

# ANNUAL HIGHLIGHTS

## 2017 - 2018

**National Centre for Disease Informatics and Research,  
Bengaluru**

*(Indian Council of Medical Research)*

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

## ICMR- NCDIR Mandate

ICMR- NCDIR was established as a permanent national institute in 2011 and has the following mandate;

- Establish collaborative network for research using modern information technology and statistical tools through epidemiological, clinical and public health research methods to address major Noncommunicable Diseases (cancer, cardiovascular diseases, stroke, diabetes) and risk factors.
- Strengthen the ethical conduct of biomedical and health research through guidelines, policies, tools and capacities in India.

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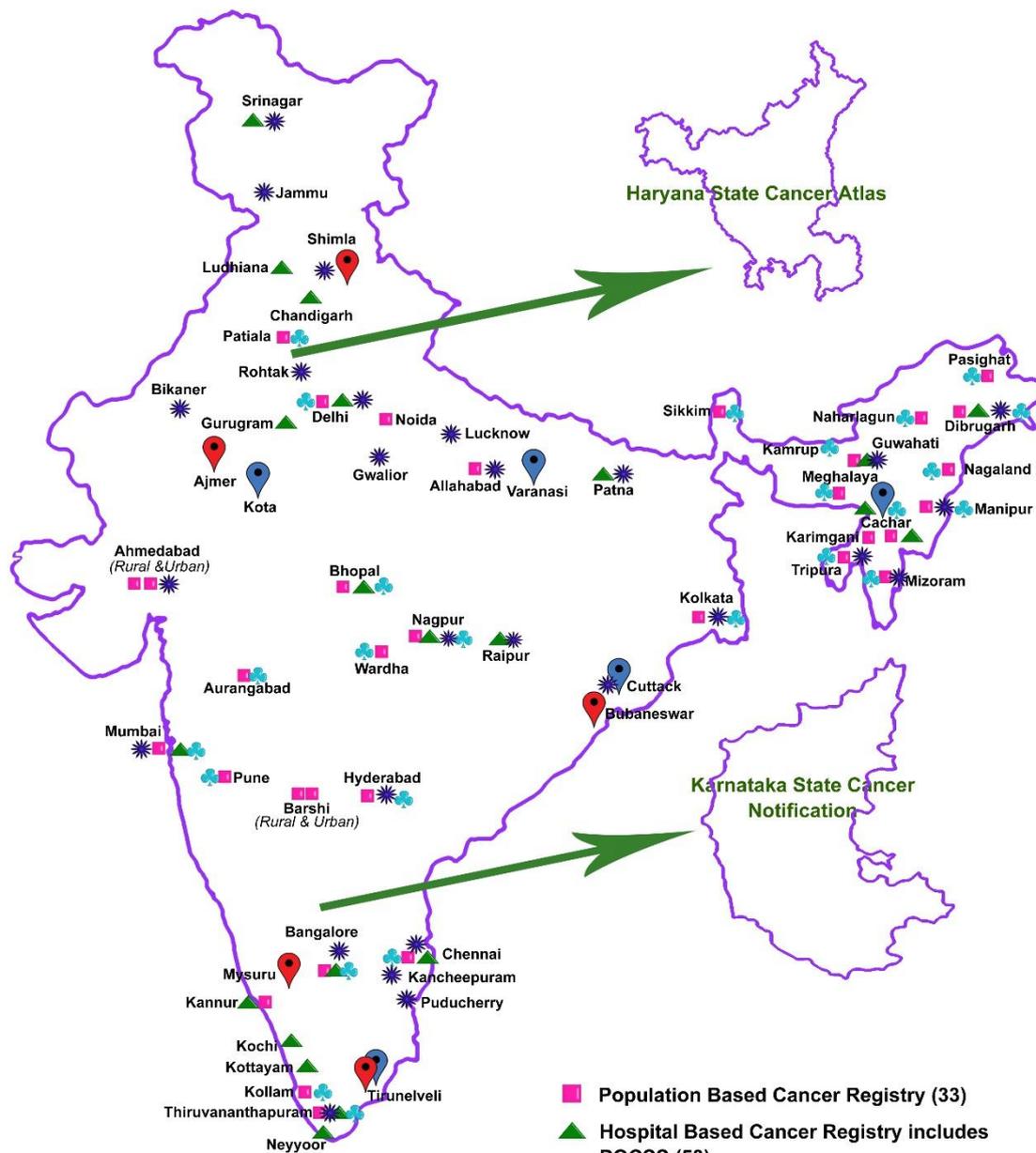
## KEY ACHIEVEMENTS

2017-18

1. National Cancer Registry Program (NCRP) covers almost 10.0% of the population of India through its network of 33 PBCRs (around 3400 Sources of Registration) and 211 HBCRs and other centres. NCDIR – NCRP also informs program and health system on magnitude of different cancers in different geographic regions and helps in envisaging the approach for cancer prevention and control. It is the only reliable database on cancer statistics in the country.
2. NCDIR has set up a Population Based Cancer Registry in Kamala Nehru Memorial Hospital, Allahabad (Uttar Pradesh), to determine the magnitude of various types of cancers.
3. The International Agency for Research on Cancer (IARC) has included the data from 15 Population Based Cancer Registries under NCRP Network in Vol XI of the Cancer Incidence in Five Continents (CIV) <http://publications.iarc.fr/> and the data from 7 PBCRs under NCRP network in International Incidence of Childhood Cancer – Vol. 3 (IICC-Vol.3). <http://iicc.iarc.fr/results>
4. “Cancer Samiksha” a web based tool on assessment and analysis of cancer data has been developed by ICMR - NCDIR, Bengaluru for the public, academia, researchers, media and policy makers to visualize and analyse the cancer registry (HBCR & PBCR) data published by NCRP for the period 2012-2014 (<http://ncdirindia.org/cancersamiksha/>). The portal has been launched on 8<sup>th</sup> September 2017 and has been accessed by 553 users during 2017-2018.
5. Cancer is now a notifiable disease in 10 States through administrative / Gazette notification - Assam, Arunachal Pradesh, Gujarat, Haryana, Karnataka, Manipur, Mizoram, Punjab, Tripura and West Bengal. NCDIR continues to guide notification of cancer in states.
6. Report on Cancer Burden in North Eastern States of India using the data for the years 2012-2014 was prepared which revealed the high burden of exposures such as tobacco consumption, alcohol, indoor air pollution is contributing to high incidence of cancers in north eastern states. The report has been shared with North Eastern registries to take it forward with State Health Authorities for further action regarding creating awareness for prevention of cancer through policy. The report has been released at NCDIR on 10<sup>th</sup> October 2017 by Smt. Anupriya Patel, Hon’ble Minister of State for Health and Family Welfare, Government of India.

7. Population Based Stroke Registries have been initiated in the 5 centres in one geographical area from the south(Tirunelveli), north (Varanasi), east (Cuttack), west (Kota) and north east (Silchar) regions of India in 2017.
8. The electronic mortality (NCDIR e-Mor) software has been developed to strengthen the medical certification of cause of death (MCCD) with features to generate MCCD and Death report (Form 4 and 2 respectively) to aid in death registration. The software has been deployed in hospitals in North Eastern States.
9. Feasibility study on the Magnitude and Patterns of causes of Heart Failure has been initiated in 5 centres across the country at Shimla, Himachal Pradesh; Ajmer, Rajasthan; Mysore, Karnataka; Tirunelveli, Tamil Nadu; Bhubaneshwar, Odisha in 2017.
10. National NCD monitoring Survey was implemented in 600 primary sampling units across the country. The survey will help to generate estimates of different NCDs related indicators on nationally representative sample of India for the year 2017-18. It will measure program being made towards achieving National NCD action plan and NCD monitoring framework.
11. NCDIR Policy on Data Processing and Disclosure-2017 has been prepared applicable and implemented to cancer registries across the country.
12. 'ICMR Guideline on Diagnosis and Management of Celiac Disease' released by Smt. Anupriya Patel, Hon'ble Health and Family Welfare Minister of State, Government of India at NCDIR, Bengaluru on 10<sup>th</sup> October 2017.
13. ICMR Bioethics Unit, NCDIR joined the Council for International Organizations of Medical Sciences (CIOMS) Geneva, as a member of the Executive Committee in 2017.
14. National Ethical Guidelines for Biomedical and Health Research Involving Human Participants and National Ethical Guidelines for Biomedical Research Involving Children were released by the Hon'ble Union Minister of Health and Family Welfare, Hon'ble Minister of State for Health and Family Welfare and in the presence of DG ICMR and Secretary DHR, and Country Representative, WHO-WR and other dignitaries on 12<sup>th</sup> October 2017 at ICMR Headquarters, New Delhi.
15. In order to create awareness about the ICMR National Ethical Guidelines, dissemination programs were organised at 8 medical colleges across the country involving participation of 5960 stakeholders including students, researchers, clinicians, nurses, ethics committee members, patient representative, legal experts and others.
16. A report providing "Definition of terms used in limitation of treatment and providing palliative care at end of life" was released at NCDIR on 12<sup>th</sup> March 2018 to provide clarity on the terminologies used in End of Life Care.

# NCDIR Network of Registries



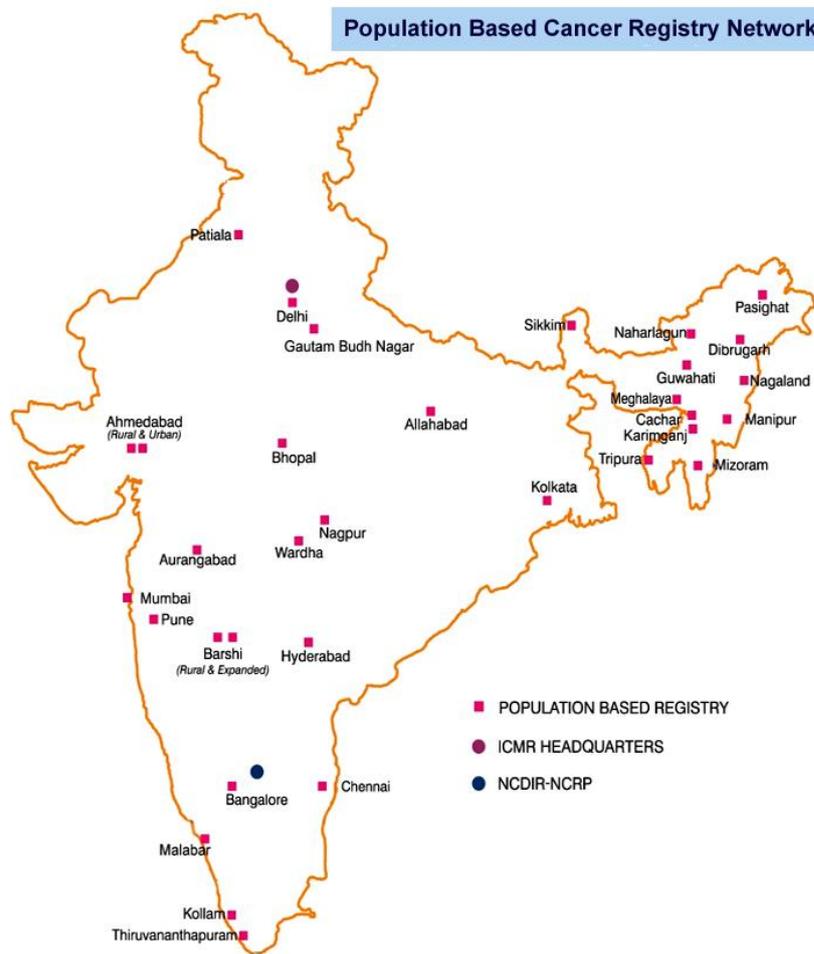
# CANCER

## ONGOING PROJECTS

### 1. Population Based Cancer Registries (PBCR) Network

#### a. Population Based Cancer Registries (PBCRs) in India

This is the regular and long term activity of NCDIR under its National Cancer Registry Program (NCRP) which provides information on the incidence rates, burden and trends of cancer in the population. There are 33 PBCRs under NCRP with addition of two PBCRs in 2017-18 at National Institute of Cancer Prevention and Research, Noida and Kamala Nehru Memorial Hospital, Allahabad.



