Narayana Multispeciality Hospital, Mysore
12	Narayana Superspeciality Hospital, Howrah
13	Shri Mata Vaishno Devi Narayana Superspeciality Hospital, Katra
14	Silchar Medical College and Hospital, Silchar
15	Zoram Medical College, Aizawl

Training Activities under HBCRs:

a. Training session for COVID section - Cancer Registries 07th and 8th Sep 2020 for all the HBCRs
b. Training workshop for newly registered Hospital Based Cancer Registries on 03rd Dec 2020 and 07th Dec 2020

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

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

The objectives include -

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

Meetings and Workshops:

Online data review meeting with the Principal investigators (PIs), CO-PIs of the study centres on 22nd December 2020.

Online Training workshop for the data entry operators of the study centres on 6th January 2021

Interim Analysis:

A total of 854 **Haematolymphoid cancer** cases and a total of 910 **Gynaecologic cancer** cases were received.

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

This multicentric longitudinal study has been initiated in ten hospitals, mainly in India's northern & eastern part to 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.

The primary objectives include –

- obtaining a detailed pattern of care (diagnosis and management) for GBCs,
- estimating demographic (Overall) survival for GBCs and
- identifying the epidemiological and clinical determinants of survival and estimating their effect.

List of Participating Centers

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

Meetings Conducted:

Online data review meetings were conducted with the Principal investigators (PIs), CO-PIs of the study centres on 25th September 2020 and 23rd December 2020.

Online data review meeting with the Principal investigators (PIs), CO-PIs of the study centres on 23rd December 2020

6. 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 analyze 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. Under ICMR Gall Bladder Task Force, the project has been initiated from December 2018. This multicentric cross-sectional study has been initiated in five hospitals having HBCRs in India.

List of Participating Centers:

Centre Name
Assam Medical College, Dibrugarh
Government Medical College and Hospital, Chandigarh
Indira Gandhi Institute of Medical Sciences, Patna
Sanjay Gandhi Post Graduate Institute of Medical Sciences, Lucknow
Vydehi Institute of Medical Sciences, Bangalore

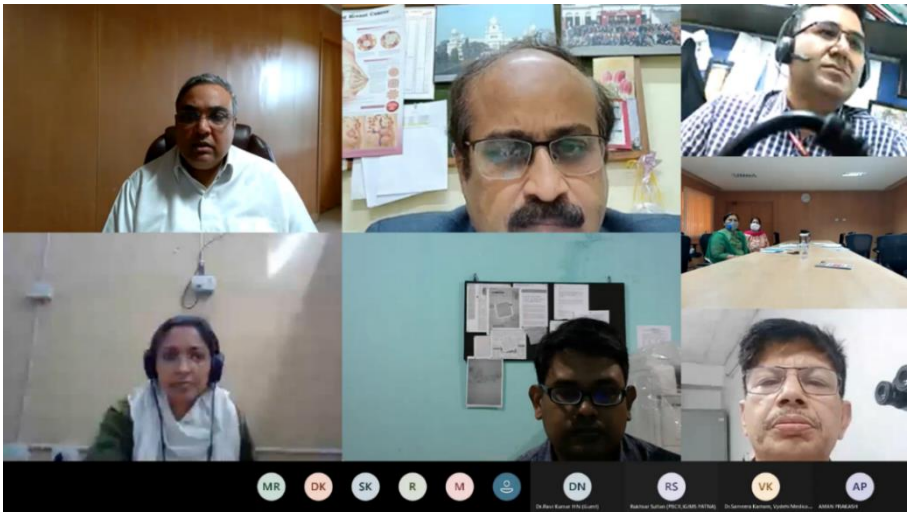
Progress:

1. **Quality Assurance Activities**:
   - Quality assurance (QA) team has developed a protocol for the selection of slides for carrying out reviews.
   - A training workshop was conducted by the QA team for the pathologists of all the IGBC study centres on 7th December 2020.

2. **Training Workshops:** Online training workshop for senior research fellows of IGBC study centres was conducted on 30th April 2020, 4th and 5th May 2020.

3. **Data Review Meetings:** Online data review meetings were conducted on 5th October 2020 and 31st December 2020.

4. **Development of Dashboard** for monitoring of cases filled and Quality control of slides was done.



Online workshop on Quality assurance and hands on training for pathologists for IGBC project on 7th December 2020

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

Owing to India's increasing cancer burden and disparities in access to diagnostic and prognostic tests for cancer, DHR-ICMR Advanced Molecular Oncology Diagnostic Services (DIAMOnDS), a multicentric study was initiated. 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. The diagnostic facilities will be provided in ten leading cancer hospitals across the country. This study has been initiated initially for lung and breast cancers wherein the biomarkers are available for these cancer patients.

NCDIR will serve as a Data Management Centre for the DIAMOnDS centres with the objectives –

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

List of Participating Centres:

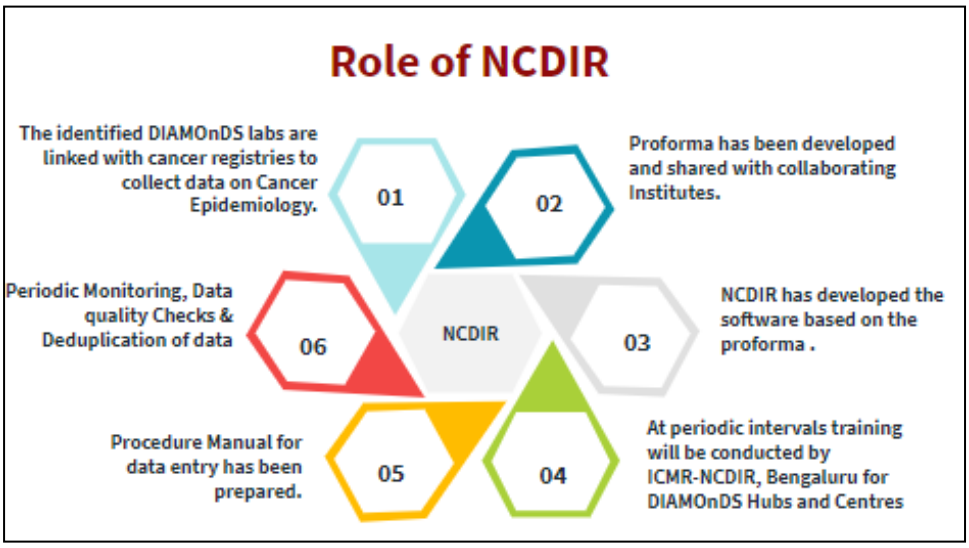
Sl. No	Centre Name
1	All India Institute of Medical Sciences, New Delhi
2	Christian Medical College, Vellore, Tamil Nadu
3	Cachar Cancer Hospital, Silchar, Assam
4	Regional Institute of Medical Sciences, Imphal, Manipur
5	Tata Memorial Hospital-Mumbai
6	Super specialty Cancer Institute, Lucknow

7	Tata Medical Center, Kolkata
8	All India Institute of Medical Sciences, Jodhpur, Rajasthan
9	Jawaharlal Institute of Postgraduate Medical Education and Research, Pondicherry

Meetings and Workshops Conducted:

a. Orientation cum training meeting for DHR-ICMR Advanced Medical Oncology Diagnostic Services (DIAMOnDS) was held on 2nd July 2020.
b. Online training workshop for the DIAMOnDS centres project staff and their respective HBCR staff was conducted on 31st July 2020, 6th August 2020 and 10th September 2020.

Role of NCDIR in the DIAMOnDS project:



8. Monitoring Survey of Cancer Risk Factors and Health System Response in the Northeast Region of India

This study aims to generate key cancer and other NCD related risk factors and health system response indicators in the 12 Population Based Cancer Registries (PBCR) in 8 states of North East India. The sample size for the survey has been calculated to be 23,040 adults above the age of 18 years spread across a total of 480 Primary Sampling Units (PSUs) in the 12 registry areas. The study has been completed in 11 of the 12 PBCR covered areas. State wise and overall survey report will be prepared.

9. Call for Proposals under CaRes 2020

Following the successful implementation of 'Call for proposals' in 2019-2020, a similar round of call was made for the year 2020-21, as a part of the CaRes NER multidisciplinary programme. Under this national call, proposals were invited from interested investigators to perform research in the priority areas in any part of India's North-Eastern states, ranging from prevention to policy research. A total of 29 submissions were received, of which a Technical Review Committee reviewed 24

proposals that met the eligibility criteria. Based on the scoring, the prospective PIs' of eight shortlisted proposals were invited to do a presentation through a web-based technical review meeting. Four proposals have been selected for consideration for funding.

STROKE

ONGOING PROJECTS

1. Development of Population Based Stroke Registry (PBSR) in Different Regions of India

The main objective of the PBSR is to generate reliable data on the magnitude and incidence of stroke. Five Population Based Stroke Registries in one geographical area each from the south (Tirunelveli), north (Varanasi), east (Cuttack), west (Kota) and north east (Cachar) regions of India are functioning.

Meetings and Training Workshop:

a. Online meeting to assess functionality status of PBSRs during COVID 19 lockdown & Research agenda for stroke & COVID-19 on 15th May 2020.
b. Training workshop for the newly recruited staff (statistician and Field workers) of Tirunelveli Medical College, Tirunelveli through video conference on 18th June, 2020.
c. Online training of COVID-section for all PBSRs on 2nd September 2020.

Data Management:

- PBSR centres have completed data submission for 2018 and 2019. The Quality of data was reviewed by the RAP and further discussed with the Principal Investigators of PBSRS in December 2020 for all the centres.
- Data collection and quality checks for 2020 is ongoing.

Software Development:

- Introduction of COVID-19 form in data entry form
- New checks (range and consistency) on variables are introduced in the data entry form
- Automatic email reminders for follow up to centres on regular intervals (once in a week). The email contains list of cases are due for follow up in upcoming week.
- Additional option to perform de-duplication of all cause mortality data with incidence cases
- Matching incidence cases with all-cause mortality data.
- Advance Search menu and Verified Quality Check list

2. HTA of National Stroke Care Registry Programme: Development of Hospital Based Stroke Registries (HBSR) in Different Regions of India

The Hospital Based Stroke Registry, sanctioned under the Health Technology Assessment projects of Department of Health Research is being implemented by ICMR-NCDIR with the objectives to generate reliable data on pattern of stroke, pattern of care and treatment for stroke.

The project was approved by DHR on 20th December 2018 and in the first two years (2019, 2020) 20 centres have joined, including 5 centres where Population Based Stroke Registries were existent. The following centres have registered during 2020-21.

Sl. No	Name of the Centres
1	All India Institute of Medical Sciences, Rishikesh
2	All India Institute of Medical Sciences, Jodhpur
3	All India Institute of Medical Sciences, Bhopal
4	All India Institute of Medical Sciences, Bhubaneswar
5	Ashwini Hospital, Cuttack
6	Galaxy Life Care Services, Varanasi
7	Sri Venkateswara Institute of Medical Sciences (SVIMS), Tirupati
8	Jaiswal Multispeciality Hospital & Neuro Institute, Kota
9	Post Graduate Institute of Medical Education & Research, Chandigarh
10	Sanjay Gandhi Postgraduate Institute of Medical Sciences, Lucknow

Meetings and Training Workshop:

a. Training workshop on usage of HBSR software application was conducted through video conferencing for the first 10 HBSRs on 6th July 2020.
b. HBSR Sensitization & Training Workshop on 19th August, 2020.
c. HBSR Sensitization & Training Workshop" for staffs of 3 HBSRs (AIIMS, Rishikesh, AIIMS, Jodhpur & AIIMS, Delhi) on 15th September 2020.
d. Discussion with experts on Development of Standard reporting format to collect imaging information in stroke registries on 18th September 2020.
e. A sensitization & training workshop on HBSR software and newer updates was held on 29th December 2020.
f. A sensitization & training workshop was held on 6th January 2021 for the newly joined HBSRs.
g. Training on ICD-10 for PBSR and HBSR staff on 25th March 2021.

Software Update:

Following new options were added in databases.

- HBSR Registration module has been developed.
- Core form request for centres
- Search and edit option including advance search

- Prospective: weekly once at Monday 10 am. (upcoming week due for follow ups list with pdf attached)
- Retrospective: every Month 1st at 9.45 am (Number of cases pending for follow-up as on end of the month pdf attached)
- Admin console to view data status of each centre (month wise/ Centre wise) and audit reports put in place
- Dashboard changes to display total cases entered and cases pending for follow up
- Auto Mail option (Prospective and Retrospectively)

COVID Section in HBSR and PBSR:

- In order to describe the neurological manifestations of COVID-19, and to understand the presence of COVID -19 infection among patients admitting for stroke, a COVID-19 section is included in the Population and Hospital based Stroke registry to capture the information on COVID-19 in patients registered in the PBSR and HBSR. Since, COVID -19 is a new disease, PBSRs and HBSRs are better placed to capture this information.

