

Annual Highlights 2018 - 2019



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

(Indian Council of Medical Research)

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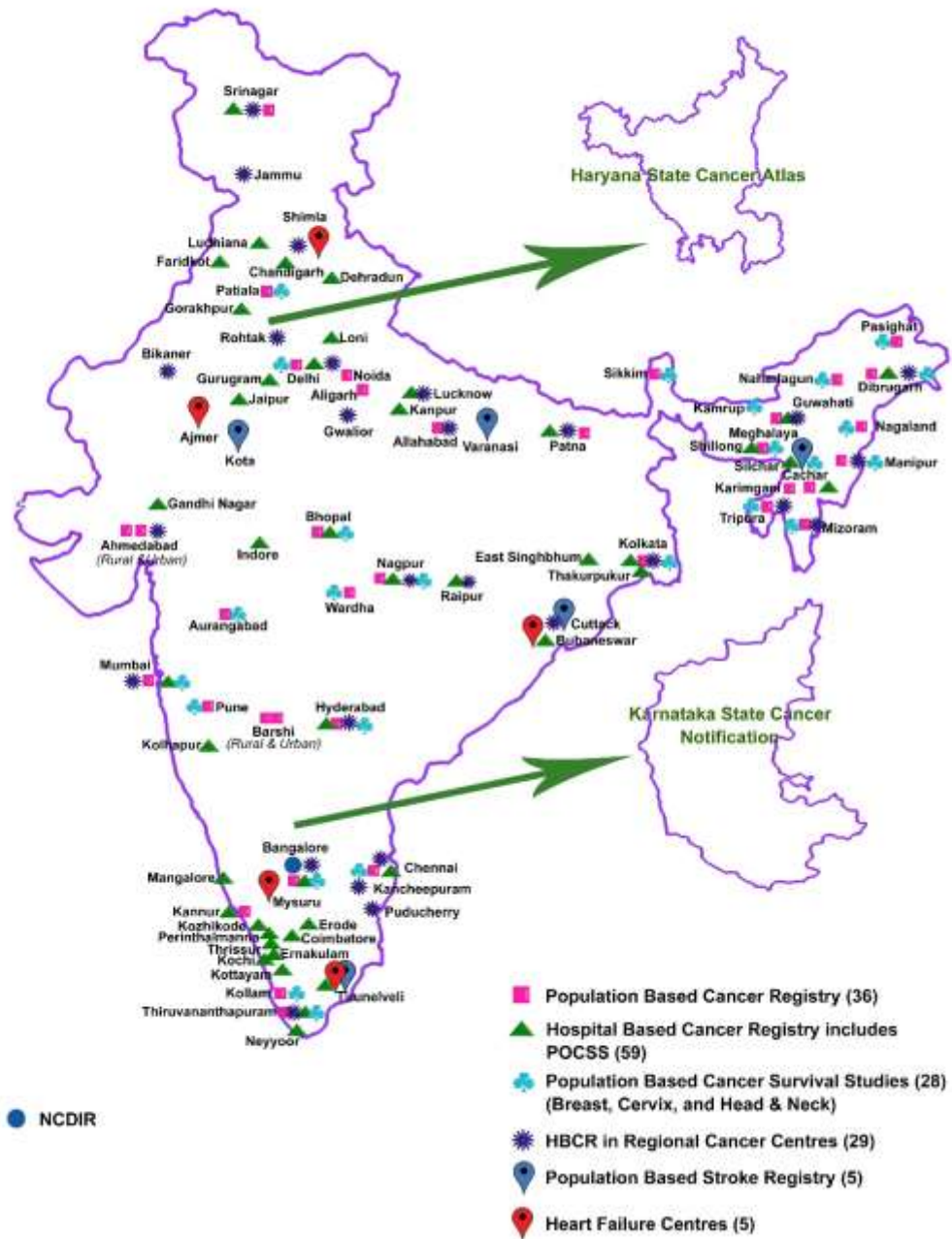
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KEY ACHIEVEMENTS