The PBCRs cover almost 10% of the Indian population and are functioning at different cities and districts across the country. These registries capture and process data through the in-house developed software which monitors the data, evaluates it for quality, seeks clarifications and analyses the cleaned data to generate tabulations on numbers and rates.

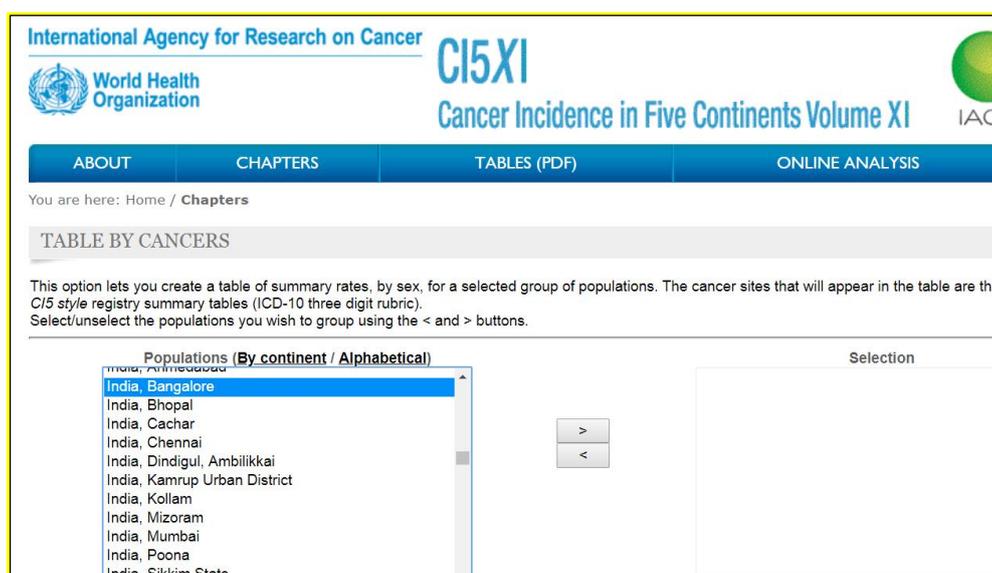
A workshop on cancer registration was held at NCDIR, Bengaluru on 26<sup>th</sup> March 2018 to train the investigators and registry staff of 4 Population Based Cancer Registries, Allahabad, PBCR covering Gautam Budh Nagar from Uttar Pradesh, PBCR from Assam covering three districts (Karimganj, Hailakandi and Dima Hasao) of Barak valley region in the state and Malabar PBCR covering three districts in south India namely, Kasargod and Kannur districts of Kerala and Mahe district of Pondicherry.



Workshop for new Population Based Cancer Registries held on 26<sup>th</sup> March 2018 at NCDIR.

### Cancer Incidence in Five Continents - Vol XI (CI 5 Vol XI):

Cancer Incidence data (2008-2012) of 22 PBCRs were submitted to International Agency for Research on Cancer for Cancer Incidence in Five Continents - Vol XI (CI 5 Vol XI). NCDIR contacted the registries for verification and evaluation of the registry data. The data from 15 PBCRs (Bengaluru, Bhopal, Ahmedabad Rural, Kollam, Kamrup Urban, Sikkim, Mizoram, Tripura, Cachar, Thiruvananthapuram, Mumbai, Barshi Rural, Chennai, Pune, Wardha) data have been accepted and published in CI 5 - Vol XI in 2017.



## **b. Setting up of Population Based Cancer Registry in select Cities/Towns along the course of the Ganga River**

The objective is to strengthen cancer registration across populations residing in the river Ganga belt in view of earlier indications of high burden of cancers especially gallbladder cancer.

During 2017, PBCR at Kamala Nehru Memorial Hospital, Allahabad was initiated covering Allahabad District (rural + urban) and the data collection has been started.

## **c. Population Based Cancer Survival on Cancers of Breast, Cervix and Head and Neck**

The project has been initiated with the aim of generating reliable data on population based cancer survival in cancers of the breast, cervix and head and neck cancers; and to know wherever feasible survival based on clinical stage/extent of disease across the Population Based Cancer Registries (PBCRs). Core proforma has been designed in the software and deployed in 25 centres.

Meeting of experts was held on 24<sup>th</sup> January 2018 to finalize the Standard Operating Procedures. Another workshop of experts in the field of cancer survival, epidemiologists and Investigators from the registries was held at NCDIR on 14<sup>th</sup> - 15<sup>th</sup> March 2018 and discussed the modalities of data collection, methodology, follow up Proforma and registry specific issues. The software for PBCR survival study is under development and testing.



Meeting of Experts 24<sup>th</sup> January 2018



Workshop of Experts 14-15 March 2018

## **2. Hospital Based Cancer Registries (HBCRs)**

This is the long term ongoing activity of NCDIR. The HBCRs are concerned with recording patient identifying information, diagnostic details, clinical stage and treatment for all the proved malignant cases that are registered/diagnosed in a particular hospital. Data collection is done by standardized common core form for all the registries. 20 new HBCRDM centres have been registered under the network of NCDIR-NCRP during 2017-18.

Sl. No.	Centre Name
1	Kokilaben Dhirubhai Ambani Hospital and Medical Research Institute, Mumbai
2	Ravi Polyclinic Maternity and Nursing Home, Shivamogga
3	Meherbai Tata Memorial Hospital, East Singhbhum
4	All India Institute of Medical Sciences, Patna
5	King George Medical University, Lucknow
6	Royal Cancer Institute and Research Centre, Kanpur
7	Apollo Gleneagles Hospitals, Kolkata
8	Shankar Institute of Cancer Therapy and Research, Mathura
9	Kurnool Medical College and Govt. General Hospital, Kurnool
10	J.N. Medical College and Hospital, Aligarh
11	Mohandai Oswal Hospital, Ludhiana
12	All India Institute of Medical Sciences, Rishikesh
13	Tirunelveli Medical College, Tirunelveli
14	B R D Medical College, Gorakhpur
15	Vivekananda Cancer Hospital, Latur
16	Rajendra Institute of Medical Sciences, Ranchi
17	Govt. Cancer Hospital, Medical College, Jabalpur
18	Sujan Surgical Cancer Hospital and Amravati Cancer Foundation, Amravati
19	Christian Medical College and Hospital, Ludhiana
20	Government Medical College and Cancer Hospital, Aurangabad

The status of HBCRs under NCRP under various projects as on 31<sup>st</sup> March 2018, is as follows:

Sl. No.	Registries	No. of Centres
1	HBCRs funded by ICMR (including HBCRDM and HBCR in Sources of Registration)	60
2	HBCRs (RCC/TCCC/SCI) funded by MoHFW	21
3	HBCRs without any financial assistance	38
4	HBCRs under Karnataka Cancer Notification	92
	<b>Total</b>	<b>211</b>

**Series of workshops/meeting were held to train the investigators and the staff working at the above registries.**

- 17<sup>th</sup> – 18<sup>th</sup> July 2017 for the centres from southern part (Puducherry, Tamil Nadu, Kerala and Telangana) at NCDIR, Bengaluru.
- 24<sup>th</sup> – 25<sup>th</sup> July 2017 for the centres from the central, eastern and north eastern (Gujarat, Maharashtra, Chhattisgarh, Tripura, Mizoram, Manipur, Assam, West Bengal and Odisha) States of India at NCDIR, Bengaluru.
- 28<sup>th</sup> – 29<sup>th</sup> July 2017, for the centres located in northern part (Uttar Pradesh, Bihar, Rajasthan, Himachal Pradesh, Jammu and Kashmir, Punjab, Chandigarh and Uttarakhand) of India at SGPGI, Lucknow
- 12<sup>th</sup> January 2018, a Sensitization for the Principal Investigators of Hospital Based Cancer Registries Data Management Centres at NCDIR, Bengaluru.

5. 19<sup>th</sup> January 2018, a Sensitization Workshop for the Principal Investigators of HBCRs in Sources of Registration of already existing PBCRs at Bengaluru, Chennai, Delhi, Mumbai and Kolkata at NCDIR, Bengaluru.
6. 8<sup>th</sup> March 2018 – 2<sup>nd</sup> Sensitization Workshop for the Principal Investigators of Hospital Based Cancer Registries who missed the first workshop at NCDIR, Bengaluru.
7. 16<sup>th</sup> March 2018 – Meeting for Review of data of HBCRs in Regional Cancer Centres at NCDIR, Bengaluru.
8. 19<sup>th</sup> - 20<sup>th</sup> March 2018- Training Workshop for staff of centres of Hospital Based Cancer Registry Data management (HBCRDM) and Hospital Based Cancer Registry in Sources of Registration (HBCR in SORs) at NCDIR, Bengaluru
9. 21<sup>st</sup> and 22<sup>nd</sup> March 2018 -Training Workshop for Hospital Based Cancer Registry in Regional Cancer Centres staff at NCDIR, Bengaluru.



### a. Setting up of Hospital Based Cancer Registry (HBCR) in Regional Cancer Centres (RCCs)

There are 27 hospital based cancer registries under this project.

List of RCC/TCCC/ SCI where HBCR is operational.