DIABETES

ONGOING PROJECT

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

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 pre-diabetes and diabetes.
- to estimate the burden of pre-diabetes, diabetes and its complications, and co-morbid NCD conditions in defined rural populations.

Four MRHRU linked medical colleges are the participating centres.

1. Grant Medical College and JJ group of Hospitals, Mumbai.
2. Raichur Institute of Medical Sciences, Raichur.
3. Agartala Medical College, Tripura.
4. SCB Medical College, Cuttack.

Training Workshop:

Training of the field investigators under Diabetes National Model Study at participating centres were conducted during 2020-21.

1. Online training on study tools and methodology was conducted for field investigators under DNMS at Grant Medical College, Mumbai during February 22-26, 2021
2. In-house training for field investigators at Raichur Institute of Medical Sciences, Raichur on study methodology, study tools, field operations with practical mock exercises and data entry tool (tablet based android software) was conducted on March 08-12, 2021
3. Online training on data entry tool (tablet based android software) for field investigators at Grant Medical College, Mumbai was conducted during March 31st – April 1st, 2021

Mock exercise of field investigators from Raichur Institute of Medical Sciences, Raichur conducting health facility assessment at Sadahalli PHC – March 10th, 2021

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

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

CARDIOVASCULAR DISEASES

ONGOING PROJECT

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

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

All five participating centres are transmitting the data. COVID-19 section has been included in the core form after the approval from ICMR - NCDIR scientific committee, to find out cardiovascular manifestations of COVID-19 and its pathophysiology among Heart Failure cases. The COVID 19 data will be collected from all the cases registered for the study at the time of discharge and during each of the follow ups done at 30 days, during 30-90 days and 90-180 days. The COVID 19 section in the core form has been designed and sent to all centres to start data collection from February 2020 onwards. Software also has been updated to include COVID 19 section.

Training Workshop:

a. Online meeting to assess functionality status of Heart Failure centres during COVID 19 lockdown & Research agenda for CVD & COVID-19 on 18th May 2020

b. Online discussion on inclusion of COVID section for Heart Failure study with all centres on 17th July 2020
c. Online training workshop of COVID section in Heart Failure study for all centres on 4th September 2020
d. Online training on Software updates of Heart Failure study on 27th January 2021

Software Developments:

- The homepage infographics has been re-designed to include follow up data
- Option provided to partially save & edit data until first follow up
- Pop-up alert at the time of data entry for consistency errors, range check and missing values alert before submitting the data
- Option provided for centres to download pending follow up cases list
- Quality check module updated to include more consistency error checks and duplicate checks
- Audit trail module
- Covid-19 module

MORTALITY

The NCDIR electronic mortality (NCDIR e-Mor) software is being implemented in hospitals with the aim to strengthen the Medical Certification of Cause of Death (MCCD) and to enable hospitals to build databases for mortality audit.

ONGOING PROJECTS / ACTIVITIES

1. Implementation of NCDIR Electronic Mortality Software (NCDIR e-Mor) in Hospitals of the National Cancer Registry Programme (NCRP) Network in Northeast India

2. Implementation of NCDIR Electronic Mortality Software (NCDIR e-Mor) – Strengthen Medical Certification of Cause of Death

Eight centres have registered to implement the NCDIR e-Mor in the state of Puducherry, Uttar Pradesh, Madhya Pradesh, Jammu, Karnataka, Chhattisgarh, Assam and Uttarakhand during the year 2020-21.

Activities Completed:

a. Following the release of emergency use of ICD-10 codes for COVID-19 by the World Health Organization, the COVID-19 ICD codes U 07.1 and U07.2 were integrated to the e-Mor software.
b. Guidelines of ICD codes for COVID 19 deaths were developed and disseminated on 9th April 2020 to all hospitals implementing the e-Mor software, and to the Civil Registration systems - Dept of Public Health, Tamil Nadu and

Directorate of Economics and Statistics, Karnataka. The Chief Registrars disseminated the guidelines to all districts. Training on recording COVID-19 as cause of death with examples was done for all centres in a series of online trainings.

c. Online training workshops for PIs, Co-PIs and recruited staffs under both projects was conducted on 13th August 2020, 28th August 2020, 2nd November 2020 and 7th January 2021. The training focussed on process of medical certification of cause of death in India, record and reporting cause of death, building mortality audit systems in hospitals and recording COVID-19 as cause of death using the ICMR-NCDIR e-Mor software.

3. NCDIR Collaborations in Setting up State wide e-Mor program

Efforts are ongoing to implement eMor in Tamilnadu and Karnataka. Discussion with officials of the Chief Registrar of Births and Deaths on implementation of e-Mor in Punjab, Goa, Maharashtra and Jharkhand have been completed. Training of medical officers of Goa on MCCD and e-Mor has been completed.

4. Guidance for appropriate recording of COVID-19 Related Deaths in India

- ### Guideline Development

Guidance document on the principles of Medical Certification of cause of death for recording COVID-19 as cause of death and its public health significance was developed and released in May, 2020. This document addressed the huge gap in recording COVID-19 as cause of death due to the poor knowledge on MCCD and also as this was a new disease, the principles of assigning cause of death was not clear. The guidance document was released in the websites of ICMR-NCDIR (https://ncdirindia.org/Downloads/CoD_COVID-19_Guidance.pdf) and ICMR.

- ### Advocacy with State Governments

It was widely disseminated to all Principal Secretaries of Health of states and union territories by DG, ICMR. It was used by several states and the death audit committees as the official document for assigning Cause of death for COVID-19. The document has been uploaded in the websites of states of Karnataka, Odisha, Himachal Pradesh, West Bengal, Haryana and Maharashtra, Goa, Jharkhand, Uttarakhand have officially circulated the guidance to all Districts.

NON COMMUNICABLE DISEASES

COMPLETED PROJECTS / ACTIVITIES

1. National Noncommunicable Disease Monitoring Survey (NNMS) – 2017-18

The ICMR- National Centre for Disease Informatics and Research (NCDIR) has implemented the survey at the behest of the Ministry of Health and Family Welfare, Govt. of India to monitor the progress made at the national level towards achieving the national NCD targets by 2025. It has been undertaken in partnership and collaboration with eleven implementing agencies across India.

The National Noncommunicable Disease Monitoring Survey (NNMS) report was released by the Honourable Union Health Minister, Dr Harsh Vardhan on 25th of January 2021.

Weblink: https://www.ncdirindia.org/nnms/

Primary Objective:

- To generate national level estimates of key NCD related indicators (risk factors and health systems response) identified in the National NCD Monitoring Framework for the year 2017 -18.

Secondary Objectives:

- To set a baseline to track changes and monitor future trends in the prevalence of risk factors associated with NCDs at the National level.
- To create a central and regional pool of resources (Capacities protocols, standard tools, training manuals etc.) to support conduct of similar surveys at state level.

Measurements in the Survey:

The survey mainly focussed on NCD risk factors, health seeking behaviours and health facility responses to NCDs, that include tobacco use (smoke or smokeless), alcohol use, dietary habits including salt intake, physical measurements, physical activities, body mass index, fasting blood sugar and blood pressure. This information has been collected using standard interview schedules installed in ODK software in handheld devices by qualified medical social workers. The study was conducted in a total of 600 primary sampling units (PSUs); 300 Urban and 300 Rural. From every PSU, 20 households were selected amounting to a total of 12000 households. The survey participants included one adult (18 – 69 years) and all adolescents (15 - 17 years) from the 20 selected households. Spot urine sample of 3000 participants have been collected from a total of selected 150 PSUs for estimation of 24-hour dietary salt intake.

Key Survey Findings:

Two in every five adults had three or more risk factors for NCDs and a quarter of adolescents were not doing sufficient physical activity. Only every two in five and one in five adults (30-69 years) got their blood pressure and glucose levels measured in last 1 year preceding the survey. Primary and secondary public health care facilities were not fully prepared to address NCDs. The survey recommends developing prioritized NCD research agenda and setting up of NCD Surveillance units to manage the rising burden of NCDs in India.

2. National Burden of Noncommunicable Diseases and Associated Risk Factors – Cancer Working Group

Objectives:

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

Methodology:

In order to quantify the burden of cancer, standard methodology by WHO was followed by using the DISMOD-II software. The main inputs were mortality, incidence and case fatality rates. These parameters were obtained from the population-based cancer registry (PBCR) of the NCRP program. By using these three inputs the prevalence, remission rate etc. was calculated from the DISMOD-II (output). Years of life lost (YLL) due to premature death was calculated by multiplying total number of deaths in each age group by the life expectancy of each age group at the time of death; Years lived with disability (YLD) was estimated by multiplying prevalence with disability weight for

cancer. Sum of calculated YLL and YLD gave the burden of cancer by DALYs for overall cancer, site wise, gender wise and region wise.

Key Findings:

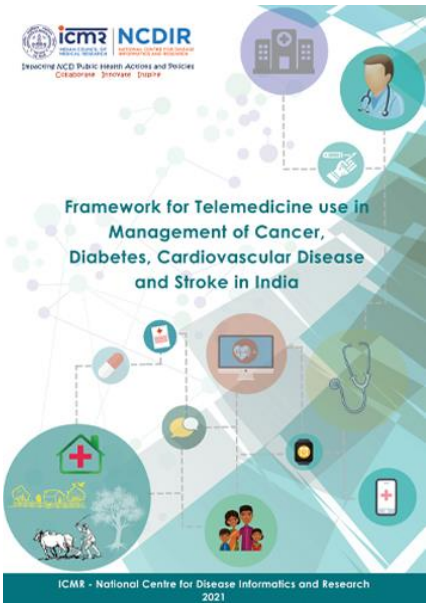
The estimated cancer DALYs for India was 17.6 million, highest contribution from cancer in central region. More than half of the total cancer DALYs were contributed by 65 years and above age groups. Lymphoid leukaemia contributed to highest DALYs among 0-14 years, testicular cancer among males in 15 - 34 years age group, lung cancer and breast cancer were highest among the age group 60+ followed by 35 – 59 years. Breast cancer and lung cancer were the leading cancer sites contributing to highest DALYs in females and males, respectively. Lung cancer (9.5%), breast cancer (9.4%), cervix uteri (8.1%), ovary(6.1%) and oesophageal cancer (5.1%) contributed to more than 5% of total DALYs among both males and females.

3. Telemedicine Practice Guidelines for Noncommunicable Diseases

Development of telemedicine guidelines on major NCDs (Cancer, Diabetes, Cardiovascular Diseases, Stroke) was done by NCDIR and Working groups of experts with the objectives –

- to provide a framework for using telemedicine for preventing and managing major non-communicable diseases by public and private healthcare providers; and
- to ensure continuity of care & to empower patients & health care providers.

The guidelines titled 'Framework for Telemedicine Use in Management of Cancer, Diabetes, Cardiovascular Diseases and Stroke in India' was released as e-Book by the Union Minister for Health and Family Welfare Dr Harsh Vardhan on the occasion of the Foundation day and launch of the Decadal year of NCDIR on 25th January 2021, and is available at



Weblink:
https://ncdirindia.org/All_Reports/Telemedicine/resources/Telemedicine_eBook.pdf

ICMR BIOETHICS UNIT

COMPLETED PROJECTS / ACTIVITIES

1. Constitution of COVID-19 National Ethics Committee (CoNEC) 6th April 2020- 5th May 2020
2. Reconstitution of the ICMR- Central Ethics Committee on Human Research (CECHR) since 6th May 2020
3. National Guidelines for Ethics Committees Reviewing Biomedical & Health Research during COVID -19 Pandemic, April 2020
4. SOP Template for Emergency EC meeting during COVID-19 Pandemic, April 2020
5. ICMR Training programs in Research Ethics
6. Dissemination of ICMR National Guidelines for Ethics Committees Reviewing Biomedical & Health Research during COVID-19 Pandemic, April 2020
7. Coordination with NECRBHR, DHR for Registration of Ethics Committee and related activities
8. Activities of WHO Collaborating Centre (WHO-CC) for Strengthening Ethics in Biomedical & Health Research
9. Activities and Guidelines of Council of International Organizations of Medical Sciences (CIOMS)
10. An International Survey of Ethics Committees (ECs)/ Institutional Board Review (IRBs): Challenges and Practices Arising During Public Health Emergencies (PHEs) sponsored by WHO.
11. Updation of ICMR Bioethics Unit Webpage
12. Miscellaneous Activities

Details of Activities:

1. Constitution of COVID-19 National Ethics Committee (CoNEC) 6th April 2020 to 5th May 2020

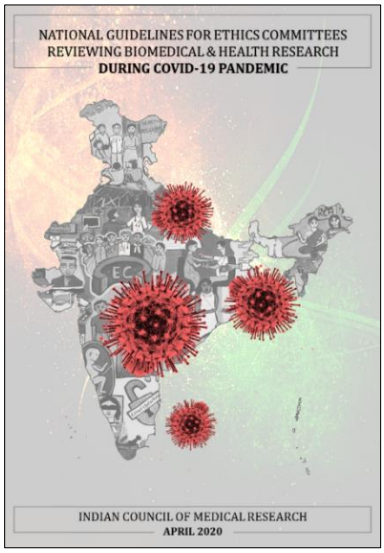
The global pandemic of Novel Coronavirus COVID 19 necessitated appropriate research to inform public health actions, and ICMR with its network of institutions planned to conduct a number of such studies. In this regard, Director General, ICMR, had constituted a special ethics committee "ICMR COVID 19 National Ethics Committee (CoNEC)" to undertake high priority expedited ethics review of COVID19 research. It was a small committee of 5 members to meet and undertake ethics review virtually. The scope was limited to the review of COVID-19 research. This committee carried out ethics review of ICMR led research and was also instrumental in guiding ICMR Bioethics Unit in the preparation, review and finalization of the National Guidelines for Ethics Committee reviewing Biomedical research during the Pandemic.