2018-19

1. National Cancer Registry Program (NCRP) covers almost 10% of the population of India through its network of 36 PBCRs & 228 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. As follow up to the thrust area by the government to expand the research activities on alarming health issues attributed to increasing pollution of rivers, NCDIR has set up Population Based Cancer Registries Jawaharlal Nehru Medical College, Aligarh (Uttar Pradesh) and Indira Gandhi Institute of Medical Sciences, Patna (Bihar) to determine the magnitude of various types of cancers along the course of Ganga during the period in addition to Kamala Nehru Memorial Hospital, Allahabad (Uttar Pradesh) that was established in 2017,
3. The project on Development of an Atlas of Cancer in Haryana State has been completed in March 2019 successfully with creation of awareness and strengthening the cancer registration till PHC/CHC level and the data obtained through the project is both from urban and rural pockets.
4. 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 five hospitals in North Eastern States and six hospitals in other parts of the country during the 2018-19.
5. National NCD monitoring Survey was implemented in 600 primary sampling units across the country has been completed which would help to generate estimates of different NCDs related indicators on nationally representative sample of India for the year 2017-18 and measure the program being made towards achieving National NCD action plan and NCD monitoring framework. The report has been finalised and submitted to MoHFW.
6. A Handbook on National Ethical Guidelines for Biomedical and Health Research Involving Human Participants was prepared to provide students, researchers and ethics committees a simplified and quick reference to the ICMR National Ethical Guidelines. The report was released on 26th March 2019.
7. ICMR Bioethics Unit developed the “Common forms for Ethics Committee review” that are easy to use, adaptable and can be customized as per requirements of Ethics Committees across the country and have been released at NCDIR, Bengaluru on 7th December 2018.
8. A Tagline depicting the mandate of the institution was developed and put in use from 28th January 2019.