Sl. No.	Name of Centres
1	Acharya Harihar Regional Cancer Centre, Cuttack
2	Acharya Tulsi Regional Cancer Treatment and Research Institute, Bikaner
3	Cancer Institute (WIA), Chennai
4	Chittaranjan National Cancer Institute, Kolkata
5	Dr. B.R. Ambedkar Institute Rotary Cancer Hospital, New Delhi
6	Dr. B. Borooah Cancer Institute, Guwahati
7	Government Medical College, Jammu
8	Govt Arignar Anna Memorial Cancer Hospital and Research Institute, RCC, Kanchipuram
9	Indira Gandhi Institute of Medical Sciences, Patna
10	JIPMER, Regional Cancer Centre, Puducherry
11	Mizoram State Cancer Institute (Civil Hospital), Aizawl
12	PGIMER, Chandigarh
13	Regional Cancer Centre Indira Gandhi Medical College, Shimla
14	Regional Cancer Centre Kamala Nehru Memorial Hospital, Allahabad
15	Regional Cancer Centre, Agartala
16	Regional Cancer Centre, Raipur
17	Regional Cancer Centre, Thiruvananthapuram
18	RST Regional Cancer Hospital, Cancer Relief Society, Nagpur
19	Sher-I-Kashmir Institute of Medical Sciences, Srinagar
20	The Gujarat Cancer and Research Institute, Ahmedabad
21	Cancer Hospital and Research Institute, Gwalior
22	Kidwai Institute of Oncology, Bengaluru
23	MNJ Institute of Oncology and Regional Cancer Centre, Hyderabad
24	Regional Institute of Medical Sciences, Imphal
25	Sanjay Gandhi Post Graduate Institute of Medical Sciences, Lucknow
26	Tata Memorial Hospital, Mumbai
27	Regional Cancer Centre, Rohtak (not funded)

### b. Hospital Based Cancer Registries - Data Management (HBCRDM) Software under NCDIR, Bengaluru

The project has been started from 1<sup>st</sup> March 2017 and 24 centres were identified and registered in 2017. Subsequently in the year 2017-2018, 15 more centres have been added in this project. A total of 39 Hospital Based Cancer Registry Database Management (HBCRDM) centres have signed the MoU and are receiving the financial support from ICMR-NCDIR and are using HBCRDM software to transmit data. The centres are transmitting data for HBCR, while the Patterns of Care and Survival Studies

for three sites of cancer namely Breast, Cervix and Head and Neck is being transmitted by 34 centres.

**c. Hospital Based Cancer Registry in Sources of Registration (SoR) of already existing PBCRs at Bengaluru, Chennai, Delhi, Mumbai and Kolkata.**

Primary aim is to ensure that coverage of cases under PBCRs in above metro cities should be as complete as possible. With more cancer treatment facilities in metros, patients with cancer in PBCR area are getting distributed among these centres and if these hospitals have full-fledged HBCRs, quality as well as coverage of cancer cases in these major centres is improved.

The project has been started from 1<sup>st</sup> March 2017, 10 centres were identified and registered in 2017.

Sl. No.	Name of Centres
1	Fortis Memorial Research Institute, Gurgaon
2	Government Royapettah Hospital, Chennai
3	Government Stanley Medical College, Chennai
4	Institute of Obstetrics and Gynaecology, Chennai
5	Madras Medical College, Chennai
6	Max Super Speciality Hospital, New Delhi
7	Medanta Cancer Centre, Gurgaon
8	Peerless Hospitex Hospital and Research Centre Limited, Kolkata
9	Rajiv Gandhi Cancer Institute and Research Centre, New Delhi
10	Tata Medical Center, Kolkata

### **3. Patterns of Care and Survival Studies (POCSS)**

**a. Patterns of Care and Survival Studies (POCSS) in Cancer Breast, Cancer Cervix and Head and Neck Cancers**

As of March 2018, 26 Regional Cancer Centres and 34 HBCRDM and SoR centres are transmitting data for the POCSS study from the year 2014 and 2017 respectively. The quality of data and follow up of the patient information is being reviewed. The data received as of March 2018 from the above centres is Cancer Breast – 23647 cases, Cancer Cervix – 14718 cases, Head and Neck Cancers – 59567 cases.

**b. Patterns of Care and Survival Studies (POCSS) on Cancers in Childhood, Lymphoid and Hematopoietic Malignancies, other Gynaecological Malignancies except Cervix in Chennai, Bengaluru, Thiruvananthapuram, Delhi and Mumbai.**

**Objectives:**

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

**Summary:**

Malignancies of childhood, lymphoid and haematopoietic system and gynaecological organs show a very specific pattern in terms of risk factors, diagnostic methods, treatments and outcome. Studies reported a much lower 5-year survival rates for these cancers in India compared to developed nations. Comprehensive survival studies from India are limited. The presented study is aimed at filling knowledge deficiency in this domain. The specific objectives are to estimate five-year survival for these three malignancies (except cervix) and to estimate the effect of epidemiological and clinical factors in hospitals of Delhi, Mumbai, Bengaluru, Chennai and Thiruvananthapuram. Survival analysis will be done by univariate (Kaplan Meier) and multivariate (Cox Proportional Regression Model) methods. The finding of this study will help the clinician from developing countries in evidence based decision making and this would be translated into cancer control policies and programmes.

The following centres have been registered for the project:

City	Centres
Delhi	1. Dr. B.R. Ambedkar Institute Rotary Cancer Hospital 2. Rajiv Gandhi Cancer Institute and Research Centre 3. Medanta Cancer Centre
Bengaluru	4. Kidwai Memorial Institute of Oncology 5. Vydehi Institute of Medical Sciences
Thiruvananthapuram	6. RCC, Thiruvananthapuram
Chennai	7. Cancer Institute, Adyar, Chennai
Mumbai	8. Tata Memorial Hospital, Mumbai

Proforma development workshop on Lymphoma and Leukaemia (For Childhood and Adults) and Gynaecological Cancers (Except Cervix) was conducted on 10 and 11 January 2018.



The proforma has been designed for Childhood, lymphoid and Hematopoietic malignancies and other Gynaecologic malignancies except cervix and the software is being designed for the same.

#### 4. Setting up of Cancer as a Notifiable Disease in Karnataka State

Cancer is a notifiable disease in Karnataka State since July 2015. As per the notification order, all the government and private hospitals, medical colleges, pathology labs are registered to the NCRP for transmission of cancer patient’s information (96 centres registered from Karnataka and 7 centres from other than Karnataka). Data transmission by the centres is being monitored through the web-application designed for Online and Dynamic e-Monitoring of Data Capture - Coverage of Cases under Karnataka Cancer Registry Programme (KCRP) which is password protected, provided to all stake holders. This allows monitoring status of registration, list of online participating institutions, status of data received (year wise) from all the districts.

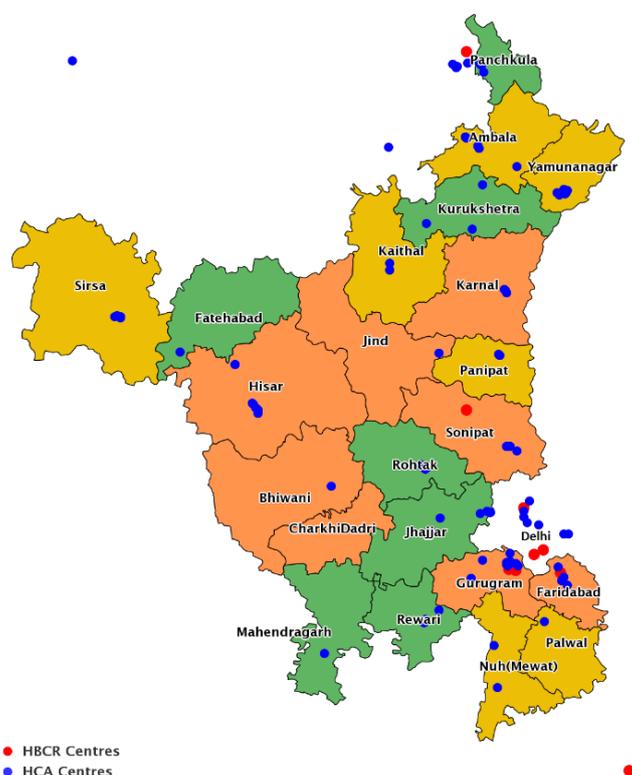
a) Information on number of centres	
Total Number of Centres Registered	96
Total Number of Centers Actively Participating in the Notification Programme	42
b) Workshops and Meetings conducted	
Meeting of NCDIR team with Deputy Director, DHFWS, Ananda Rao Circle, Bengaluru	26 <sup>th</sup> and 27 <sup>th</sup> September 2017 and 2 <sup>nd</sup> February 2018

#### 5. Development of an atlas of cancer in Haryana state

The above project was sanctioned by Department of Health Research (DHR) under the scheme “Inter-Sectoral convergence and Coordination for Promotion and Guidance on Health Research” in December 2015. The objective of this project was to get to know the similarities and differences in patterns of cancer across this state of the country in a cost-effective way, using recent advances in computer and information technology transmission. Knowing patterns of cancer for the state of Haryana would provide important leads in undertaking aetiological research, in targeting cancer control measures and in examining clinical outcomes.

The project was undertaken in partnership of Office of DGHS, Haryana State Government. The project has provided district wise cancer statistics for Haryana. Besides creating awareness and strengthening cancer registration till CHC/PHC level, the data obtained through the project is both from urban as well as rural pockets of Haryana state. This gave an overview of cancer incidence rates in rural areas. The project has boosted the existing cancer registry network within and outside state of Haryana. New HBCRs have joined the network and have started contributing data to NCRP.

127 centres in 21 districts of Haryana have been registered as on date and 96 centres are transmitting data. Information on a total of 39567 confirmed malignancy cases has been transmitted from centres with 992 cases (December 2015), 19457 cancer cases for the year 2016, 17226 cases for 2017 and 1982 cases for 2018 as on 31 March 2018. Data is being processed for quality check and removal of duplicates.



## 6. Exploratory study to standardize PCR tests on paraffin sections to detect *Helicobacter pylori* and compare with other detection tests

The project started in February, 2017. This is a collaborative project of NCDIR, Bengaluru and NICED Kolkata, for a period of two years. NICED will provide technical expertise in carrying out the *H. pylori* tests and the main objective is to assess validity of PCR tests in identification of *Helicobacter pylori* in gastric biopsy samples as compared to other diagnostic tests in patients with gastro-duodenal diseases, especially gastric cancer.

Software for online data entry has been developed using Microsoft asp.net version 4. The functionality of the data entry form is tested.

## OTHER ACTIVITIES RELATED TO AREA OF CANCER

### 1. A Report on Cancer Burden in North Eastern States of India 2012-2014

The report was released at NCDIR by Smt. Anupriya Patel, Hon'ble Minister of State for Health and Family Welfare and Government of India on 10<sup>th</sup> October 2017. The report is based on the data of PBCRs and HBCRs of the north east region. Apart from highlighting the incidence pattern from PBCR data and exposures such as tobacco consumption, alcohol, indoor air pollution that can be contributory to high cancer incidence, the HBCR data also brought to notice that high proportion of cancer patients were travelling outside north east for treatment, low participation in screening programmes were contributory to late stage presentation and that stage adjusted survival rates of cancer patients is lower in NE compared to the rest of the country. The report has been shared with North Eastern registries to take it forward with State Health Authorities for further action regarding creating awareness for prevention of cancer through policy.



Release of the Report on Cancer Burden in North Eastern States of India

### 2. Sharing of Tamil Nadu State Cancer Registry data with NCRP

In response to a request for sharing data of state wide cancer registry from the state of Tamil Nadu by NCDIR, Health Secretary, Govt. of Tamil Nadu has agreed to share the Tamil Nadu State Cancer registry data through cancer institute Adyar, Chennai with NCDIR regularly so as to be part of NCRP.