2. Reconstitution of the ICMR- Central Ethics Committee on Human Research (CECHR) since 6th May 2020

ICMR-Central Ethics Committee on Human Research (CECHR) is multidisciplinary and multi-sectoral in composition and functions as per ICMR National Ethical Guidelines for Biomedical and Health Research Involving Human Participants, 2017 and New Drugs and Clinical Trials Rules, 2019. ICMR Bioethics Unit serves as the Secretariat for the CECHR. In order to undertake high priority quality ethics review of COVID-19 related biomedical and health research and the committee was reconstituted by DG ICMR. The committee has about 17 members including primary as well as alternate members with age, gender representation and to conduct reviews of all types of biomedical and health research studies, including both COVID-19 related and non-COVID research, led by ICMR. In the present COVID-19 pandemic situation to expedite the review process, the committee has been meeting virtually through web conference or tele/video conference. The committee has met regularly and reviewed more than 26 large multicentre research studies being led by ICMR Headquarters (with a short turn around time of 24-72 hours). In this regard, 20 virtual full committee meetings of ICMR-CECHR have been organized so far along with expedited and exempt from review of research proposals. It is proposed that the CECHR would take up a greater role and be involved in also closely guiding the development of all ethics policy documents, advisories and guidelines being coordinated by ICMR Bioethics Unit.

3. National Guidelines for Ethics Committees Reviewing Biomedical & Health Research during COVID-19 Pandemic, April 2020

In the ongoing COVID-19 pandemic situation, research has to be at the forefront in order to confront the novel challenges that have flared up in an unprecedented manner. In such a situation, safeguarding the rights, safety, welfare and dignity of the research participants becomes equally important, yet not compromising the response time for ethics review. In this regard, under the direction of DG ICMR, an initiative was taken to prepare a guideline document "National Guidelines for Ethics Committees Reviewing Biomedical & Health Research during Covid-19 Pandemic" and the draft was finalized after several deliberations by the expert group. The guidelines encouraged fast track but robust virtual EC review of proposals pertaining to COVID-19 to benefit the society in immediate future. It is expected that this guideline will be useful not only for ethics committees but for all stakeholders in research including researchers, sponsors and even public at large to inform them about the ethical conduct and review of research for ensuring participant safety and right at all time.

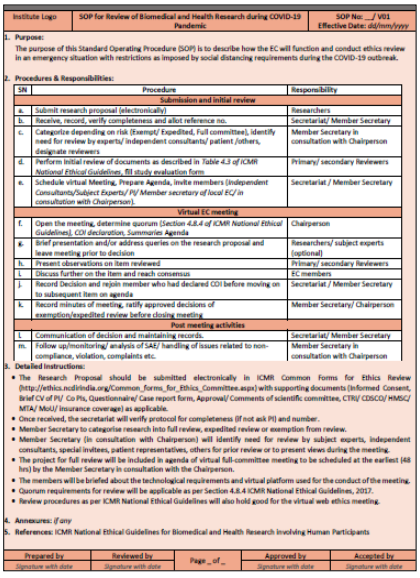


Reference: http://ethics.ncdirindia.org//asset/pdf/EC_Guidance_COVID19.pdf

4. SOP Template for Emergency EC Meeting during COVID-19 Pandemic, April 2020

The Standard Operating Procedure (SOP) template was developed to guide the Ethics Committee for the conduct of ethics review in an emergency situation with restrictions as imposed by social distancing requirements during the COVID-19 outbreak. The SOP can be adopted by EC reviewing biomedical and health research during Covid-19 Pandemic. The SOP template highlights the step by step procedure for submission and initial review of the protocol, virtual EC Meetings and post meeting activities. A table has been used for illustration which succinctly describes the roles and responsibilities of the EC Members and researchers during the conduct of EC Review of a submitted protocol. The template intends to serve as a handy reference for all ECs across the country to ensure facile and sturdy ethics review of not only COVID-19 related research but also other new and ongoing non-COVID health research.

Reference: http://ethics.ncdirindia.org//asset/pdf/SOP_Template_EC_COVID19.pdf



Institute Logo	SOP for Review of Biomedical and Health Research during COVID-19 Pandemic	SOP No: __/ V01 Effective Date: dd/mm/yyyy

1. **Purpose:**

The purpose of this Standard Operating Procedure (SOP) is to describe how the EC will function and conduct ethics review in an emergency situation with restrictions as imposed by social distancing requirements during the COVID-19 outbreak.

2. **Procedures & Responsibilities:**

SN	Procedure	Responsibility
	Submission and initial review	
a.	Submit research proposal (electronically)	Researchers
b.	Receive, record, verify completeness and allot reference no.	Secretariat/ Member Secretary
c.	Categorize depending on risk (Exempt/ Expedited, Full committee), identify need for review by experts/ independent consultants/ patient /others, designate reviewers	Member Secretary in consultation with Chairperson
d.	Perform initial review of documents as described in *Table 4.3 of ICMR National Ethical Guidelines*, fill study evaluation form	Primary/ secondary Reviewers
e.	Schedule virtual Meeting, Prepare Agenda, invite members (Independent Consultants/Subject Experts/ PI/ Member secretary of local EC/ in consultation with Chairperson).	Secretariat / Member Secretary
	Virtual EC meeting	
f.	Open the meeting, determine quorum (*Section 4.8.4 of ICMR National Ethical Guidelines*), COI declaration, Summaries Agenda	Chairperson
g.	Brief presentation and/or address queries on the research proposal and leave meeting prior to decision	Researchers/ subject experts (optional)
h.	Present observations on item reviewed	Primary/ secondary Reviewers
i.	Discuss further on the item and reach consensus	EC members
j.	Record Decision and rejoin member who had declared COI before moving on to subsequent item on agenda	Secretariat / Member Secretary
k.	Record minutes of meeting, ratify approved decisions of exemption/expedited review before closing meeting	Member Secretary/ Chairperson
	Post meeting activities	
l.	Communication of decision and maintaining records.	Secretariat/ Member Secretary
m.	Follow up/monitoring/ analysis of SAE/ handling of issues related to non-compliance, violation, complaints etc.	Member Secretary in consultation with Chairperson

3. **Detailed Instructions:**

- The Research Proposal should be submitted electronically in ICMR Common Forms for Ethics Review (http://ethics.ncdirindia.org/Common_forms_for_Ethics_Committee.aspx) with supporting documents (Informed Consent, Brief CV of PI/ Co PIs, Questionnaire/ Case report form, Approval/ Comments of scientific committee, CTRI/ CDSCO/ MMGC/ MTA/ MoU/ insurance coverage) as applicable.
- Once received, the secretariat will verify protocol for completeness (if not ask PI) and number.
- Member Secretary to categorise research into full review, expedited review or exemption from review.
- Member Secretary (in consultation with Chairperson) will identify need for review by subject experts, independent consultants, special invitees, patient representatives, others for prior review or to present views during the meeting.
- The project for full review will be included in agenda of virtual full-committee meeting to be scheduled at the earliest (48 hrs) by the Member Secretary in consultation with the Chairperson.
- The members will be briefed about the technological requirements and virtual platform used for the conduct of the meeting.
- Quorum requirements for review will be applicable as per Section 4.8.4 ICMR National Ethical Guidelines, 2017.
- Review procedures as per ICMR National Ethical Guidelines will also hold good for the virtual web ethics meeting.

4. **Annexures:** *if any*
5. **References:** ICMR National Ethical Guidelines for Biomedical and Health Research Involving Human Participants

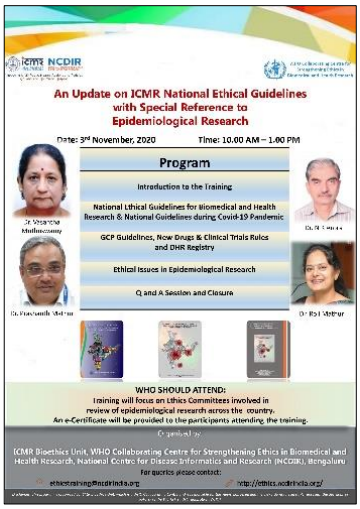
Prepared by	Reviewed by	Page _ of _	Approved by	Accepted by
Signature with date	Signature with date		Signature with date	Signature with date

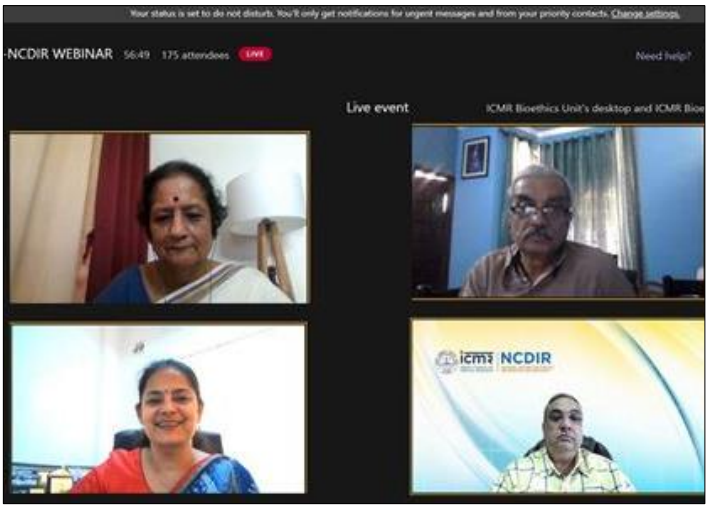
5. ICMR Training Programs in Research Ethics

Ethical conduct of research is of prime importance in strengthening national and global health at large and Ethics Committee training is one of the crucial factors for its implementation. There is an imperative need for organising training programs but due to the ongoing COVID-19 pandemic, from March 2020 the physical programs had to be cancelled due to the new requirements related to social distancing. However, 3 virtual training programs were organised where the online registration portal link was posted on relevant websites for registration of the participants to ensure maximum participation and outreach and the e-Certificates were provided to the participants. Each program was conducted and coordinated by an eminent panel of experts and panel discussion was one of the major highlights of all the programs which allowed for ample discussion.

a. ICMR Training on an Update on ICMR National Ethical Guidelines with Special Reference to Epidemiological Research on 3rd November 2020

ICMR Bioethics Unit organised a training program for relevant stakeholders involved in Epidemiology Research across the country. ICMR-NCDIR coordinated this training for ethics committee members from various Central/ Regional/ State medical institutions and medical colleges, non-governmental or private centres who were involved in the review of research related to establishing data collection for Registry purpose mainly focused on cancer, CVD, Diabetes and Stroke. The Webinar held on a virtual platform encompassed about 190 participants from around 159 institutes. The duration of this webinar was 3 hours. Subject Experts were invited as resource persons and the key highlights of the program were the ethical issues related to epidemiological research and registries. The participants were briefed about the recent ICMR National guidance on EC review during COVID-19 pandemic. The feedback received was very encouraging and the participants expressed their satisfaction and looked forward to more such trainings.





b. ICMR-CCRAS Training on Research Ethics, GCP and Regulations for Biomedical and Health Research on 21st January 2021

The Central Council for Research in Ayurvedic Sciences (CCRAS) is an autonomous and apex body of the Ministry of AYUSH for the formulation, coordination, development and promotion of research on scientific lines in Ayurveda and Sowa-Rigpa system of medicine. ICMR Bioethics Unit, organized an online training program in collaboration with CCRAS for the members of Institutional Ethics Committee of the CCRAS Institute involved in the Clinical Research. Central Ayurveda Research Institutes coordinated this training programme on behalf of CCRAS. Around 191 participants benefitted from this training. The participants were briefed about the ICMR National Ethical Guidelines for Biomedical and Health Research, 2017/ ICMR Guidelines for Ethics Committees during COVID-19 Pandemic, 2020, roles and responsibilities of Ethics Committees, ethical Issues related to traditional medicine research studies, GCP Guidelines / New Drugs and Clinical Trial Rules, 2019 and limitations and pitfalls of Research in Ayurveda. Each session was made interactive and was followed by a question and answer session.

c. ICMR Training on Roles & Responsibilities of Ethics Committee members held on 16th March 2021

An online training program was organized by ICMR Bioethics Unit to train the Ethics Committee members in their roles & responsibilities. Participants were from across the country as well as from several neighbouring countries. An eminent panel of experts representing a multidisciplinary ethics committee shared their perspectives on their respective roles in an EC and the difficulties encountered. The training was also live streamed on You Tube (vailable at: https://www.youtube.com/watch?v=IBhi8KrBsl0). Almost 700 participants benefitted from this training. The feedback received from the training was overwhelming and the participants anticipated many such interactive training programs in the future.