NCDIR Network as of March 2019



CANCER

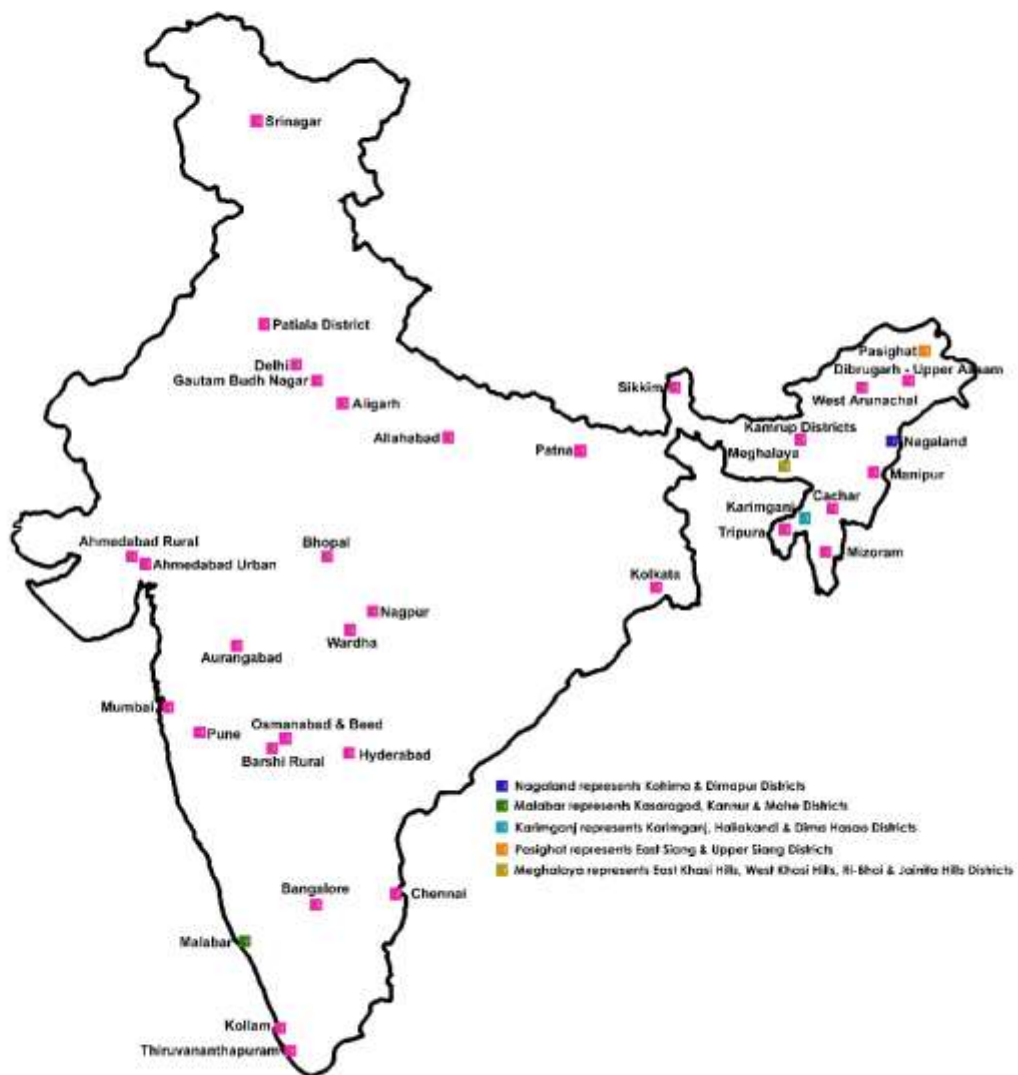
Ongoing Projects

1. Population Based Cancer Registries (PBCR) Network

a. Population Based Cancer Registries (PBCRs) in India

PBCRs provide information on the incidence rates, burden and trends of cancer in the population. Three PBCRs have been initiated in 2018-19 at Sher-I-Kashmir Institute of Medical Sciences, Srinagar, J.N. Medical College, Aligarh and Indira Gandhi Institute of Medical Sciences, Patna making the total number of PBCRs to 36.

Population Based Cancer Registry Network (36)



The following ongoing PBCRs have extended their area of coverage and have been renamed.

1. Kamrup Urban PBCR to cover entire Kamrup District including rural areas renamed as Kamrup District PBCR.
2. PBCR at Dibrugarh, to cover entire upper Assam (Sibsagar, Jorhat, Tnsukia, Golaghat, Lakhimpur and Dhemaji) along with existing Dibrugarh District is renamed as PBCR Dibrugarh – Upper Assam.
3. Naharlagun PBCR (Arunachal Pradesh) is renamed to West Arunachal.
4. Barshi Expanded is renamed to Beed and Osmanabad.

Software updates for PBCR:

Out of the total 36 PBCRs, 17 PBCRs are using the online and 18 are using the offline version of the PBCR software. Enhancements to this application along with features to find the duplicates and matching the incidence and mortality cases and additional reporting tool for book report publication have been developed.

Following the launch of Cancer Samiksha, a data visualisation portal in September 2017, time trends for cancer incidence is under testing based on the PBCR data available from 1982-2014.

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

During 2018-19, PBCR at J.N. Medical College, Aligarh was initiated covering Aligarh Urban and the data collection has been commenced. The PBCRs at Indira Gandhi Institute of Medical Sciences, Patna has also been initiated.

c. Population Based Cancer Survival in Cancers of Breast, Cervix and Head & Neck

The project has been initiated in 26 PBCRs 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 survival based on clinical stage/extent of disease across the Population Based Cancer Registries (PBCRs) wherever feasible.

Training on the PBCR survival study and its software was provided for registry staff during the workshop on Population Based Cancer Registries held on 21st-22nd January 2019 & 30th-31st January at NCDIR, Bengaluru.

2. Hospital Based Cancer Registries (HBCRs) Network

The following 28 new centres have been registered for HBCRDM under the network of NCDIR-NCRP during 2018-19.