### **3. Annual Review Meeting of NCDIR – NCRP held from 28.11.2017 to 30.11.2017 at Amrita Institute of Medical Sciences, Kochi.**

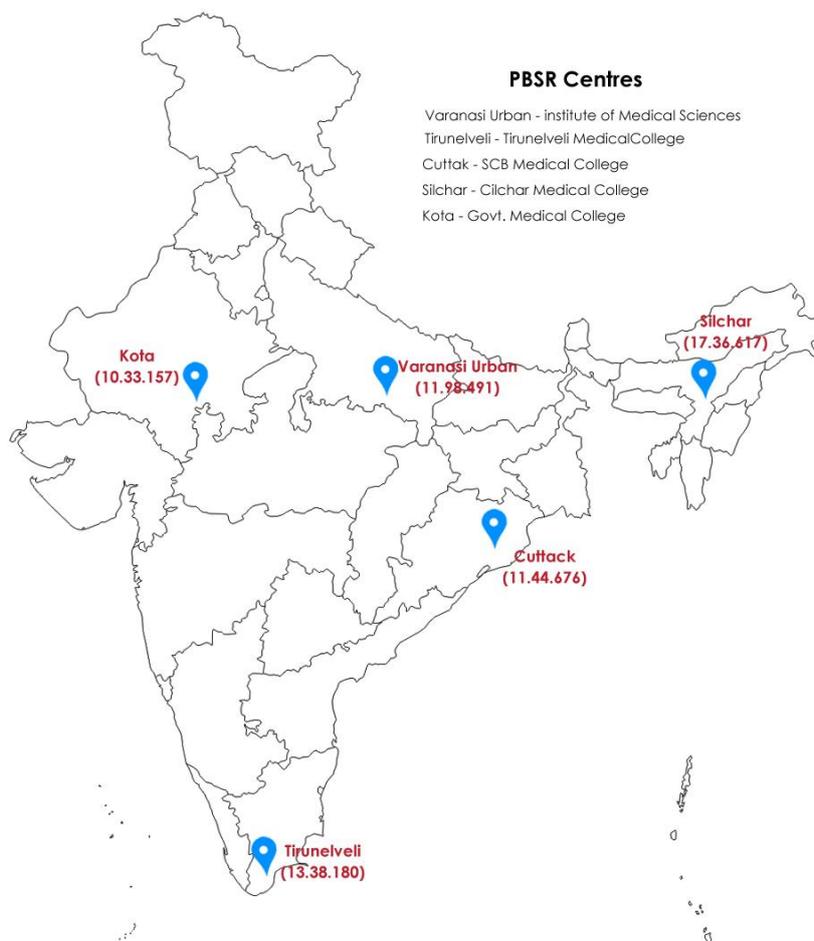
Annual Review meeting of the NCRP held at Kochi in November 2017 in which the investigators and the staff from all Population and Hospital based cancer registries across the country participated.



## STROKE

### Development of Population Based Stroke registry (PBSR) in different regions of India

Population Based Stroke Registries have been initiated in 5 PBSR centres in one geographical area from the south (Tirunelveli), north (Varanasi), east (Cuttack), west (Kota) and north east (Cachar) regions of India with the main objective to generate reliable data on the magnitude and incidence of stroke.



#### Software development:

- Homepage of National Stroke Registry Programme (NSRP) was designed with infographics and factsheets
- Core form for incidence and mortality with the procedure manual has been developed and supplemented.
- Quality check module developed

Data transmission by registered centres is ongoing from January 2018 and the Quality of data has been reviewed.

### **Workshops held during the year:**

Training Workshops on overview of NCD and stroke burden and setting up of Population based stroke Registry were conducted for the investigators and the stroke registry staff at NCDIR-Bengaluru on 2<sup>nd</sup> August 2017 and 13<sup>th</sup> - 14<sup>th</sup> March 2018.



## CARDIOVASCULAR DISEASES

### **A Study on the Magnitude and Pattern of Causes of Heart Failure-a feasibility study**

The Heart failure study is designed as hospital based feasibility study across five centres in small to medium sized towns in north, north west, south west, south and east region of India.

The project has been initiated from March 2017 with the objectives:

#### **Primary objectives:**

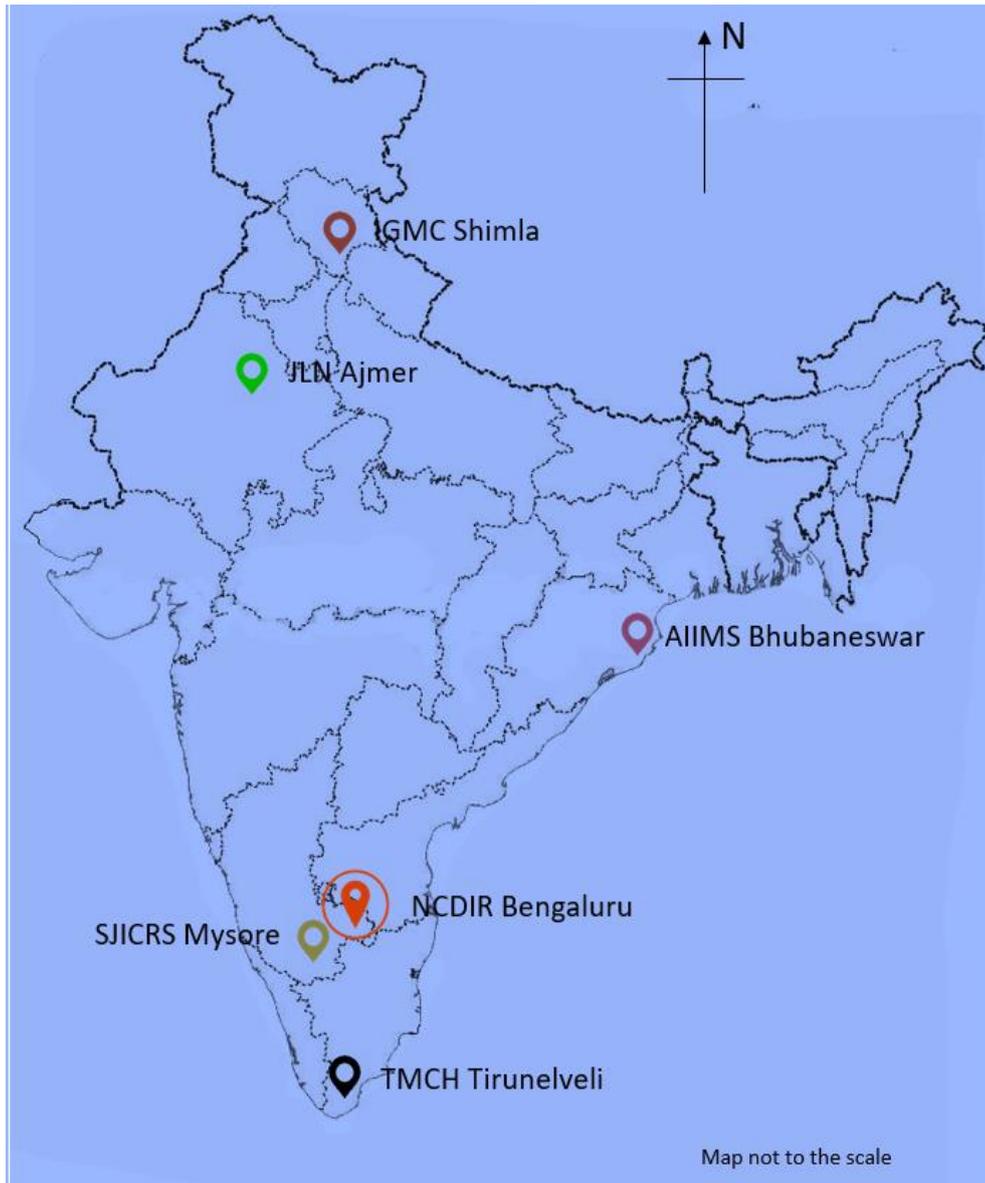
- To understand the pattern of causes of heart failure among attending and hospitalised patients
- To understand the pattern of care and outcomes of heart failure among attending and hospitalised patients.
- To assess the feasibility of establishing the heart failure registry in different geographies of India.

#### **Secondary objectives:**

- To upscale the present model with similar objectives to national level with more number of centres.

#### **Activities:**

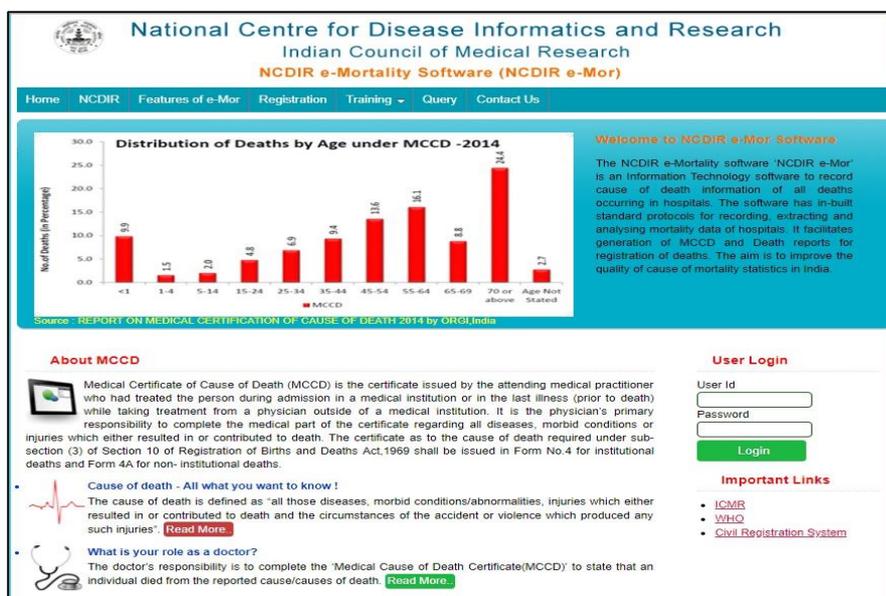
The study protocol and core proforma were reviewed and revised based on review of currently available literature on heart failure in India. A meeting of Research Area Panel on Cardiovascular Diseases was held in March 2018 to discuss and finalize the study tools for study. Procedure Manual was drafted and sent for comments of centres and Research Area Panel members.



## MORTALITY

The National Cancer Registry Programme has been collecting data on deaths due to cancer from the Civil Registration System (CRS) of respective geographical areas for the purpose of incident mortality matching under the Population Based Cancer Registries. Cause of death is unavailable or incomplete and inadequate, making it difficult to estimate cause specific mortality, which is an important indicator of a Registry. NCDIR electronic mortality (NCDIR e-Mor) software has been developed for reporting, recording and improving cause of death by hospitals that captures all causes of deaths with ICD-10 coding as per National list of Office of Registrar General of India. It has features to generate medical certificate of cause of death (MCCD) and Death report (Form 4 and 2 respectively) to aid in death registration.