These programs have reached out to several participants from several institutions or organisations and will ensure that research is carried out in an ethical manner to improve public trust towards research.

6. Dissemination of ICMR National Guidelines for Ethics Committees Reviewing Biomedical & Health Research during COVID-19 Pandemic, April 2020

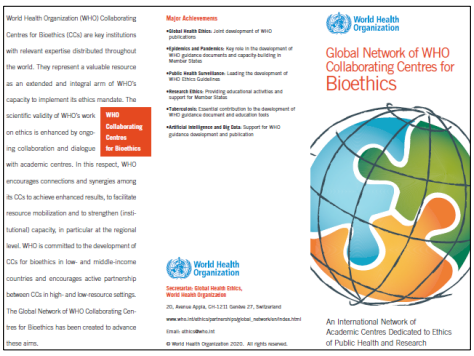
Following the New Drugs and Clinical Trial Rules announced in March 2019, it is mandatory to follow the ICMR National Ethical Guidelines, 2017 for all biomedical & health research in India. In this regard, approximately 1000 copies of the National Guidelines for Ethics Committees Reviewing Biomedical & Health Research during Covid-19 Pandemic, 2020 were printed. The document highlights the important facilitatory role that ethics committees must play in supporting the ethical conduct of research in India in the changed circumstances in the COVID-19 pandemic. A poster was also designed for display which included all the salient features of the guidelines. These guidelines along with the Handbook on National Ethical Guidelines for Biomedical and Health Research Involving Human Participants, 2017 were sent to the medical and research institutions involved in biomedical and health research across the country. The main guideline consists of 12 sections and this handbook is a supplement to the main guidelines. The primary aim of this handbook is to serve as an easy reference to the main guidelines and briefly summarizes the 12 sections. It is expected to be useful to students, researchers and faculty members.

7. Coordination with NECRBHR, DHR for Registration of Ethics Committee and related activities

New Drugs and Clinical Trials Rules, 2019 rules mandates that an Ethics Committee reviewing biomedical and health research shall be required to register with the authority designated by the Central Government in the Ministry of Health and Family Welfare, which is Department of Health Research (DHR). To facilitate the registration of ECs, DHR has developed a separate online portal "National Ethics Committee Registry for Biomedical and Health Research (NECRBHR)" that is available at https://naitik.gov.in/DHR/Homepage. Dr. Roli Mathur, Head, ICMR Bioethics Unit is serving as Scientific Advisor for NECRBHR and Nodal Officer for the Ethics Committee Registry and is actively involved in the review of application for EC registrations and documents like Standard Operating Procedures (SOPs), Frequently asked Questions (FAQs) etc. The queries received and related activities in this regard are also being reviewed and followed up. In addition, ICMR Bioethics Unit was a part of the several stakeholder consultation meetings that were held as an exercise for minimizing Regulatory Compliance Burden by DHR and also in the review of documents to examine all the acts and regulations with the objective of rationalizing, reducing and simplifying the compliance burden.

8. Activities of WHO Collaborating Centre (WHO-CC) for Strengthening Ethics in Biomedical & Health Research

ICMR Bioethics Unit was designated as WHO Collaborating Centre for Strengthening Ethics in Biomedical and Health Research on 7th February 2020 and is the first centre for strengthening ethics amongst 11 countries of the South East Region. In this context, the brochure for the Global Network of WHO Collaborating Centre for Bioethics was updated to include India as one of the centres. The centre has been working relentlessly in compliance with the proposed terms of reference ever since and recently an annual report highlighting the activities done by the Unit (as agreed upon with WHO) was submitted.



WHO-SEARO as well as WHO-WR have identified Dr. Roli Mathur, Head, ICMR Bioethics Unit as the nodal person and she was part of number of reviews, ethics queries and deliberations for WHO SEARO activities. She has been appointed in the following committees of WHO Headquarters, Geneva.

a. Expert Member of the WHO-Covid-19 and Ethics Group
b. Expert member for Ethics and Governance of Using Artificial Intelligence for Health
c. Expert Member of Sub-committee on Monitored Emergency Use of Unregistered Interventions (MEURI).
d. Member of the Global Network of WHO Collaborating Centres on Bioethics.
e. Expert member of the Asia Pacific Network of National Ethics Committees (WHO-APNEC)

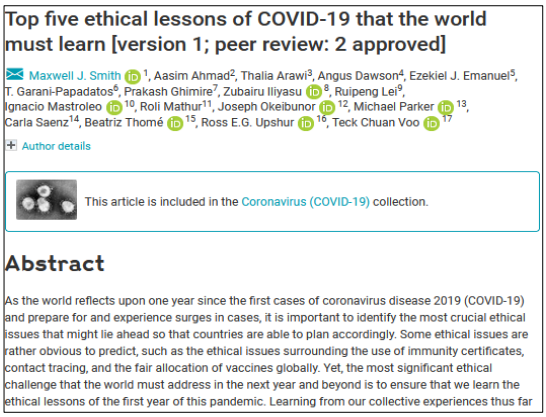
In this regard, the following are the details:

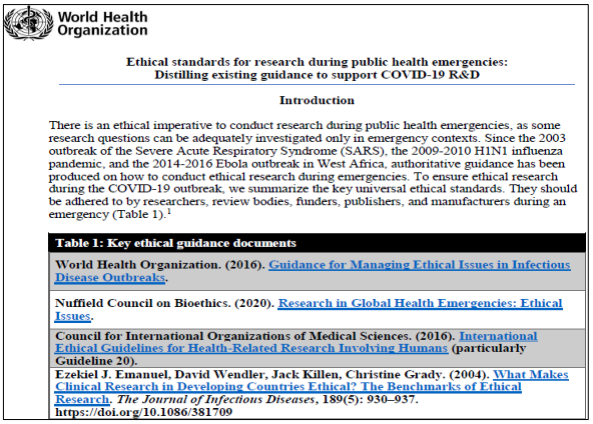
- Participated in the ethics review of the GLOBAL SOLIDARITY Protocol and the informed consent form for the trial to be conducted across the world, and contributed to the WHO paper on Top 5 considerations of Ethics for research during Covid-19 pandemic, and to development of WHO SOPs for Ethics committees.
- Participation in weekly meeting of WHO Ethics and Covid Working group, weekly meeting on WHO-MEURI, bi weekly meetings of WHO Artificial Intelligence group, attending weekly webinars hosted by Public Health Emergency preparedness and Response Ethics Network (PHEPREN) hosted by WHO.
- Participated in a WHO organized International webinar as representative of National Ethics Committee in India and presented an update from India to >130 participants from national ethics committees, WHO and other agencies from across the world.
- Invited to share the Report on Ethics Preparedness in India during the International Global Summit Meeting of WHO Headquarters conducted online and participated by more than 500 participants from 100 countries from across the globe.
- Presented the India report pertaining to activities pursued as Member Secretary of Central Ethics Committee on Human Research during the Asia Pacific Network of National Ethics Committees in South East Asia and The Western Pacific Region.

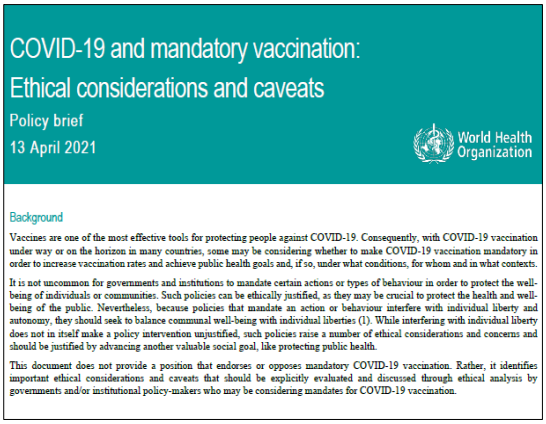
- Presented the Regulatory and governance framework related to using Artificial Intelligence for Health during the Meeting of the WHO Artificial Intelligence Expert committee. Participated by representatives from more than 25 countries and different agencies across the world.
- Presented the activities being pursued as the first WHO Collaborating Centre for Strengthening Ethics in India and South East Asia.

These deliberations as being part of WHO Ethics and COVID Working Group have resulted in the following publications:

- Ethical Standards for research during public health emergencies: Distilling existing guidance to support COVID-19 R&D, WHO March 2020 (Member of WHO Working Group Ethics and COVID-19). Available at: https://apps.who.int/iris/bitstream/handle/10665/331507/WHO-RFH-20.1-eng.pdf?sequence=1&isAllowed=y
- Mastroleo I et al. Allocating Scarce Unproven Interventions during Public Health Emergencies: Insights from the WHO MEURI Framework. The American Journal of Bioethics.2020 Aug 25;20 (9):41-44. Available at: https://www.tandfonline.com/doi/abs/10.1080/15265161.2020.1795539
- Smith MJ et al. Top five ethical lessons of COVID-19 that the world must learn. Wellcome Open Research. Available at: https://wellcomeopenresearch.org/articles/6-17
- World Health Organization. (2021). COVID-19 and mandatory vaccination: ethical considerations and caveats: policy brief, 13 April 2021. World Health Organization. https://apps.who.int/iris/handle/10665/340841







9. Activities and Guidelines of Council of International Organizations of Medical Sciences (CIOMS)

Dr. Roli Mathur, Head of the ICMR Bioethics Unit has been appointed as Member of the Executive Committee of CIOMS as well as member of the Working Group preparing the Guidelines for Ethical issues related to the conduct of research in low resource setting. She participates in bimonthly meetings of working group and biannual meetings of the Executive committee. She is also appointed as a member of the Editorial Group finalizing the guideline document with biweekly meetings. As a member from developing country, her role is important in this committee and she was able to share ICMR Guidelines and other practical experience of conducting research in resource limited settings and was involved in the finalization of the CIOMS guidelines for research in low resource settings.

10. An International Survey of Ethics Committees (ECs)/ Institutional Board Review (IRBs): Challenges and Practices Arising during Public Health Emergencies (PHEs) Sponsored by WHO

An online international survey was conducted in collaboration with Good Clinical Practice Alliance – Europe (GCPA), which was funded by World Health Organisation for the members of ECs (national, regional, local, institutional) to identify specific ethical values, issues, procedures, and practices that arise regarding the ethics review of COVID-19 research, previous public health emergencies (PHE) research, or future PHE research. As a WHO Collaborating Centre for Strengthening Ethics in Biomedical & Health Research for South East Asia Region and leading all ethics related work in India, it was approached to be a collaborator and to coordinate this survey involving ethics committees in India. There was no foreign funding involved for India as google forms were used for collecting information. All relevant approvals were obtained and study was registered before initiation of the study (SAC, HMSC, IEC, CTRI). Around 210 members of ECs across India participated in the survey and the information collected was completely anonymous as no sensitive or identifiable information was collected from the participants. The anonymised data has been shared with the foreign collaborative agency for collation of data with other countries and drafting of recommendations that are expected to benefit ECs around the world. An in-country analysis of the data collected is in progress. The study would also help us understand the responses of ethics committees within the country in handling ethics reviews during the present pandemic which will be useful for formulating future policies and guidelines by ICMR.