SI No.	Name of the Centre
1	All India Institute of Medical Sciences, Jodhpur
2	Aster MIMS, Kozhikode
3	Civil Hospital, Ambala Cantt
4	Cytecare Hospitals Pvt Ltd, Bengaluru
5	Eden Medical Centre, Dimapur
6	G Kuppuswamy Naidu Memorial Hospital, Coimbatore
7	Government Dental College, Kozhikode
8	Government Medical College and Hospital, Chandigarh
9	Government Medical College, Srinagar
10	Government Medical College, Thiruvananthapuram
11	Government Royapettah Hospital, Chennai
12	Government Stanley Medical College, Chennai
13	Government Villupuram Medical College Hospital, Villupuram
14	Guru Gobind Singh Medical College, Faridkot
15	Institute of Obstetrics and Gynaecology, Chennai
16	J K Cancer Institute, Kanpur
17	Kurnool Medical College & Govt. General Hospital, Kurnool
18	Lok Nayak Hospital and Maulana Azad Medical College, New Delhi
19	Madras Medical College, Chennai
20	Max Super Speciality Hospital, Vaishali
21	MVR Cancer Centre and Research Institute, Kozhikode
22	Nayathi Health Care, Mathura
23	North Eastern Indira Gandhi Regional Institute of Health and Medical Sciences, Shillong
24	Sanjeevani CBCCA USA Cancer Hospital, Raipur
25	Saroj Gupta Cancer Centre and Research Institute, Thakurpukur
26	Shalby Hospital, Indore
27	State Cancer Institute, Guwahati
28	Tamil Nadu Government Multi Super Speciality Hospital, Chennai

The status of HBCRs under NCRP in various projects is as follows:

Sl. No.	Registries	No. of Centres
1	HBCRs (RCC/TCCC/SCI) funded by ICMR	6
2	HBCRs (RCC/TCCC/SCI) funded by MoHFW	23
3	HBCRs funded by ICMR (including HBCRDM and HBCR in Sources of Registration)	59
3	HBCRs without any financial assistance	48
4	HBCRs under Karnataka Cancer Notification	92
	Total	228

Workshops/meetings were held to train the investigators and the staff working at the above registries.

1. Sensitization workshop on ‘Hospital Based Cancer Registries in Regional Cancer Centre’ on 28th and 29th August 2018 at NCDIR, Bengaluru.
2. 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) on 15th and 16th November 2018 at NCDIR, Bengaluru
3. Training Workshop for HBCRs in Sources of Registration (SoR) on 17th and 18th January 2019 at NCDIR, Bengaluru.
4. Training Workshop on Hospital Based Cancer Registries at NCDIR, Bengaluru on 21st and 22nd January 2019 (South Zone)
5. Training Workshop on Hospital Based Cancer Registries at NCDIR, Bengaluru on 30th and 31st January 2019 (North Zone)



a. Setting up of Hospital Based Cancer Registry (HBCR) in Regional Cancer Centres (RCCs)/ Tertiary Care Cancer Centres (TCCC)/ State Cancer Institute (SCI)

Under the 12th Five Year plan, the Regional Cancer Centre (RCC) Scheme was renamed as Tertiary Cancer Care Centres/State Cancer Institutes (TCCC/SCI) and the Ministry has identified 70 hospitals across the country to be funded. NCRP aims to establish HBCRs in these hospitals as and when they get the scheme approved.

There are 29 Hospital based Cancer Registries under this project.

List of RCC/TCCC/ SCI having HBCR initiated in 2018-2019.

Sl. No.	Name of Centres
1	State Cancer Institute, Guwahati
2	Vivekananda Cancer Hospital, Latur

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

During 2018-2019, 16 centres have been added in this project. Accordingly, the total of HBCRDM centres receiving the financial support from ICMR-NCDIR and using HBCRDM software has been increased to 40. Centres are transmitting data for HBCR as well as Patterns of Care and Survival Studies data for three sites of cancer namely Breast, Cervix and Head and Neck.

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

To ensure the coverage of cases under PBCRs in above metro cities to be as complete as possible the project has been initiated. In view of 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 assured. The state wise number of HBCRDM and HBCR in SoR is given below.