Home page of NCDIR e-Mortality Software (NCDIR e-Mor)



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

In the first year, the following centres are implementing the project:

<b>Arunachal Pradesh</b> <ul style="list-style-type: none"> <li>Bakin Pertin General Hospital, Pasighat</li> <li>TomoRiba Institute of Health and Medical Sciences, Naharlagun</li> </ul>	<b>Assam</b> <ul style="list-style-type: none"> <li>Cachar Cancer Hospital and Research Centre, Meherpur, Silchar</li> <li>Dr. B. Borooah Cancer Institute, Guwahati</li> <li>Silchar Medical College, Ghungur, Silchar</li> </ul>
<b>Nagaland</b> <ul style="list-style-type: none"> <li>Naga Hospital Authority, Kohima</li> </ul>	<b>Manipur</b> <ul style="list-style-type: none"> <li>Regional Institute of Medical Sciences, Imphal</li> </ul>
<b>Sikkim</b> <ul style="list-style-type: none"> <li>STNM Hospital, Gangtok</li> </ul>	<b>Mizoram</b> <ul style="list-style-type: none"> <li>Civil Hospital, Aizawl</li> </ul>

Sensitization workshop on 'Strengthening Cause of Death Information using NCDIR e-Mor in North East India' at NCDIR, Bengaluru was conducted on March 15<sup>th</sup> 2018 where the Heads of the Institutions and Principal Investigators of 8 centres from North East and few representatives of Chief Registrars of Births and Deaths from North East states were present.



## NONCOMMUNICABLE DISEASE SURVEILLANCE

### 1. National NCD Monitoring Survey- 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 AIIMS Delhi, National Institute of Medical Statistics (NIMS) New Delhi, National Institute of Epidemiology (NIE) Chennai, AIIMS Bhopal, AIIMS Jodhpur, AIIMS Bhubaneswar, National Centre for Disease Control New Delhi, Assam Medical College Dibrugarh, BJ Government Medical College Pune, National Institute of Nutrition Hyderabad and AMCHSS Sree Chitra Tirunal Institute of Medical Sciences Thiruvananthapuram.

#### **Objectives:**

##### **Primary:**

- To generate country/national level estimates of key NCD related indicators (risk factors and health system response) identified in the national NCD monitoring framework for the year 2017-18.

##### **Secondary:**

- To create a central and regional pool of resources (protocols, standard tools, training manuals etc.) to support conduct of similar surveys at state level.
- To strengthen capacities for monitoring of NCDs at national and sub-national level

#### **Measurements in the survey:**

The survey mainly focus on NCD risk factors mainly tobacco consumption both smokeless and smoking, harmful intake of alcohol, dietary habits, dietary 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 tablets by qualified medical social workers. Urinary sample of 3000 participants has been collected from selected 150 PSUs for estimation of 24-hour dietary salt intake.

#### **Current status:**

The survey has been rolled out from 25<sup>th</sup> October 2017 for a period of 6 months and the survey has been completed in 450 PSUs (200 urban and 250 rural) as of 31<sup>st</sup> March 2018. A NNMS Dashboard system has been developed at NCDIR for regular monitoring of data

collection. The application provides an overall and detailed view of data collection status of each centre. Dashboard provides a feature to report the grievances by the field team and also feature for field supervisor to submit their report to the central core team.

### Meetings held:



Meeting of the National Technical Working Group (TWG) on 24.04.2017 at NCDIR, Bengaluru.



Training of Trainers (TOT) for NCD Survey held on 26.07.2017 to 29.07.2017 at New Delhi

## 2. National Burden of Non Communicable 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 is followed by using the DISMOD-II software. The main inputs are mortality rate, incidence rate and case fatality rate. These parameters are collected by using the population based cancer registry (PBCR) of the NCRP program. By using these three inputs the prevalence, remission rate etc. can be calculated from the DISMOD-II output. Years of life lost (YLL) due to premature death is also calculated by multiplying total number of deaths in each age group by the life expectancy of each age group at the time of death ( $YLL = \text{No of deaths} * \text{life expectancy}$ ). For Years lived with disability (YLD) calculation, the incidence and prevalence methods ( $YLD = \text{Incidence} * DW * \text{Remission or prevalent} * DW$ ) are used. Finally, DALY is calculated by adding both YLL and YLD. Final report preparation is underway.

## BIOETHICS

### 1. ICMR National Ethical Guidelines for Biomedical and Health Research Involving Human Participants, 2017

The ICMR National Ethical Guidelines for Biomedical and Health Research Involving Human Participants, 2017 were finalized after several rounds of consultations with relevant stakeholders as well as with public. The guidelines were released by Hon'ble Union Minister of Health and Family Welfare, Hon'ble Minister of State for Health and Family Welfare and in the presence of DG ICMR and Secretary DHR, and Country Representative, WHO-WR and other dignitaries on 12<sup>th</sup> October 2017 at ICMR Headquarters, New Delhi. The ICMR National Ethical Guidelines have the following 12 sections:

SI No.	Name of Sections of Guidelines	SI No	Name of Sections of Guidelines
1.	Statement of general principles	7.	Clinical trials of drugs and other interventions
2.	General ethical issues	8.	Public health research
3.	Responsible conduct of research	9.	Social and behavioural sciences research for health
4.	Ethical review procedures	10.	Human genetics testing and research
5.	Informed consent process	11.	Biological materials, biobanking and datasets
6.	Vulnerability	12.	Research during humanitarian emergencies and disasters

The initial six sections of the Ethical Guidelines, 2017 cover generic topics that are applicable to all types of biomedical and health research and later six sections focus on specific areas of research such as clinical trials, human genetics, etc. For the first time, these guidelines have addressed concerns in subject areas where there is scanty guidance available such as responsible conduct of research, public health research, socio-behavioural research, conducting research during humanitarian emergencies or disasters, dealing with vulnerable populations or conducting collaborative research, conflict of interest at various levels, use of stored samples, biological materials, bio banking and datasets. The guidelines explain the processes of benefit risk assessment, protecting privacy and confidentiality, prevention against stigmatization or discrimination, community engagement and benefit sharing with the research participants or communities or population. In case of injury during participation in a biomedical research the payment of compensation is a difficult and cumbersome area and for the first time it is suggested that any institution engaging in biomedical and health research must arrange prior provisions such as to create a corpus fund in the institution or to seek insurance coverage, or to seek grants from various agencies who sponsor research.

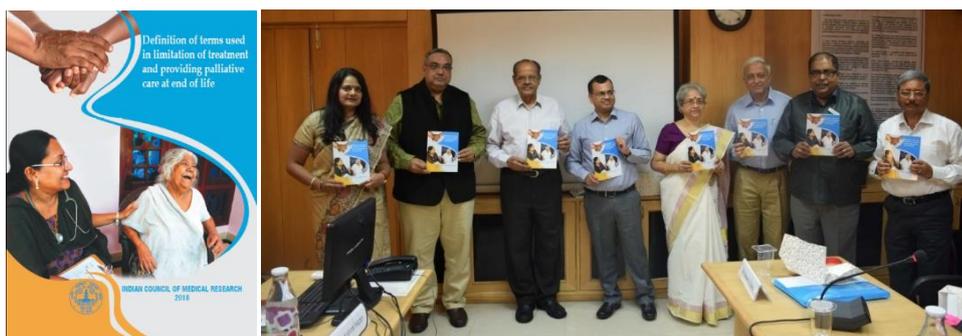
The newly released ICMR National Ethical Guidelines have become effective from 12<sup>th</sup> October, 2017 and are applicable to all biomedical and health research in India.



**ICMR National Ethical Guidelines for Biomedical Research Involving Children, 2017** was drafted by expert groups and activity was coordinated by Reproductive Biology and Maternal Health, Child Health Division, ICMR Headquarters, New Delhi. The finalised document was sent to ICMR Bioethics Unit, NCDIR, Bengaluru for finalization. The document was reviewed by Ethics Advisory Committee (EAC) and Central Ethics Committee on Human Research (CECHR) and was finalized and copy edited accordingly. These guidelines specifically provide guidance to researchers for the conduct of research on children. It was released along with National Ethical Guidelines for Biomedical and Health Research Involving Human Participants, 2017 on the same day.

## **2. Definitions of terms used in limitation of treatment and providing palliative care at end of life**

End-of-Life Care (EOLC) refers to health care, not only for patients in the final hours or days of their lives, but more broadly care of all those with a terminal illness or terminal disease condition that has become advanced, progressive and incurable. The correct consensus definition of terms related to EOLC has not been clear yet due to different interpretations of these terminologies nationally and internationally resulting in inappropriate decision making at different levels. A group of experts was commissioned to create definitions of terms pertaining to EOLC which consisted of a multi professional panel from the fields of Palliative Care, Critical care, Pulmonology, Neurology, Disease Informatics and Research, Basic Sciences, Ethics and Law. The expert group drafted the definitions pertaining to EOLC which were posted on ICMR website for public consultation. The comments and feedbacks received from various stakeholders were incorporated in the document and the ICMR commission finalized the definitions. The final draft of EOLC was reviewed and approved by Ethics Advisory Committee and CECHR and released on 12<sup>th</sup> March, 2018 at NCDIR, Bengaluru.



Release of the "Definition of terms used in limitation of treatment and providing palliative care at end of life on 12<sup>th</sup> March 2018

### 3. An International study entitled “A Survey of What Information Research Participants Would Like to Know in Informed Consent Forms in Biomedical Research”

**Forum for Ethical Review Committees in the Asian and Western Pacific Region (FERCAP)** initiated the study as an inter-country research, and Dr. Roli Mathur, ICMR Bioethics Unit, NCDIR, Bengaluru, took up this research as the Country Coordinator for all the study sites in India. Four regional investigators and centres were identified for the survey in different parts of the country were Dr Paul P Kumaran, NIRT, Chennai (South); Dr Ragini Kulkarni NIRRH, Mumbai (West); Dr Subhash Yadav, SGPPI, Lucknow (North) and Dr Suman Kanungo, NICED, Kolkata (East). A common anonymous, paper-based, structured and self-administered questionnaire related to informed consent elements and there were no sensitive questions was used in English and regional languages at the sites to collect information from research participants after necessary approvals from scientific committees, ethics committees and Health Ministry’s Screening Committee (HMSC). The data collated and pooled for analysis. The objective of this study was to identify the elements and the extent of information in ICFs that research participants in biomedical and health research would like to know.

The majority of the respondents were female (57.9%), middle-aged adults (mean age, 43.3 ± 16.2 years), and had the high-school level of education or lower (64.5%). Major foreseeable risk, direct benefit, and common adverse effects of the intervention were considered to be of most concern among the respondents. In contrast, number of participants involved, source of funds and sponsors, conflict of interest, and payment and/or remuneration were considered to be of relatively least concern. The maximum, acceptable number of pages in the ICF that research participants preferred to read was 6.3 ± 6.1 pages. The results of this FERCAP Multi-Country ICF study, involving thousands of actual research participants at 54 study sites across 7 Asia-Pacific countries, could be representative of the perspectives of general populations in the Asia-Pacific region. The

study results provide important insights to better address the challenges of determining the extent of information in ICFs that is considered to be important and adequate from research participants perspectives.