11. Updation of ICMR Bioethics Unit Webpage

The website has more than 40000 visitors and is regularly updated for the national/ international guidelines, EC tools, publications, reports, training programs etc. (http://ethics.ncdirindia.org/). It has the provision to download the relevant resources as well as guidance documents. The homepage of the website was recently updated to include the decadal year logo of ICMR-NCDIR and recent activities of the Unit.

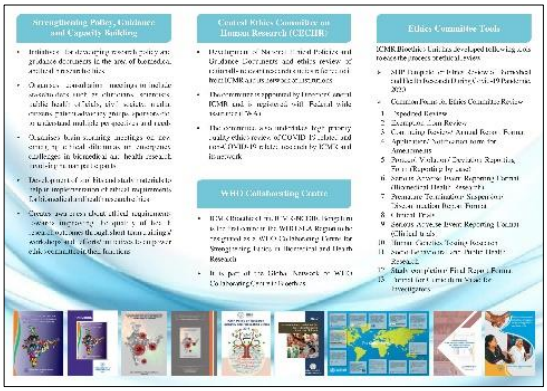
12. Miscellaneous Activities

a. Registration of ICMR-CECHR with US Federal Wide Assurance

ICMR Bioethics Unit had applied for Federal wide assurance (FWA) for Central Ethics Committee on Human Research (CECHR) and the committee is now registered with the Office for Human Research Protections (OHRP) under The U.S. Department of Health and Human Services (HHS). (No. IRB00012875, Dated 7th Dec 2020) to facilitate ICMR-NIH Collaborative Research.

b. Brochure for ICMR Bioethics Unit

A brochure was designed for highlighting the activities, relevant links and mandate of ICMR Bioethics Unit. It provides a bird's eye view of the activities and will serve as a handy tool for participants attending the training/ dissemination programs.



c. ICMR Salutes Women Scientists for their Contribution in Fight against COVID-19

As ICMR was at the forefront for devising policy for diagnostic, testing platform, treatment strategies and vaccine development during the coronavirus pandemic, women scientists and staff came forward and made valuable contributions towards effective response against coronavirus pandemic. ICMR appreciated these sheroes in the e-Samvaad published in February, 2021 and acknowledged the substantial contribution of Dr. Roli Mathur in the field of ethics during the pandemic.

ICMR Salutes Women Scientists For Their Contribution In Fight Against COVID - 19

OTHER ACTIVITIES

1. Webinars on Disease Awareness and Other Topics

a. Webinar on Cancer Awareness Day on 7th November 2020

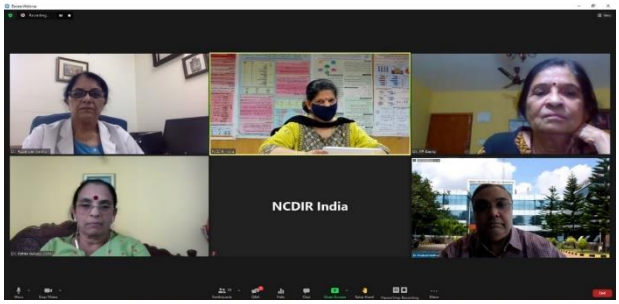
ICMR – NCDIR organised a webinar titled "My Cancer Awareness: Empowering through knowledge" on the occasion of National Cancer Awareness Day on 7th November 2020 . Speakers included eminent physicians, oncologists, public health experts, ministry official, Cancer Care and Support Groups, Patient representative and others who addressed the participants and responded to their queries on specific topics.

b. Webinar on 'Preparing for the Call for research proposals 2020 under CaResNER Programme' on 27th November 2020

A webinar on 'Preparing for the call for research proposal under CaResNER Programme' took place on 27th November 2020. The objective of the webinar was to brief prospective investigators about the call and to enhance skills for identifying relevant areas of research and writing a sound research proposal. The sessions were conducted by eminent experts in the field. The webinar had an enthusiastic participation of around 85 attendees from all over the country.

c. Cervical cancer awareness webinar organised by ICMR-NCDIR on 30th January 2021

A virtual webinar on Cervical cancer awareness was organised by ICMR-NCDIR on 30th January 2021 culminating the cervical cancer awareness month. This webinar aimed to create awareness by recognizing the symptoms early and touched upon cervical cancer care. Strategies towards prevention and screening of cervical cancer were discussed in the webinar.



d. Gall bladder cancer awareness webinar on 26th February 2021

A webinar on Gall bladder cancer awareness was organized by ICMR-NCDIR on 26th February 2021 to create awareness regarding the occurrence of gall bladder cancers, detection, management and prevention. The sessions were conducted by eminent experts in the field. The webinar had good participation of around 82 attendees from all over the country.

e. Public Webinar on Salt Awareness in connection with 'World Salt Awareness Week' held on 10th March 2021

A public webinar was conducted on 10th March 2021 to observe the 'World Salt Awareness Week', from 8 to 14 March 2021. The webinar's purpose was to educate the public and remind health professionals about the health effects of excess salt consumption, dietary interventions for low salt intake, substitutes for high sodium food items and the role of the Food Safety and Standard Authority of India (FSSAI) in the regulation of salt intake in India. The webinar hosted eminent resource persons and provided an opportunity for interaction with the audience of about 180 persons.

2. Launch of Foundation Day and 10th Anniversary of ICMR – NCDIR on 25th January 2021

Hon'ble Union Minister of Health and Family Welfare, Govt. of India, Dr Harsh Vardhan launched the Decadal year celebrations of ICMR-NCDIR on 25th January 2021 and released the Report of "National Noncommunicable Disease Monitoring Survey 2017-18" and the e book on "Framework for Telemedicine use in Management of Cancer, Diabetes, Cardiovascular Diseases, and Stroke".
Various scientific activities are being done as part of the Decadal year of NCDIR celebrations and 40th year of NCRP.

3. COVID-19 and NCDs

- An information sheet on COVID-19 and NCDs was developed and shared on the NCDIR website (http://www.ncdirindia.org/COVID_Web/Docs/COVID19_NCDs_Info.pdf
- COVID section in NCDIR registry forms: In order to describe the pattern of disease and outcomes among registered patients with COVID-19, COVID section form was developed to collect information on COVID infection among patients registered in cancer, stroke and heart failure registries.

4. Internship at NCDIR

Seven students (postgraduates in Public health and statistics) completed internship at ICMR-NCDIR between January to June,2020 for a period of 2 to 6 months. Due to the lockdown of the pandemic, the internship was completed online. In 2021, three MPH students pursued internship in January and February 2021, and 3 more joined in March 2021.

5. Communication Unit

a. Ideated tweets for several important international/ national days and events organized by ICMR-NCDIR.
b. Starting 12th March 2021, ICMR-NCDIR planned for public engagements/ webinars / social media postings to observe an initiative of the Government of India to

celebrate and commemorate 75 years of India's independence, Azadi Ka Amrit Mahotsav.

c. A weeklong campaign on Twitter was launched in coordination with ICMR, New Delhi's Communication Unit to showcase cancer statistics, advocacy messages and generate awareness from the Report of NCRP 2020 released in August 2020.

SOFTWARE DEVELOPMENT

1. Population Based Cancer Registry and Survival Studies (Breast, Cervix and Head & Neck)

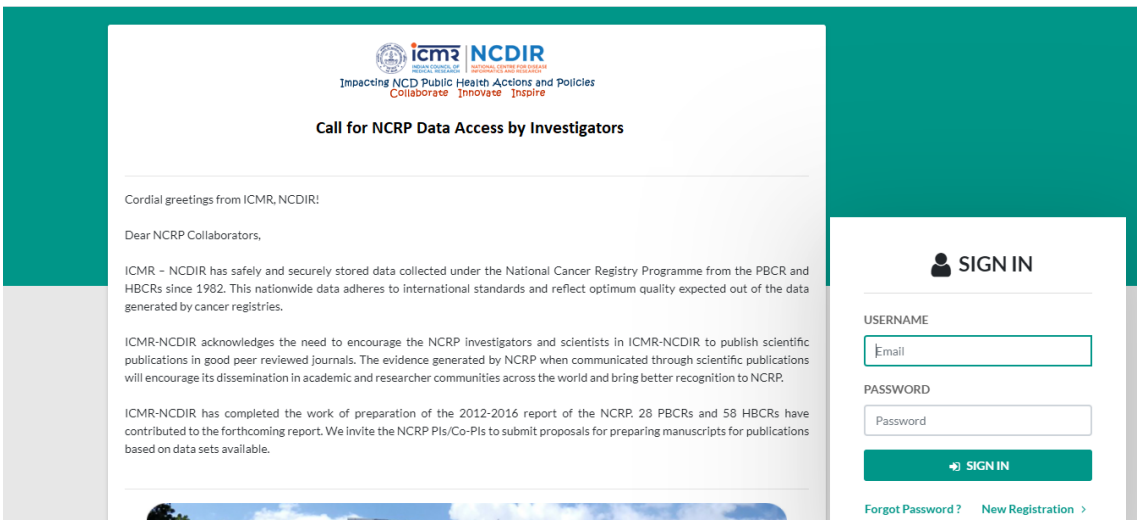
Tamil Nadu Cancer Registry Programme (2012-2016) data imported with customization in software and database. Options to customize selection of variables to generate tables for numbers, AAR, trends using combination/single cancer sites/ age group/ years/ registry. Online software was provided to 6 more PBCRs. Covid-19 module developed and deployed both in offline and online versions of PBCR software.

2. Data visualization of NCRP data - CANCER SAMIKSHA

Updates on Cancer Map using GIS- PBCRs.

3. Call for NCRP Data access by investigators

A portal to accept proposals from NCRP investigators for development of manuscripts based on the 2012-2016 data in the Report of NCRP 2020 was opened. It was open from November 2020 till 11 January 2021. It offered Registration, login, query window and proposal submission. An Admin dashboard to view status of registrations and submissions was also made for NCDIR.

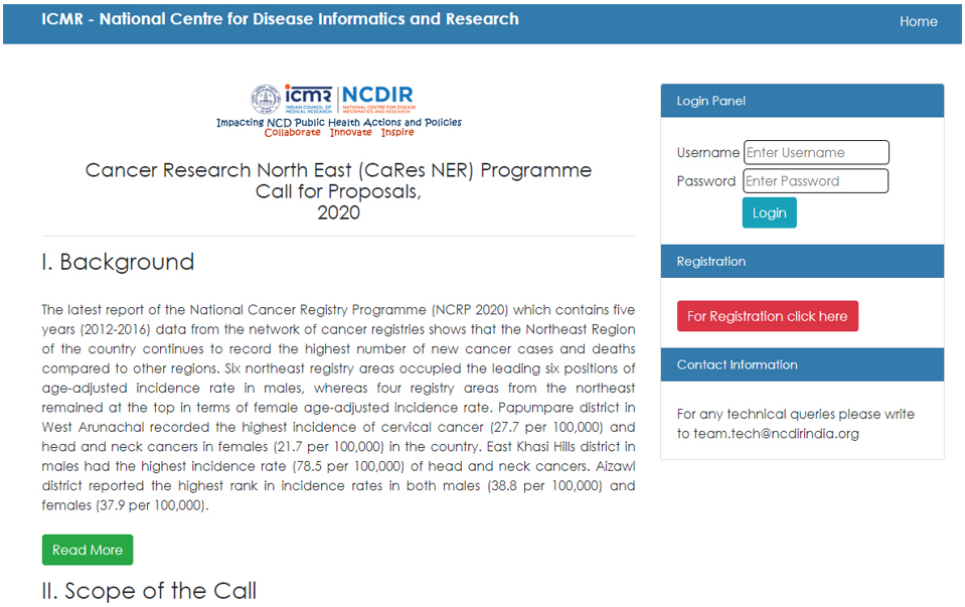


4. DHR-ICMR Advanced Molecular Oncology Diagnostic Services

An online application was developed to capture the information on cancer breast and lung. The application contains the modules such as data capture, search, modify & save the patient records and data export to excel format. The login credentials were provided for nine hospitals to transmit the data.