Sl.No	State	HBCRDM	HBCR in SoR
1	Assam	2	-
2	Bihar	2	-
3	Chandigarh	1	-
4	Chhattisgarh	1	-
5	Delhi	1	3
6	Gujarat	1	-
7	Haryana	-	2
8	Jharkhand	1	-
9	Karnataka	2	4
10	Kerala	6	-
11	Madhya Pradesh	2	-
12	Maharashtra	2	1
13	Meghalaya	1	-
14	Orissa	2	-
15	Punjab	3	-
16	Rajasthan	2	-
17	Tamil Nadu	4	6
18	Telangana	2	-

19	Uttar Pradesh	4	-
20	Uttarakhand	1	-
21	West Bengal	-	3
Total		40	19

Further expansion of the project to 40 centres (15 in existing 5 Metros plus 25 in new PBCR areas) has been approved by Research Area Panel(RAP) on Cancer in August 2018 and 30 new SoR centres for north east has been approved in Scientific Advisory Committee(SAC) in January 2019 and expansion is in progress.

3. Patterns of Care and Survival Studies (POCSS)

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

As of March 2019, 28 TCCC/SCI/RCCs and 34 HBCRDM & SoR centres are transmitting data for the POCSS study. The quality of data and follow up of the patient information is being reviewed. The data received as of March 2019 from the above centres is Cancer Breast 26324, Cancer Cervix 15016, Head & Neck Cancers 38937.

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.

Following activities were done under the project during 2018-19

Purpose	Date	Details
1. Piloting of the developed Proforma	13 th – 17 th August 2018	Proforma for POCSS Childhood cancers, Lymphoma, Leukemia and Gynaecological Cancers (Except Cervix) was pilot tested in two institutes – Vydehi Institute of Medical Sciences and Research Centre, Bengaluru and Kidwai Memorial Institute of Oncology, Bengaluru to examine the feasibility of study which is ultimately intended to be used in a large scale study.
2. Sensitization Workshop for the Principal Investigators (PIs)	30 th August 2018	Sensitization Workshop for the Principal Investigators of selected HBCR-POCSS centres was conducted to discuss about the methodology and data collection for the above study. The proforma for the same has been reviewed in detail and valuable inputs have been taken from the Expert group as well as the respective Principal Investigators.
3. Training Workshop for the Co- Principal Investigators (Co-PIs)	30 th November 2018	The different strategies for data abstraction and integration was discussed with the corresponding Co-Principal Investigators and other representing members of the study centres.

Present status and steps

The proforma has been designed for childhood, lymphoid and hematopoietic malignancies and other Gynaecologic malignancies except cervix and the software has been developed for the same.

1. The Proformas have been integrated with the existing HBCR Core form for improved data abstraction.
2. Quality check module has been developed, containing checks on:
 - a. Missing date
 - b. Consistency
 - c. Unknown valueThe above checks are executed on the raw data available in POCSS online database.
3. Duplicate check module has been developed and implemented for identifying duplicates in the POCSS database.
4. Follow up data is of importance for survival analysis and hence can be updated on a timely interval.

The validation of quality checks and duplicate checks will be done before deploying the software.

4. Setting up of Cancer Registries in Karnataka

Cancer is notifiable in the State of Karnataka as per the Government of Karnataka notification order dated 25/07/2015. All the government and private hospitals, medical colleges, pathology labs are registered to the NCRP for transmission of cancer patient's information.

96 centres have been registered under NCDIR while 42 centres are actively transmitting data.

Workshops and Meetings conducted

1. Workshop for District Health & Family Welfare Officers and District Surgeons was conducted on 23rd, 26th & 27th October.
2. Review Meeting and Training Programme for the Karnataka Cancer Notification and Cancer Registry Program was held on 18th March 2019.

The data collected is of notification data so the actual completeness of data in terms of data quality and other quality indicators (as in registry data) needs to be checked.

5. Development of an Atlas of Cancer in Haryana state

The project has been in progress since December 2015 with the objective of finding out 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.

During 2018-19, visits were done and meetings were held with District surgeons of 4 districts i.e; Jind, Kaithal, Yamuna Nagar and Karnal where coverage of cancer registration data was found to be low. The project has been completed in March 2019.

The findings were presented to Research Area Panel on Cancer of NCDIR in August 2018. Meeting for review of data was held in March 2019 with Health Secretary for the state of Haryana and the representatives of Department of Medical Education and Head of Departments of Medical Colleges.

The previous cancer atlas activities such as the Cancer Atlas India, North-east Cancer Atlas and Punjab cancer atlas have given a fair estimates of cancer burden in the respective geographic area and the present Haryana cancer atlas has added to the list.