**Publication: What information and the extent of information research participants need in informed consent forms: a multi-country survey. BMC Med Ethics. 2018;19(1):79.**

#### **4. ICMR Dissemination programs of the ‘National Ethical Guidelines for Biomedical and Health Research Involving Human Participants, 2017’.**

In order to create awareness about the newly released ICMR National Ethical Guidelines for Biomedical and Health Research Involving Human Participants, 2017 and to reach out to various stakeholders, a series of 8 dissemination programs were organized in all parts of the country. 4 of them were funded and coordinated by ICMR and another 4 were conducted with funding support from CDSA (THSTI).

Relevant stakeholders from various medical colleges, biomedical research institutions, paramedical institutes, universities, colleges, industry personnel, etc. were identified and contacted through email, online advertisement, social media, brochures etc. The interested participants were required to register online or on spot without any registration fee to attend the program. The attendees were given e-certificates of attendance after confirming attendance during the program.

During the half day program, key issues were highlighted from the ICMR National Ethical Guidelines and an expert panel answered to the questions from the audience to clarify doubts. Details were shared with around 6000 people including EC members, students (medical/ non-medical), nurses, clinicians, faculty, scientists, lawyers and other interested stakeholders. Participants from 24 States/ Union territories, covering around 500 institutes from the country benefitted from these programs. The outreach programs were successful as the dissemination reached to the large number of expected stakeholders involved in biomedical and health research.

##### **Details of Dissemination programs conducted across the country**

Sl. No	Date	Venue	No. of Participants
<b>ICMR – NCDIR Dissemination Programs</b>			
1.	November 16, 2017	JLN Auditorium, AIIMS, Ansari Nagar, New Delhi	650
2.	December 14, 2017	Bhargava Auditorium, PGIMER, Chandigarh	1201
3.	February 7, 2018	Sri Ramachandra Medical College, Chennai	939
4.	February 17, 2018	All India Institute of Medical Sciences, Bhubaneswar	642
			<b>3432</b>

ICMR-NCDIR and CDSA Dissemination programs			
1.	November 30, 2017	AMCMET Medical College, Maninagar, Ahmedabad	669
2.	December 21, 2017	Andhra Medical College, Visakhapatnam	322
3.	February 22, 2018	Amrita Institute of Medical Sciences, Kochi	752
4.	March 8, 2018	Guwahati Medical College, Guwahati	785
<b>Total Participants</b>			<b>2528</b>
<b>Grand Total</b>			<b>5960</b>

## 5. ICMR-THSTI-Preparation of Common Forms and Checklists for Ethics Committees in India and its piloting at 5 institutes

In India, different formats were followed by various Ethics Committees (ECs) for the ethical review of proposals submitted, leading to difficulties and confusion especially when multi-centric research studies are to be conducted using common protocols. To address the felt need, ICMR in collaboration with Translational Health Science and Technology Institute (THSTI) developed common EC forms in order to harmonize, facilitate and improve EC submissions and functioning in an efficient and uniform manner. As part of this process online available national and international forms were used as source material and also 10 institutes and hospitals in India were requested to provide their EC forms, formats/checklists/tools etc. currently in use by them.

Information provided in these forms were collated to generate a common form to identify the common as well as unique questions pertaining to different sections in the forms. A total of fourteen forms were created namely:

Sl. No.	Forms
1	Application Form for Initial Review
2	Application Form for Expedited Review
3	Application Form for Exemption from Review
4	Continuing Review /Annual report format
5	Application/Notification form for Amendments
6	Protocol Violation/Deviation Reporting form (Reporting by case)
7	Serious Adverse Event Reporting Format (Biomedical Health Research)
8	Premature Termination/Suspension/Discontinuation Report Format
9	Application Form for Clinical Trials
10	Serious Adverse Event Reporting Format (Clinical Trials)
11	Application form for Human Genetics Testing and Research
12	Application form for Socio-Behavioural and Public Health Research
13	Study Completion/Final report format
14	Format for Curriculum Vitae for Investigators

These forms were piloted at 5 institutions (Jawaharlal Nehru University, New Delhi; Sree Chitra Tirunal Institute for Medical Sciences and Technology SCTIMST, Thiruvananthapuram, Kerala; Jawaharlal Institute of Postgraduate Medical Education and Research, Puducherry; Postgraduate Institute of Medical Education and Research, Chandigarh and Tata Memorial Hospital, Mumbai) under the supervision of Dr. Mala Ramanathan, Professor, SCTIMST as Principal Investigator and Dr. Roil Mathur, Scientist 'E' and Head ICMR Bioethics Unit, NCDIR, Bengaluru as Co-Principal Investigator with the following objectives:

- To evaluate the structural and functional ease in translating a research protocol to the EC submission protocol.
- To identify gaps/bottle necks in the draft forms that need to be addressed.
- To evaluate the draft form's ability to capture the ethical and legal requirements of reporting by EC.

From the pilot study, various aspect of the forms were identified for modification. It was suggested that the forms are to be revised further and finalized based on the results of the pilot study. These forms would further ease the work of ECs and provide a much-needed common EC format for promoting biomedical research in the country.

## **6. ICMR National Symposium on Draft New Drugs and Clinical Trials Rules, 2018**

The Draft New Drugs and Clinical Trials Rules 2018 were posted on CDSCO website for public comments, for a period of 45 days in February 2018. These draft rules had proposed that all ECs involved in review of biomedical and health research would be required to register with DHR and follow the ICMR National Ethical Guidelines, 2017. In this regard a half day ICMR symposium was organized to discuss the Draft New Drugs and Clinical Trial Rules 2018 at NCDIR, Bengaluru on 12th March, 2018. The program was attended by 22 experts who deliberated on the draft rules, addressed Issues related to constitution of ECs, registration process and documentation, time period for application, grant of registration, validity, review of biomedical and health research by ECs registered for clinical trials and vice versa, conduct of biomedical and health research, academic clinical trials, payment of compensation for injury, training for new and existing committee members, etc. After a detailed discussion during the symposium, various suggestions were made which were communicated to the Secretary, Ministry of Health and Family welfare, Government of India, New Delhi.



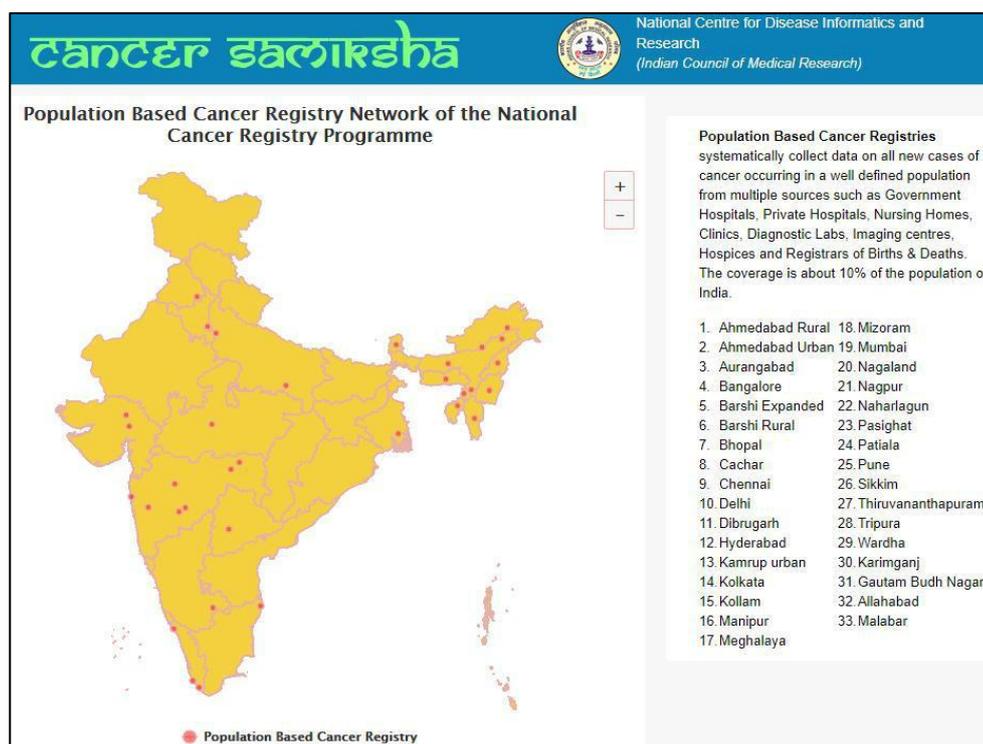
ICMR- Symposium on Draft New Drugs and Clinical Trials Rules, 2018

## SOFTWARE DEVELOPMENT AT NCDIR

### 1. Cancer Samiksha

A data visualization portal was developed and launched in September 2017 which showed the point of presence of Hospital Based Cancer Registries (HBCRs) and Population Based Cancer Registries (PBCRs) in the map of India. The location of centres contributing to the Karnataka and Haryana Cancer Atlas are also depicted in the respective state maps. The tool offers cancer statistics, allows online analysis, provides dashboard, generates tables and charts for further analysis. A feedback window seeking opinions and suggestions from the users was provided for improvement. It can be accessed from [www.ncdirindia.org/cancersamiksha](http://www.ncdirindia.org/cancersamiksha).

Online Analysis is available only using PBCR data and requires visitors to register using a simple registration form to generate credentials for access. Following the launch, time trends for cancer incidence is under development based on the PBCR data available from 1982-2014.

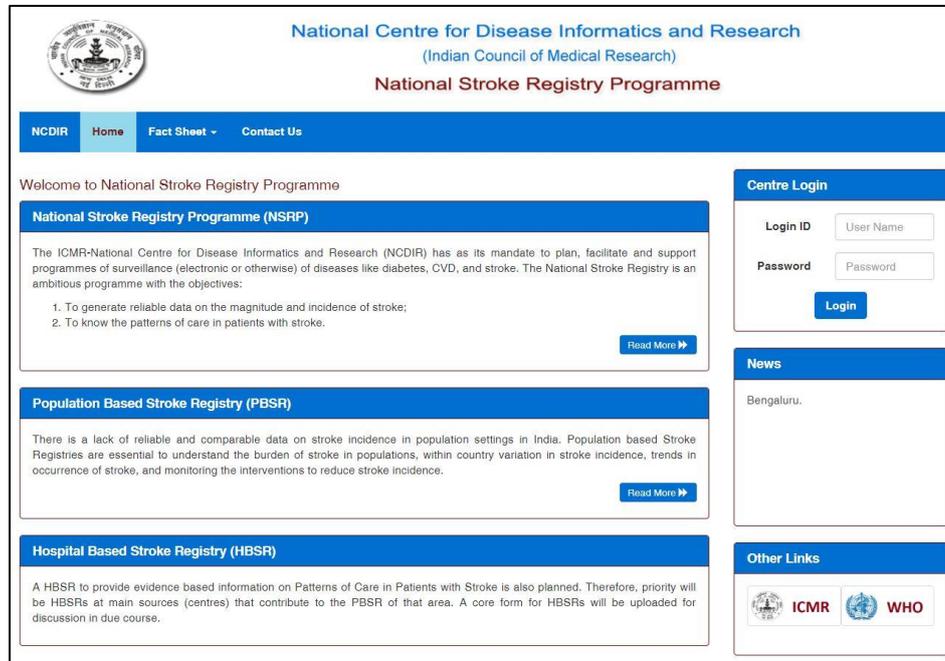


### 2. Population Based Stroke Registry (PBSR)

Population Based Stroke Registry (PBSR) application is an online portal available at [www.ncdirindia.org/stroke/](http://www.ncdirindia.org/stroke/) for recording the confirmed stroke cases in a defined population. The user manual for the PBSR software was prepared and shared with centres.