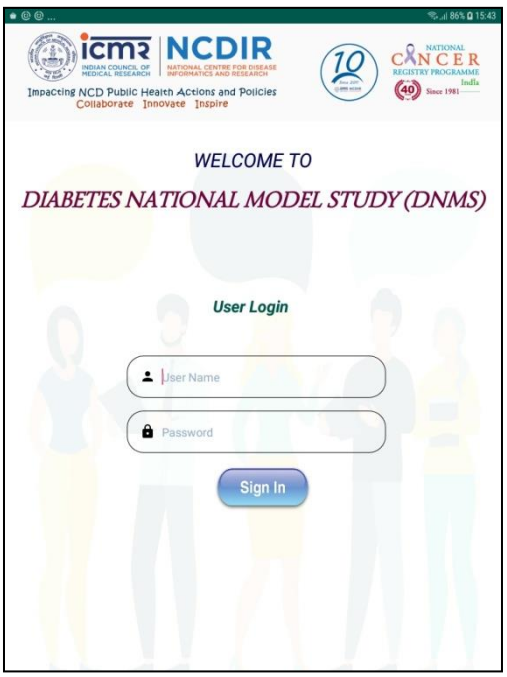
5. Call for Concept Proposals for Prevention and Control of Cancer in the North Eastern States in India (CaRes NER Programme), 2020

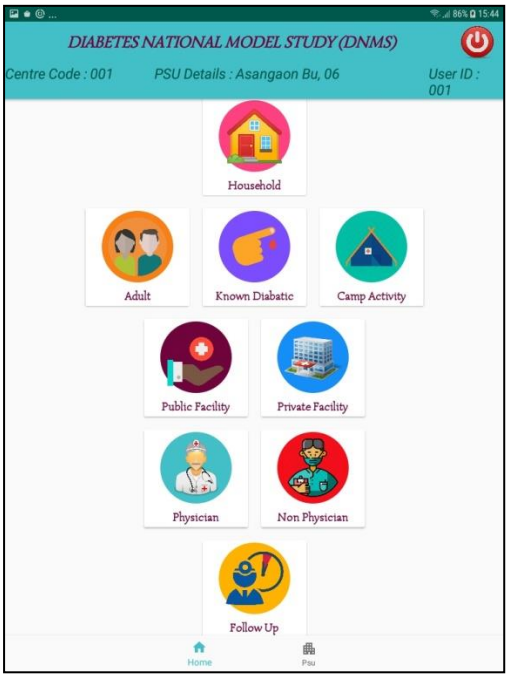
A web based application was developed to receive the proposals as per ICMR proposal format such Section A, B and C. The application captures the information on principal investigator, aim and other proposal details including budget and provision for uploading the CV of all the investigators was provided. The final copy of the proposal was made available in the form of single PDF.



6. Diabetes National Model Study

Open-source field application tool to capture the survey data has been developed. Primarily consists of Household, Adult, Known Diabetes, Physician /Non-physician and Health facility questionnaires. Application has quality checks / Skip patterns, De-duplication check, Validation across questionnaires. Tool works in offline and online mode.





7. Population Based Stroke Registry

Development – New features were added in Stroke Registry software and have following features.

Data Entry Form

- Introduction of COVID-19 form

- Modification/Addition of features as per the requirement. These changes will involve changes in design and in database. As per the request many behavioral changes in the controls are done
- New checks (range and consistency) on variables are introduced in the data entry form
- New warning messages are incorporated to alert the users about the possible wrong entries. – invalid/ out of area pin codes are not accepted, out of range ICD10 codes are prompted
- Fresh date checks are introduced.

Follow-up form

- Email reminders are automatically initiated to centres on regular intervals (once in a week). The email contains list of cases are due for follow up in upcoming week.

Duplicate Form

- Additional option to perform de-duplication of all cause mortality data with incidence cases.

Duplicate View/Editing/Tagging

- Option to transfer of information of only selected variables during vertical screen tag and delete process.

Importing of all cause mortality

- Option to import all-cause mortality information to match with incidence cases.
- Matching incidence cases with all-cause mortality data.

Analysis

- Advance Search menu – Enables user to retrieve records on the basis of random combination of fields.
- Verified QC list – helps user to flag the record as particular quality check verified and omits such records getting listed in future checks.

All features will improve the quality of data and ease the data analysis at National level.

8. Hospital Based Stroke Registry

Data Entry Form

- User friendly design - replica of core form.
- Option to save record with Incomplete information (as draft). Draft records can be revisited for final submission.

- Built-in checks for quality checks - calculate 28 days follow up, 3 months follow up, calculation of NIHSS score, Date validation, BMI calculation, recording of first / recurrent stroke cases, validating ICD10 codes, recording MRS functional status.
- Option to record COVID-19 information during the time of Discharge, Day28 and 3 months.

Presentation/ Training

- Currently rolled out to 19 centres. Out of which 17 centres are transmitting data.
- Training/Retraining sessions to centres on software updates of HBSR application.

Follow-up Form

- Email reminders are automatically initiated to centres on regular intervals. The email of prospective and retrospective cases are sent to centres. Prospective cases are sent every week and retrospective cases list will be emailed once in a month.

Core Form Request

- Online feature for requesting core forms

Analysis

- Advance Search menu – Enables user to retrieve records on the basis of random combination of fields.
- Audit report- tracking of changes made on the data

Data Maintenance / Review

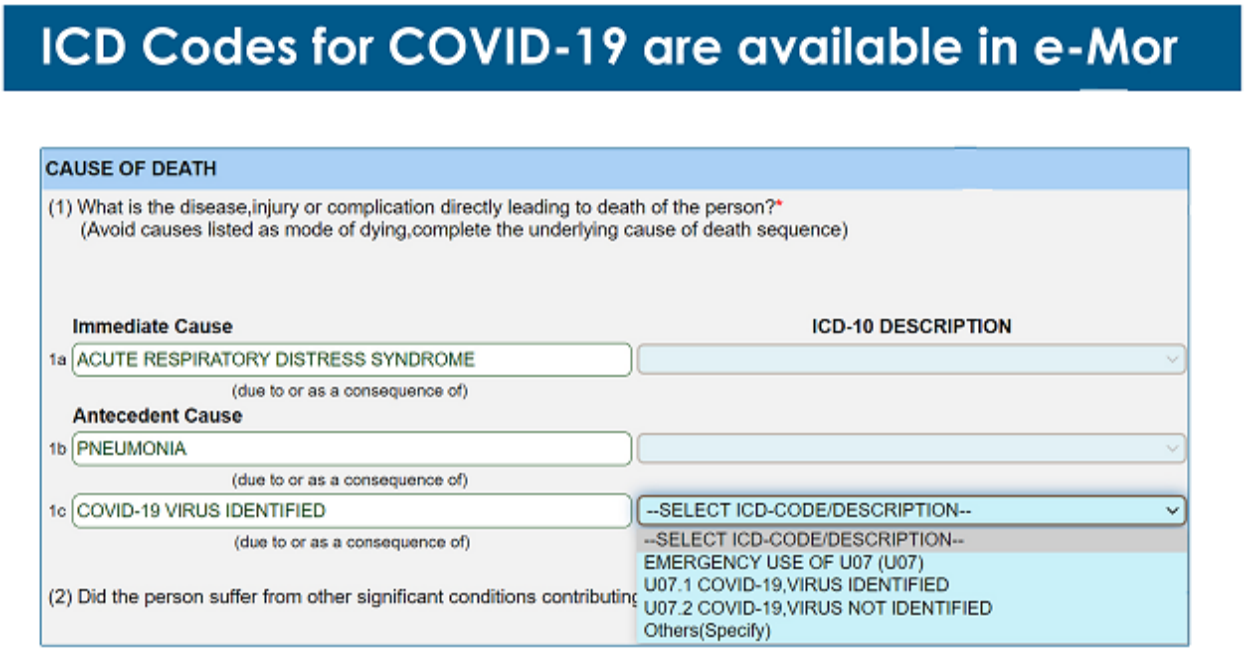
- Data is regularly reviewed and datasets are shared with supporting staffs for additional analysis of data. Bug fixes if any reported.

9. e-MoR software

.Net and MS SQL Server version in use by centres

- Eight additional hospitals were given access. Software changes to revamp e-Mor for mobile responsiveness was commenced.
- Covid-19 ICD10 Codes (U07.1: COVID-19, virus Identified & U07.2: COVID-19, virus Not Identified) were added to the list of ICD10s for cause of death codes at immediate and antecedent causes.
- Online e-monitoring module developed, core form changes incorporated, new tables were developed in the RGI format by leading cause of death.
- SNOMED CT integration initiated with the .Net version.
- e-Mor Application for Karnataka State with Registration module, Dashboard for NCDIR, district health officer and state health under testing, License / MOU developed for software and Software User Manual Reviewed.

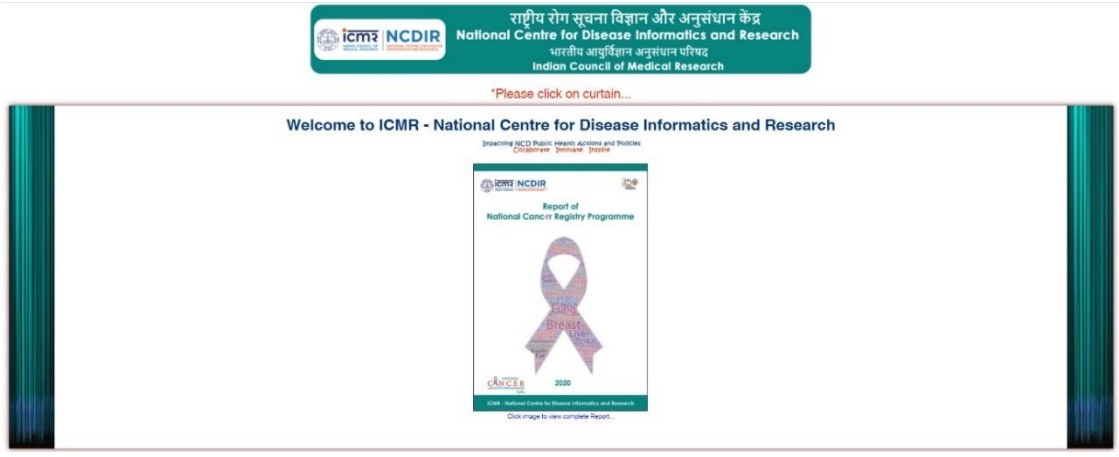
- e-janma software was compared with the NCDIR e-Mor software for Integrating e-Mor with e-janma software. Probable integration plan was drawn.
- User credentials was provided for testing to Karnataka DES.



API for Medical codes

- ICD10 (RGI National List) and ICD-O3 (PSTT and PHM)
- An API hosted has been hosted on NCDIR Web server for use by TN CRS team to access codes in the cause of death section for the cause of death software provided by ICMR-NCDIR. The API can be used by any other project within ICMR-NCDIR.

10. Web Application Development for Launching NCDIR Reports Released in 2020-21.



राष्ट्रीय रोग सूचना विज्ञान और अनुसंधान केंद्र
National Centre for Disease Informatics and Research
भारतीय आयुर्विज्ञान अनुसंधान परिषद
Indian Council of Medical Research
*Please click on curtain to Release Haryana Cancer Atlas Book Report
Welcome to ICMR - National Centre for Disease Informatics and Research
Development of an Atlas of Cancer in Haryana State
2016-17
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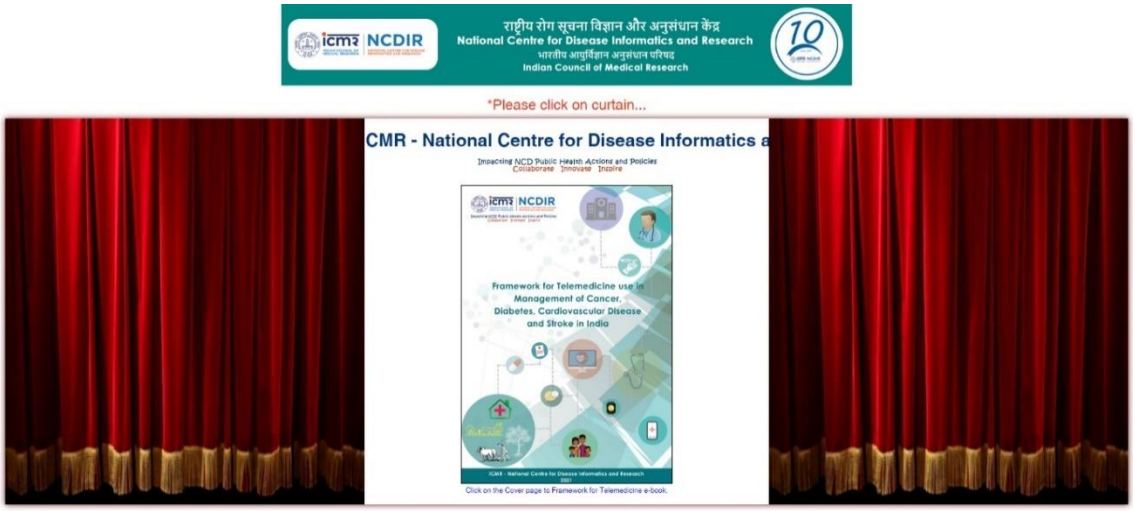
राष्ट्रीय रोग सूचना विज्ञान और अनुसंधान केंद्र
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CMR - National Centre for Disease Informatics a
Framework for Telemedicine use in Management of Cancer, Diabetes, Cardiovascular Disease and Stroke in India
Click on the Cover page to Framework for Telemedicine e-book.