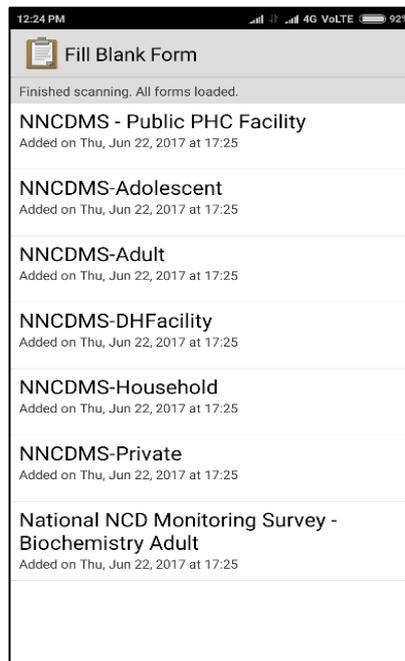
The application has the following features:

- a) Home page with Introduction to PBSR and HBSR
- b) Fact sheets on Stroke burden, NCD country profile, NCD monitoring Framework
- c) Login module for PBSRs



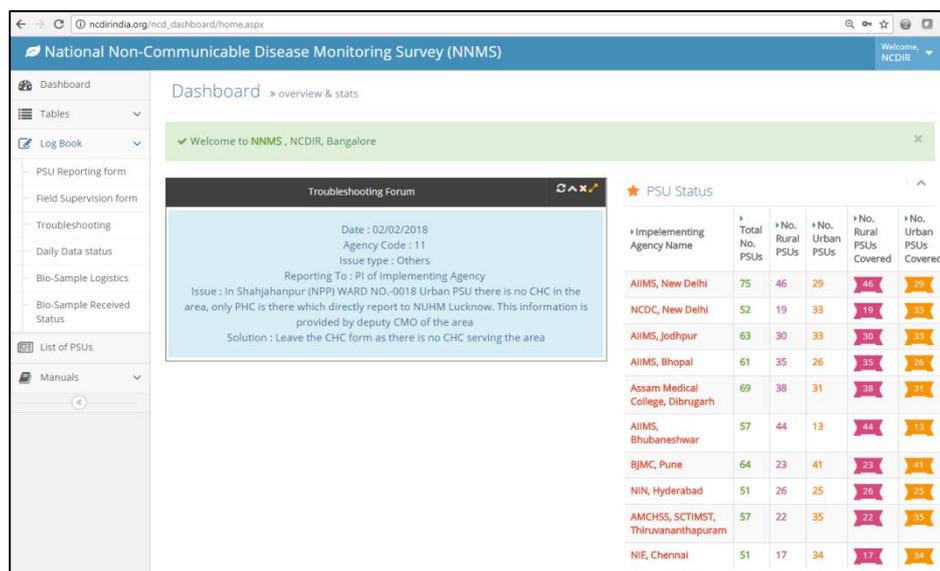
### 3. National NCD Monitoring Survey (NNMS) 2017-18

- Software developed in collaboration with ICMR–NIE, Chennai
- NNMS is developed on Open source application platform in Eleven Indian languages with built-in quality assurance checks for Range errors and Consistency errors.
- NNMS uses Barcode scanning to uniquely identify each household and thus eliminating the typographical errors across various forms. Application provides option to save the partially filled form as a draft copy. Completed records will be transmitted to central server through internet.
- NNMS captures the GPS co-ordinates of the survey location.



**Tablet application**

- Dashboard has a provision to report and readdress the issues encountered during the field activity.
- Survey activity, data status, team movement, biochemical sample logistics are monitored by central team through dashboard application.



**NNMS dashboard application**

#### 4. E-MoR (Electronic Mortality Software)

- .Net Version and Java Version: Developed to function at par with the .Net version. Also made to be mobile compatible
- SNOMED CT** (multilingual clinical healthcare terminology in the world owned, maintained, and distributed by the SNOMED International, United Kingdom) is

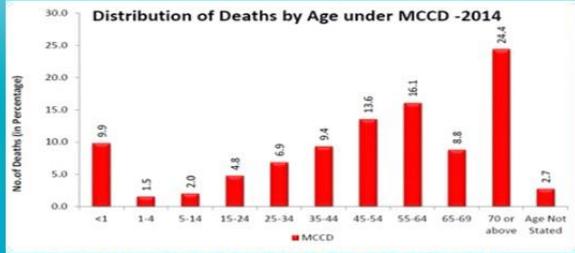
distributed in India through NRCeS (National Resource Centre for EHR Standards – CDAC Pune). Integration with cause of death module as a sample application was done

- c) SoA Plug in for integration with Tamil Nadu CRS software for coding for cause of death is under development.



**National Centre for Disease Informatics and Research**  
 Indian Council of Medical Research  
**NCDIR e-Mortality Software (NCDIR e-Mor)**

Home
NCDIR
Features of e-Mor
Registration
Training ▾
Query
Contact Us



Age Group	No. of Deaths (in Percentage)
<1	9.9
1-4	1.5
5-14	2.0
15-24	4.8
25-34	6.9
35-44	9.4
45-54	13.6
55-64	16.1
65-69	8.8
70 or above	24.4
Age Not Stated	2.7

Source: REPORT ON MEDICAL CERTIFICATION OF CAUSE OF DEATH 2014 by ORGI, India

**Welcome to NCDIR e-Mor Software**

The NCDIR e-Mortality software 'NCDIR e-Mor' is an Information Technology software to record cause of death information of all deaths occurring in hospitals. The software has in-built standard protocols for recording, extracting and analysing mortality data of hospitals. It facilitates generation of MCCD and Death reports for registration of deaths. The aim is to improve the quality of cause of mortality statistics in India.

**About MCCD**



Medical Certificate of Cause of Death (MCCD) is the certificate issued by the attending medical practitioner who had treated the person during admission in a medical institution or in the last illness (prior to death) while taking treatment from a physician outside of a medical institution. It is the physician's primary responsibility to complete the medical part of the certificate regarding all diseases, morbid conditions or injuries which either resulted in or contributed to death. The certificate as to the cause of death required under sub-section (3) of Section 10 of Registration of Births and Deaths Act, 1969 shall be issued in Form No.4 for institutional deaths and Form 4A for non-institutional deaths.

- 

**Cause of death - All what you want to know !**  
 The cause of death is defined as "all those diseases, morbid conditions/abnormalities, injuries which either resulted in or contributed to death and the circumstances of the accident or violence which produced any such injuries". [Read More](#)
- 

**What is your role as a doctor?**  
 The doctor's responsibility is to complete the 'Medical Cause of Death Certificate(MCCD)' to state that an individual died from the reported cause/causes of death. [Read More](#)

**User Login**

User Id

Password

**Important Links**

- [ICMR](#)
- [WHO](#)
- [Civil Registration System](#)

## AWARDS AND HONORS

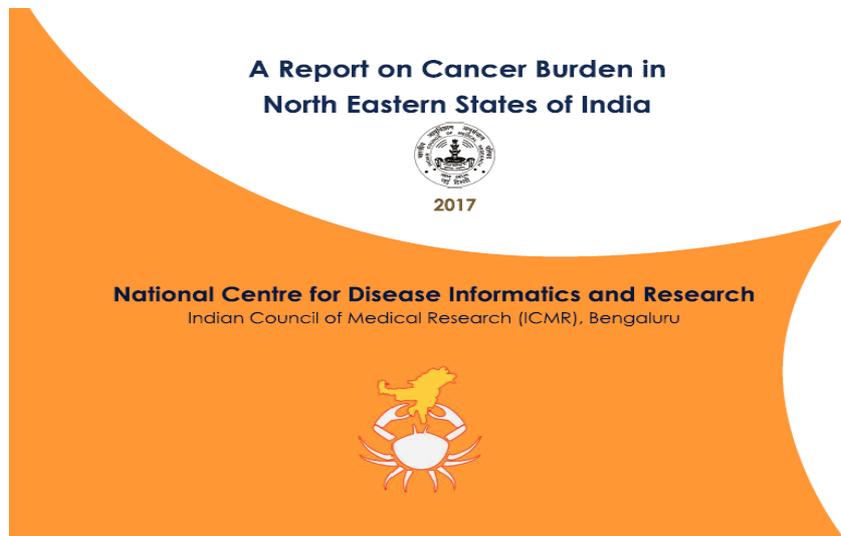
1. Dr. Roli Mathur, Scientist E and Head, ICMR Bioethics Unit elected as a member of Executive Committee of Council of International Organization of Medical Sciences (CIOMS), 2017.
2. Dr. Roli Mathur, Dr. Rajib Hazam, Dr. Kalyani Thakur received the International TRUST award for case study which was ranked in the five best case studies by INSERM, 2017.
3. Two students from IIT Kharagpur, Mr. Anil Kumar and Mr. Sai Kashyap were in NCDIR for internship of 2 ½ months (May to July 2017) and developed the Android application CANCER APP for ICD10 and ICD-O-3 with procedure Manuals PBCR and HBCR – NCDIR for which they were awarded the Medtech Summer Internship award 2017 (Rs.2 Lakh).