राष्ट्रीय रोग सूचना विज्ञान और अनुसंधान केंद्र
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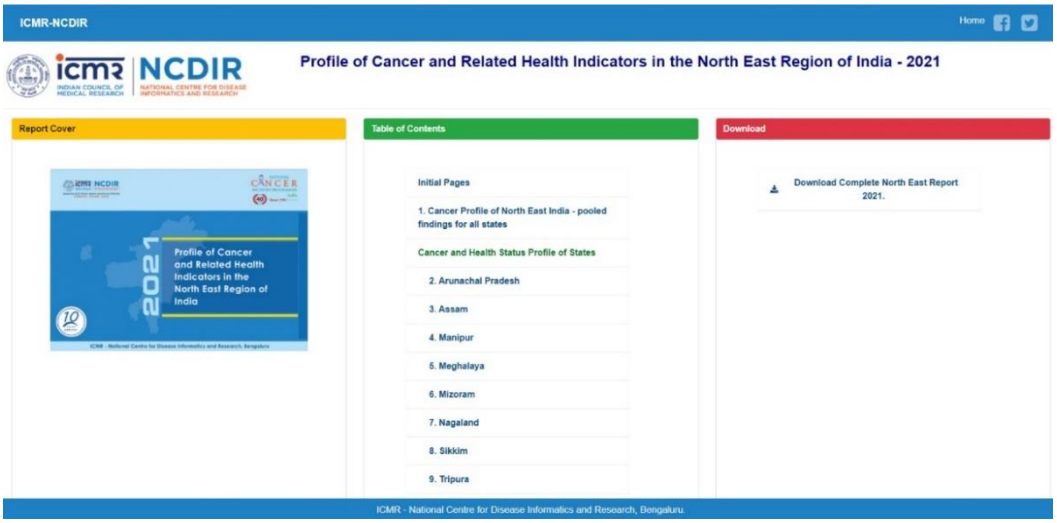
Indian Council of Medical Research
Online Release of
Click on the cover page to view North East Report 2021.
2021
Profile of Cancer and Related Health Indicators in the North East Region of India
Click on the Cover page to view North East Report 2021.

11. Web Version of NCRP Report, 2020

12. Web Version of Telemedicine Guidelines

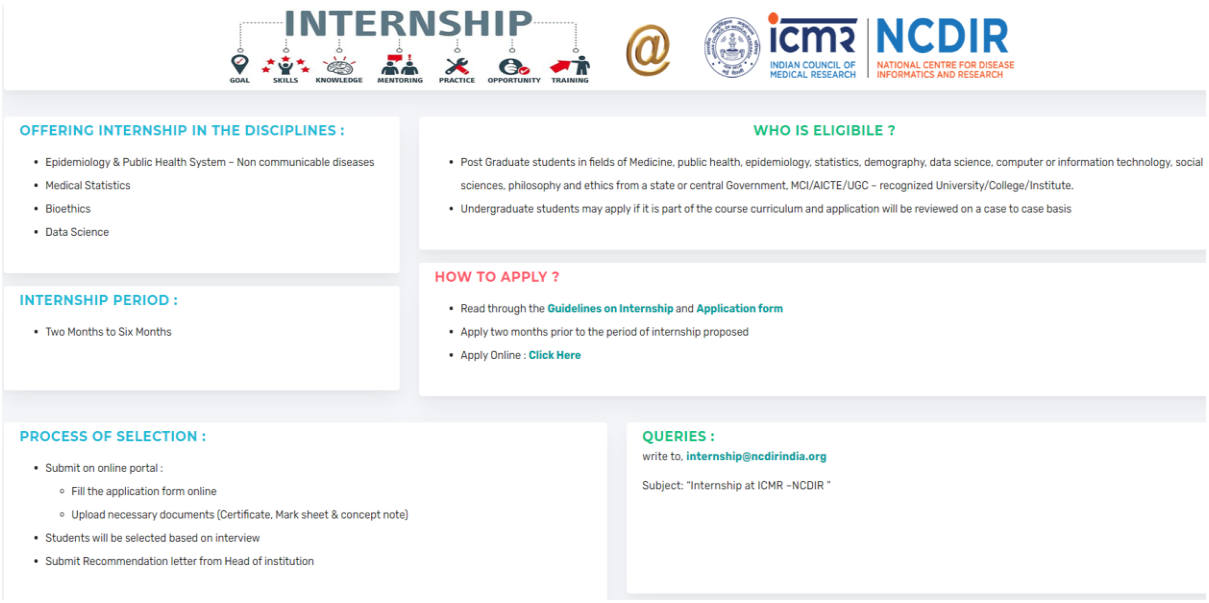
13. Web Version of Northeast Report



14. Interns Application Module

A Web Application was developed for receiving the online application and the complete process is paperless. It has been deployed in the ncdirindia.org domain. This application has the following options apart from data entry module.

- Option to download the filled in application / registration form and also send to the registered email id.
- Option given to the user to reupload the signed application with the Email OTP validation to receive filled application form with supporting documents from eligible candidates.
- Dashboard in the home page of the software to display user count and the status of application
- Option given for the admin to download and approve the related document uploaded by the candidate.
- Admin Approval Module development.



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1. Mathur R, Garg P, Muthuswamy V, Mathur P. Authors' response to the paper entitled 'Indian Council of Medical Research consensus guidelines on Do Not Attempt Resuscitation: Communication is key'. Indian J Med Res 2020;152:428 **(IF-1.503)**
2. India State-Level Disease Burden Initiative Air Pollution Collaborators. Health and economic impact of air pollution in the states of India: the Global Burden of Disease Study 2019. Lancet Planetary Health 2021; 5(1): e25-e38 **(IF – 60.392)**
3. NCD Risk Factor Collaboration (NCD-RisC). Height and body-mass index trajectories of school-aged children and adolescents from 1985 to 2019 in 200 countries and territories: a pooled analysis of 2181 population-based studies with 65 million participants. Lancet 2020; 396: 1511–24 **(IF – 60.392)**
4. Mathur P, Rangamani S, Kulothungan V, Huliyappa D, Bhalla B.B, Urs V, National Stroke Registry Programme in India for Surveillance and Research: Design and Methodology. Neuroepidemiology 2020;54:454–461 **(IF-2.186)**
5. Rai RK, Barik A, Mazumdar S, Chatterjee K, Kalkonde YV, Mathur P, Chowdhury A, Fawzi WW. Non-communicable diseases are the leading cause of mortality in rural Birbhum, West Bengal, India: a sex-stratified analysis of verbal autopsies from a prospective cohort, 2012–2017. BMJ Open 2020; 10(10) **(IF-2.496)**
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9. Mathur R. ICMR Consensus Guidelines on 'Do Not Attempt Resuscitation'. Natl Med J India 2020. 4(4);338-40 DOI: 10.4103/0970-258X.284970 **(IF – 0.64)**
10. Mathur P, Sathishkumar K, Chaturvedi M, Das P, Sudarshan KL, Stephen S, Vinodh N, Anish J, Sandeep N, Roselind FS, Cancer Statistics, 2020: Report From National Cancer Registry Programme, India. JCO Global Oncol 2020;6:1063-75. **(IF-1.413)**
11. Mathur P, Rangamani S. COVID-19 and noncommunicable diseases: Identifying research priorities to strengthen public health response. Int J Non-Commun Dis 2020;5:76-82 **(IF – Not available)**
12. Sarveswaran G, Kulothungan V, Mathur P. Clustering of Non-Communicable Disease Risk Factors among adults (18-69 years) in Rural Population, South-India. Diabetes & Metabolic Syndrome 2020;14(5):1005-14 **(IF – 2.842)**
13. NCD Risk Factor Collaboration (NCD-RisC). Repositioning of the global epicentre of non-optimal cholesterol. Nature 2020; 582:73–77 **(IF – 42.778)**
14. Mathur R. ICMR Consensus Guidelines on 'Do Not Attempt Resuscitation'. Indian J Med Res 2020;151:303-10 **(IF – 1.503)**

15. Smith MJ, Ahmad A, Arawi T, Dawson A, Emanuel EJ, Papadatos TG, Ghimir P, Iliyasu Z, Lei R, Mastroleo I, Mathur R, Okeibunor J, Parker M, Saenz C, Thome B, . Upshur REG, Voo TC. Top five ethical lessons of COVID-19 that the world must learn. Wellcome Open Res 2021; 6:17 **(IF – 1.86)**
16. Mathur P, Kulothungan V, Leburu S, Krishnan A, Chaturvedi HK, Salve HR, et al. (2021) National noncommunicable disease monitoring survey (NNMS) in India: Estimating risk factor prevalence in adult population. PLoS ONE 16(3): e0246712. https://doi.org/10.1371/journal. pone.0246712 **(IF-2.740)**
17. NCD Risk Factor Collaboration (NCD-RisC). Heterogeneous contributions of change in population distribution of body mass index to change in obesity and underweight. eLife 2021;10:e60060 DOI: 10.7554/eLife.60060 **(IF-7.080)**
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19. Chaturvedi M, Sathishkumar K, Vijaykumar DD, Sathya N, Roselind FS, Rekha S, Rath GK. Cancer Atlas Project–Haryana: Insights for Healthcare Planners. Asia Pacific journal of Cancer Care 6(1) 19-26. DOI : 10.31557/APJCC 2021.6.1.19 **(IF – Not available)**

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1. The Report of "National Noncommunicable Disease Monitoring Survey 2017-18"
2. Report of National Cancer Registry Programme 2020
3. Profile of Cancer and Related Health Indicators in the North East Region of India – 2021

GUIDELINES and POLICY

1. National Guidelines for Ethics Committees Reviewing Biomedical & Health Research during Covid-19 Pandemic, April 2020
2. Guidance for appropriate recording of COVID-19 related deaths in India, April 2020
3. ICMR Consensus Guidelines on 'Do Not Attempt Resuscitation', May 2020
4. Framework for Telemedicine use in Management of Cancer, Diabetes, Cardiovascular Diseases, and Stroke in India
5. SOP Template for Emergency EC meeting during COVID-19 Pandemic, April 2020
6. Ethical Standards for research during public health emergencies: Distilling existing guidance to support COVID-19 R&D, WHO March 2020 (Member of WHO Working Group Ethics and COVID-19).
7. World Health Organization. COVID-19 and mandatory vaccination: ethical considerations and caveats: Policy Brief, 13 April 2021.
8. Information on COVID-19 and NCDs

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

1. Web Consultation with members of ICMR CoNEC for the review of "Informed consent format for obtaining Biological Samples (Blood/Convalescent Plasma)/ for future research related to COVID 19 in India" on 16 April 2020
2. 1st Virtual Meeting of ICMR CoNEC for the review of Generic Protocol entitled "Hydroxychloroquine Prophylaxis for COVID-19 Infection Among Healthcare Workers: A Proof-of-Concept, Observational Study" on 17 April 2020
3. 2nd Virtual Meeting of ICMR CoNEC for the review of Generic Protocol entitled "A Phase II, Open Label, Randomized Controlled Trial to Assess the Safety and Efficacy of Convalescent Plasma to Limit COVID-19 Associated Complications in Moderate Disease"j on 20 April 2020
4. Centre wise Training of Senior Research Fellow conducted (through Zoom) for the Project on Incidental Gall Bladder Carcinoma held on 30 April 2021, 4 and 5 May 2021
5. Central Ethics Committee on Human Research - virtual meetings were organised to conduct ethical review of proposals by ICMR-CECHR on 6, 9 and 12 May 2020
6. Training of Senior Research Fellow conducted for the Project on POCSS Gall Bladder Cancer centres on 15 May 2020
7. Meeting (Webinar) with Principal Investigators of centres participating in Heart Failure study regarding functional status during ongoing pandemic. Participating centers were: JLN Ajmer, Medical College Thirunelveli, AIIMS Bhuvneshwar, IGMC Shimla, SJIMC Mysore on 18 May 2020
8. Web Meeting on 'Review of monitoring survey of cancer risk factors and health system response in North East India' on 22nd May 2020
9. ICMR-CECHR virtual meetings held to conduct ethical review of proposals on 19, 24, 30 May 2020
10. ICMR-CECHR virtual meetings held to conduct ethical review of proposals by ICMR-CECHR on 2, 5 and 10 June 2020
11. Review of efforts towards developing CanEST Programme on 3 June 2020
12. Meeting with experts regarding Telemedicine Practice Guidelines for Non Communicable Diseases on 15 June 2020
13. Training workshop for HBSR and PBSR staff of Tirunelveli Medical College on 18 June 2020
14. Web meeting on Need for Strengthening MCCD in India through collaboration on 25th June 2020
15. Webinar on "Ethics Review of Biomedical projects during a Pandemic" on 27th June, 2020 (jointly organised by Indian Society for Clinical Research (ISCR), ICMR Bioethics Unit, ICMR-NCDIR, Bengaluru and WHO Country Office India
16. Re-training of staff for 'Monitoring survey of cancer risk factors and health system response in NER on 1 July 2020
17. Virtual training for staff of DIAMOnDS project Staff on progress and future scope on 2 July 2020
18. Online Demonstration & Training of HBSR application to HBSR centres on 6 July 2020
19. Orientation cum training session for the staff under the project on "DHR-ICMR Advance Medical Oncology Diagnostic Services (DIAMONDS) under HTAIn Pilot Research Project" on 7 July, 2020
20. Virtual Brainstorming meeting with NCDIR staff on NCDIR-NHA collaboration on 13 and 15 July 2020

21. Virtual Meeting on State wide implementation of NCDIR e-Mor software in hospitals of Karnataka for cause of death strengthening during COVID-19 pandemic on 15 July 2020 Dept of Health and Family Welfare, Govt. of Karnataka
22. Online discussion on inclusion of COVID section for Heart Failure study with all centres on 17th July 2020
23. Virtual Training for DHR-ICMR Advanced Medical Oncology Diagnostic Services (DIAMOnDS) (North and west zone centres) on 31 July 2020
24. Virtual Meetings of ICMR-CECHR held on 4 August 2020 and 7 August 2020.
25. Meeting with the Software team, Principal Investigator and MRD officer of JIPMER, Pondicherry to discuss on e-Mor integration held on 5 August 2020
26. Orientation cum training session for the staff under the project on "DHR-ICMR Advance Medical Oncology Diagnostic Services (DIAMONDS) under HTAIn Pilot Research Project" for North East and South centres on 6 August 2020
27. Meeting with Department of Health, Government of Karnataka (GoK) on implementation of e-Mor in hospitals in Karnataka, 6 August 2020
28. Meetings of Working group on Telemedicine Practice guidelines on Non communicable Diseases (Cancer) on 10 August 2020
29. Training on Implementation of NCDIR e-Mor software in Hospitals of Karnataka on 13 August 2020
30. Meetings of Working group on Telemedicine Practice guidelines on Non communicable diseases(Stroke and Diabetes) on 17 August 2020
31. Online Release of the National Cancer Registry Programme Report 2020, by the Secretary, DHR and Director General, ICMR held on 18 August 2020.
32. Online HBSR sensitization & training workshop for new HBSR centres on 19 August 2020
33. Online meeting for working group members on Telemedicine Practice Guidelines-Cardiovascular Diseases on 27 August 2020
34. Training on implementation of emor for new centres on 28 August 2020
35. Review meeting of Monitoring Survey of Cancer Risk Factors and Health System Response in North East India on 3 September 2020
36. Sensitization and training on Covid-19 section for Heart failure study 4 September 2020
37. NNMS Report Review on 4 September 2020
38. Editorial Committee Meeting for Reference Book on Bioethics on 4 September 2020
39. Training on COVID section implementation – PBCR on 7 September 2020
40. Training on COVID section implementation – HBCRDM Centres on 7 September 2020
41. Training on COVID section implementation HBCR SOR+NEHBCR+ Additional SOR on 8 September 2020
42. Training on COVID section implementation RCC+ NF HBCR on 8 September 2020
43. Virtual Training for the recruited staff of new PBCRs (PBCR Rishikesh, PBCR Patna and Nagpur Rural PBCR) on 9 September 2020 and 16 September 2020.
44. Virtual Training for the staff of the centres under DHR-ICMR Advanced Medical Oncology Diagnostic Services (DIAMOnDS) on 10 September 2020
45. HBSR sensitization and training workshop on 15 September 2020
46. Discussion on "Development of standard reporting format to record imaging findings for ICMR-NCDIR National Stroke Registry Programme" on 18 September 2020
47. Data quality meetings for monitoring survey in NER – Arunachal Pradesh and Mizoram on 22 September 2020
48. Data quality meetings for monitoring survey in NER – Dibrugarh -Assam, Sikkim and Tripura on 24 September 2020
49. 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 25 September 2020

50. Data quality Review meetings for monitoring survey in NER – Kamrup Assam, Manipur and Meghalaya on 28 September 2020
51. Demonstration on VPN and Cloud storage on 28 September 2020
52. Virtual training on HBCR for the project under NHA - NCDIR collaboration on 25 and 29 September 2020
53. Brainstorming meeting on developing Cardiovascular Diseases atlas for North-East region of India on 30 September 2020
54. Meeting of the Research Area Panel on Diabetes on 1 October 2020
55. Data Review Meeting for Incidental Gall Bladder Cancer and Other Pre-malignant Gall Bladder Condition in India towards early detection of Gall Bladder Cancer on 5 October 2020
56. Internal committee meeting on Prevention of Sexual Harassment of women at workplace on 5 October 2020
57. Meeting of the Research Area Panel on Cancer on 6 October 2020
58. Sensitisation workshop for setting up Hospital Based Cancer Registry by NHA in collaboration with ICMR-NCDIR on 6 October 2020
59. Presentation of the project findings 'Research study to develop intellisense mapping of SNOMED CT to ICD-10' on 8 October 2020
60. Meeting of the Research Area Panel on Cardiovascular Diseases on 9 October 2020
61. Virtual meetings of ICMR Central Ethics Committee on Human Research held on12 and 23 October 2020
62. Discussion on NCDIR decadal and NCRP 40th year celebrations on 14 October 2020
63. Meeting of the Research Area Panel on Stroke on 15 October 2020
64. Demo of emor to 4 districts of Karnataka on 16 October 2020
65. Demo of e-Mor and plan for implementation meeting for Health officials at State level on 22 October 2020
66. HBSR training on 22 October 2020
67. Online Training on NCDIR e-Mor software on 2 November 2020
68. Online Training program on "An update on ICMR National Ethical Guidelines with special Reference to Epidemiological Research" on 3rd November 2020
69. Data Review meeting for CaRes monitoring survey - Mizoram, Tripura and Naharlagun on 3 November 2020
70. Discussion on conducting 'NCD risk factor survey' in Andhra Pradesh on 4 November 2020
71. Data Review meetings for CaRes monitoring survey on 5 November 2020
72. MCCD discussion -e-Mor for Bihar and UP on 6 November 2020
73. Webinar titled "My Cancer Awareness: Empowering through knowledge" on the occasion of National Cancer Awareness Day on 7th November 2020
74. Demonstration of online portal for proposal submissions under CaRes on 9 November 2020
75. Virtual meetings of ICMR Central Ethics Committee on Human Research held on 10 November, 2020
76. Data review (Monitoring survey) meeting for PBCR Dibrugarh on 10 November 2020
77. Guest talk by Prof Anoop Misra, Diabetologist at Fortis Hospital Delhi & Editor of Diabetes Journal has agreed to deliver a talk on "How to write an effective manuscript" for a peer reviewed journal on 12 November 2020
78. Scientific Advisory Committee Meeting of NCDIR on 25 November 2020
79. Webinar on 'Preparing for the Call for research proposals 2020 under CaResNER Programme' on 27 November 2020
80. Cancer Epidemiology and Surveillance (CanEST) - Interaction with second reviewers on 1, 2 and 7 December 2020
81. Training for the new 37 HBCRs in two batches on 3 December and 7 December 2020

82. Online webinar on Introduction to benefits of "Ayushman Bharat Pradhan Mantri Jan Arogya Yojana" Scheme for the empaneled centres by NHA and NCDIR on 3 December 2020
83. Online workshop on Quality assurance and hands on training for pathologists for Incidental Gallbladder Cancer on 7 December 2020
84. Data Review Meeting for Monitoring Survey of Cancer risk factors with Team Arunachal Pradesh on 10 December 2020
85. Institutional Ethics Committee meeting of NCDIR on 15 December 2020
86. Sensitisation Training on Prevention of Sexual Harassment of women at workplace on 16 December 2020
87. Meeting with PBSRs on Data Quality Review of 2018-19 data on 17 December 2020
88. Data Review Meeting on monitoring survey for cancer risk factors for Team Dibrugarh on 18 December 2020
89. Data review meeting cum training sessions for POCSS - Childhood, Lymphoid and Hematopoietic malignancies and other Gynaec cancers on 22 December 2020
90. Data review meeting cum training sessions Patterns of Care and Survival Studies (POCSS) on Gall Bladder Cancer (GBC) in Hospital Based Cancer Registries on 23 December 2020
91. Review course material for establishing a Training and Capacity Building mechanism on Cancer Epidemiology and Surveillance, ICMR-NCDIR on 24 December 2020
92. HBSR Sensitization & Training Workshop on 29 December 2020
93. Launch of NCDIR Foundation day by Hon'ble Union Minister of Health & Family Welfare, Dr. Harshvardhan and Release of the NCDIR Reports on NNMS and Telemedicine Guidelines.
94. Discussion meeting regarding the discrepancies in eMoR software by TN DPH team with NCDIR team on 4 January 2021
95. Data review meeting for monitoring survey for cancer risk factors team Tripura on 5 January 2021
96. Online training workshop for the staff of centres of Patterns of Care and Survival Studies (POCSS) on Cancers in Childhood, Lymphoid and Hematopoietic Malignancies, other Gynaecological Malignancies in Chennai, Bangalore, Thiruvananthapuram, Delhi and Mumbai on 6 January 2021
97. Training workshop on HBSR for new centres on 6 January 2021
98. Training workshop on implementation of e-Mor on 7 January 2021
99. Virtual meetings of ICMR Central Ethics Committee on Human Research held on 9, 11, 15 January 2021
100. Discussion with NHA team on working paper on stroke on 12 January 2021
101. Sensitisation and Training on Covid vaccine implementation and follow up for centres of various projects on 15, 17, 18 and 20 January 2021
102. Discussion on HBCR Report 2012-2019 on 21 January 2021
103. Training Programme on "GCP Guidelines & Bio-Medical & Health Research Ethics" on 21 January 2021
104. Data review meeting for monitoring survey for cancer risk factors - Team Mizoram on 22 January 2021
105. Institute Foundation Day and launch of Decadal year celebrations of ICMR-NCDIR, Bengaluru by Dr Harsh Vardhan, Hon'ble Union Minister of Health & Family Welfare, Govt. of India was held on 25th January 2021. The Report of "National Noncommunicable Disease Monitoring Survey 2017-18" and the e book on "Framework for Telemedicine use in Management of Cancer, Diabetes, Cardiovascular Diseases, and Stroke" were released by the Hon'ble Minister.
106. Online training on Software updates of Heart Failure study on 27th January 2021.
107. Webinar on Cervical Cancer Awareness Month on 30 January 2021

108. Online Release of Report on Profile of Cancer and Related Health Indicators in the North Eastern Region of India by ICMR-NCDIR on World Cancer Day on 4 February 2021
109. Data review meeting on monitoring survey for cancer risk factors for Kamrup, Cachar and Karimganj
110. Overview of Stroke project on 16 February 2021
111. Review of proposals submitted under 'Call for Proposals for Prevention and Control of Cancer in the North Eastern States in India (CaRes NER Programme) 2020.' On 17 February 2021
112. Training on study tools and field operations for field investigators at Grant Medical College, Mumbai under Diabetes National Model Study form 22 to 26 February 2021
113. Presentation by Interns on the work done by them during their training in NCDIR on 26 February 2021
114. Webinar on "Gall Bladder Cancer Awareness" on 26 February 2021
115. Review meeting on monitoring survey for cancer risk factors for team Meghalaya on 2 March 2021
116. Overview of e-MoR project on 3 March 2021
117. Training of recruited field staff under DNMS at RIMS, Raichur from 8 to 12 March 2021
118. International Women's Day Celebration at ICMR-NCDIR, Bengaluru on 8 March 2021
119. Public Webinar on Salt Awareness in connection with 'World Salt Awareness Week' on 10 March 2021
120. ICMR Training on Roles & Responsibilities of Ethics Committee Members on 16 March 2021
121. Data Review Meeting on Resource Centre virtual Review Meeting Ca Res Risk Factor survey with Nagaland Team on 23 March 2021
122. Training on Usage of Android Software for Field Investigators at Grant Medical College, Mumbai on 31 March 2021

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