## RELEASES

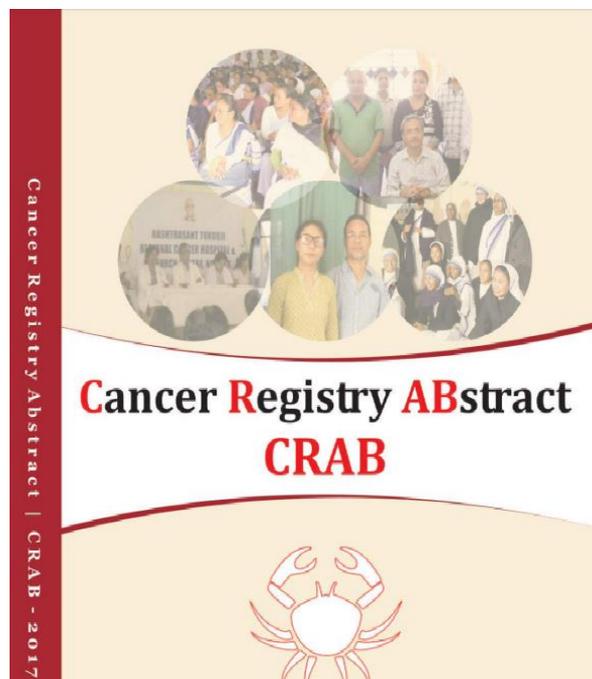
1. Launch of Cancer Samiksha web based tool on assessment and analysis of cancer by Dr. Soumya Swaminathan, Secretary, DHR and Director General ICMR at NCDIR on 08.09.2017
2. Release of ICMR National Ethical Guidelines for Biomedical and Health Research Involving Human Participants, 2017 on 12.10.2017 at ICMR Hqs. by Shri Jagat Prakash Nadda, Hon'ble Union Minister, MoHFW and Smt. Anupriya Patel, Hon'ble Union Minister of State, MoHFW, in the presence of various other dignitaries Dr. Soumya Swaminathan, DG ICMR and Secretary DHR, Dr. P N Tandon, Former Chairperson, Central Ethics Committee on Human Research (CECHR) and Dr. Henk Bekedam, WHO-WR.
3. Release of ICMR National Ethical Guidelines for Biomedical Research Involving Children, 2017 on 12.10.2017 at ICMR Hqs. by Shri Jagat Prakash Nadda, Hon'ble Union Minister, Ministry of Health and Family Welfare and Smt. Anupriya Patel, Hon'ble Union Minister of State, Ministry of Health and Family Welfare.
4. Release of the document "Definition of terms used in limitation of treatment and providing palliative care at end of life" on 12.03.2018 at NCDIR, Bengaluru.
5. Release of North East Report 2012-2014 by Smt. Anupriya Patel, Hon'ble Union Minister of State, MoHFW on 12.10.2017 at NCDIR, Bengaluru
6. Release of ICMR Guideline on Diagnosis and Management of Celiac Disease by Smt. Anupriya Patel, Hon'ble Union Minister of State, MoHFW on 12.10.2017 at NCDIR, Bengaluru



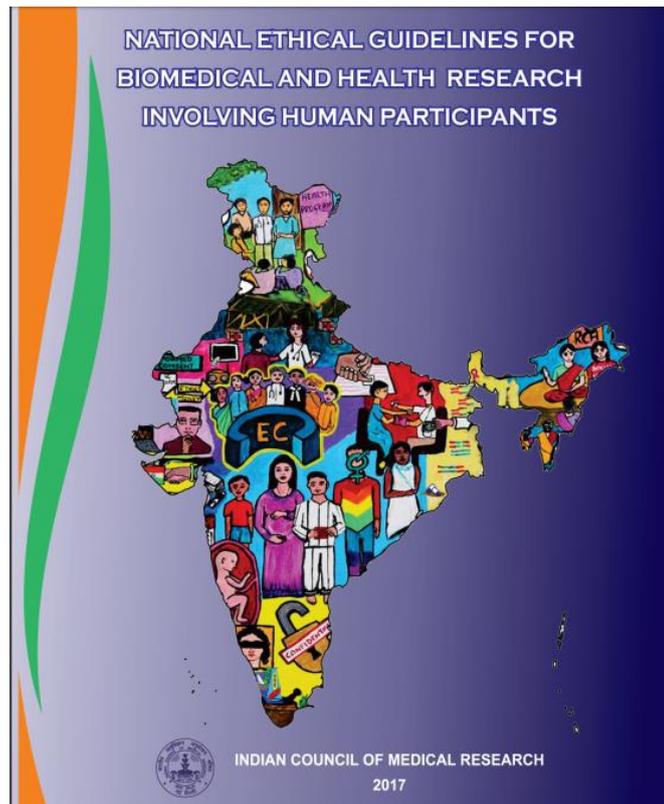
## REPORTS PUBLISHED



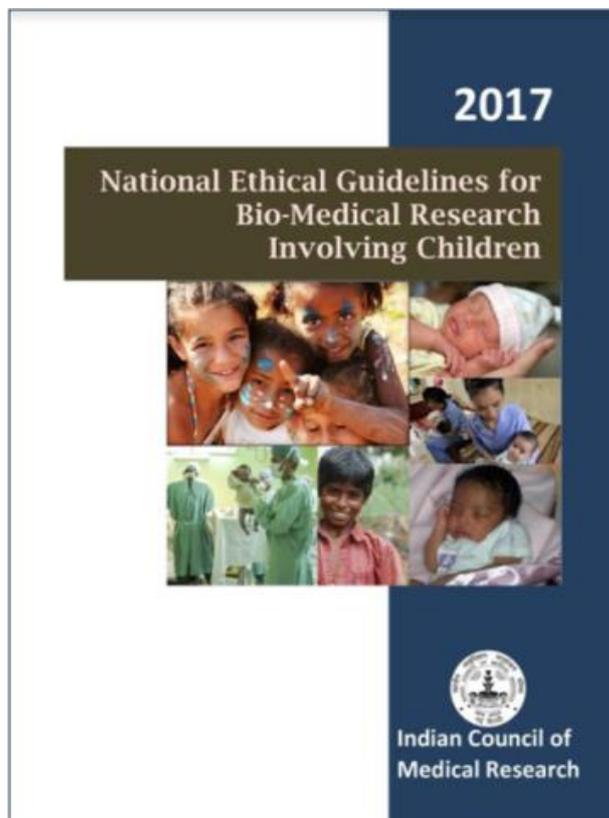
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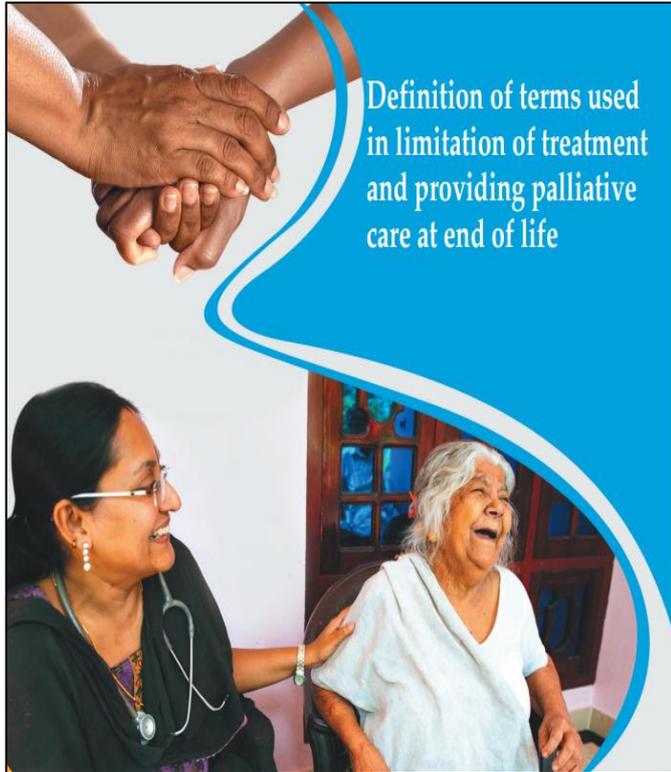
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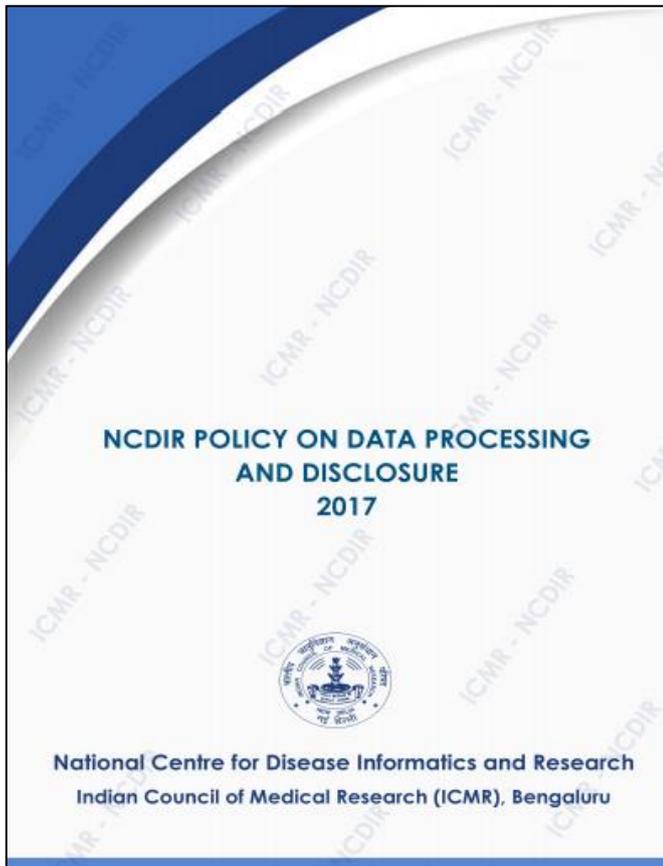
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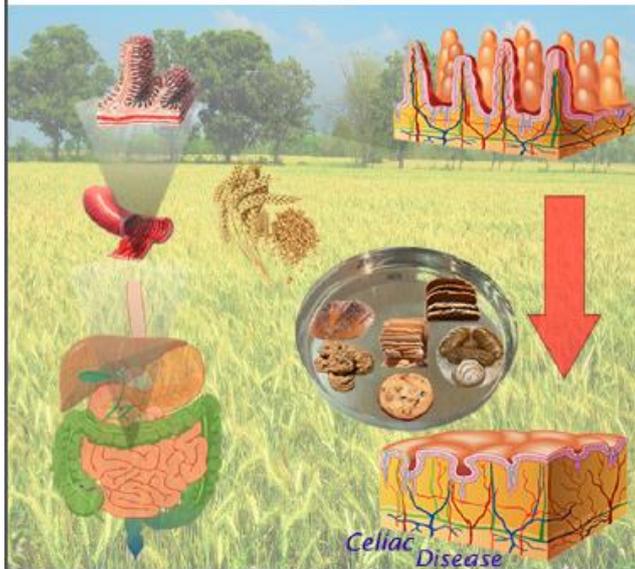


**URL:** <http://ncdirindia.org/Downloads/EOLC.pdf>



**URL:** [http://ncdirindia.org/Downloads/NCDIR\\_Policy.pdf](http://ncdirindia.org/Downloads/NCDIR_Policy.pdf)

**ICMR GUIDELINE ON DIAGNOSIS AND MANAGEMENT  
OF CELIAC DISEASE  
2016**



Division of Noncommunicable Diseases  
Indian Council of Medical Research  
New Delhi

**URL:** <https://www.icmr.nic.in/sites/default/files/guidelines/ICMR%20-%20Diagnosis%20and%20Managmemnt.pdf>

## PUBLICATIONS

1. Srinivasan S, Swaminathan G, **Kulothungan V**, Ganesan S, Sharma T, Raman R. Age-related macular degeneration in a South Indian population, with and without diabetes. *Eye (Lond)*. 2017 Aug;31(8):1176-1183. doi: 10.1038/eye.2017.47. Epub 2017 Apr 7. PubMed PMID: 28387762; PubMed Central PMCID: PMC5558219 **(IF:2.275)**
2. **Manimunda SP** et al., Nutritional status of preschool children in Andaman and Nicobar Islands and food insecurity, food groups and nutrient consumption among population. *Indian J Community Med*; 2017 Apr-Jun;42(2):88-93 **(IF:1.22)**
3. **Manimunda SP** et al., Alcohol consumption, hazardous drinking and alcohol dependency among the population of Andaman and Nicobar Islands, India. *Indian J Public Health* 2017 April to June; 61:105-1**(IF:1.09)**
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