Map of Haryana State depicting centres of Cancer Atlas State



Achievements:

1. Complete analysis of data received as per international norms for Cancer Atlases. It is ensured that data is collected as per uniform standardized core proforma and analysed.
2. District wise coverage was comparable to other functioning Population Based Cancer Registries in neighbouring districts (Delhi and Patiala) which have been functional for more number of years.
3. Random verification of data from the Haryana population of the cases received from a small village Kharal which is in Narwana taluk of Jind district received through the Haryana Cancer Atlas software through various sources of registration was verified and was equal to actual number of cases in village thereby proving the authenticity of data.

The Reports is under finalization.

New projects Initiated

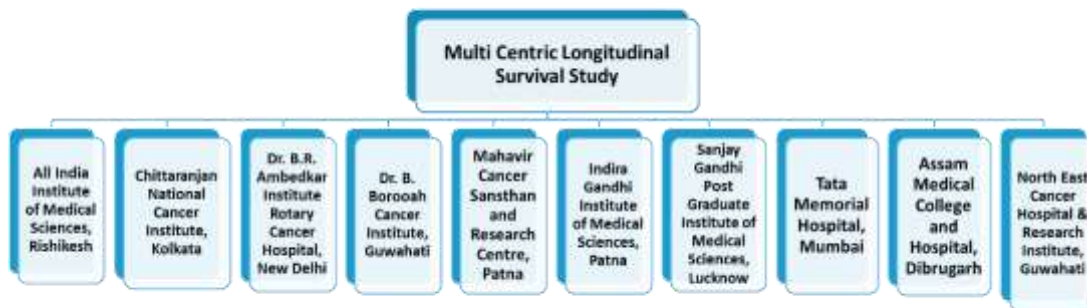
1. Patterns of Care and Survival Studies (POCSS) on Gall Bladder Cancer (GBC) in Indian Hospital Based Cancer Registries

Primary Objectives:

- To determine detailed pattern of care (diagnosis and management) for GBCs
- To estimate demographic (Overall) survival for GBCs
- To identify the epidemiological, clinical and health system determinants of survival and estimate their effect.

Secondary Objectives:

- To estimate disease free survival for GBC.
- To compare the outcome of incidental GBCs with symptomatic ones.
- This multicentric longitudinal study is being initiated in ten hospitals mostly in northern & eastern part of India. Comparison between symptomatic and incidental GBCs will also be done. The finding of this study will help clinician and public health experts to develop evidence based decision making algorithm and this could be translated into GBC prevention, early detection, control policies and programmes.



Activities Underway: The proforma and software are being developed.

2. Incidental Gall Bladder Cancer and Other Pre malignant Gall Bladder Condition in India towards early detection of Gall Bladder Cancer

Primary Objective:

- To estimate the prevalence of IGBC and other preneoplastic condition in cholecystectomy specimen
- To map the preoperative diagnosis with the postoperative pathological findings for early suspicion of GBCs

Secondary Objective:

- To identify risk factors and clinical correlates for IGBC and other preneoplastic lesion.
- To identify sensitivity, specificity, positive and negative predictive value of preoperative diagnostic method for malignancy.

Five hospitals in different regions of the country are being considered for implementation of this project. Standardized proforma is being designed and software development is being done.

STROKE

Ongoing Projects

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

Five Population Based Stroke Registries in one geographical area each from the south, north, east, west and north east regions of India (figure below) are functioning. Data transmission is ongoing with login credentials provided by NCDIR.

NCDIR – Population Based Stroke Registries in India (PBSR)



Training Workshop:

Training workshop for Population Based Stroke Registry for PBSR staff (Field investigators, Statisticians and Data entry operators) was conducted on 3rd and 4th July, 2018 at NCDIR, Bengaluru.



Training Workshop for staff of Population Based Stroke Registry centres (PBSR) in India held on 3rd and 4th July, 2018 at ICMR-NCDIR, Bengaluru.

Software development:

- Home page of the National Stroke Registry Programme—designed with infographics and factsheets. Login webpage of Population Based Stroke Registry is used by the centres for data entry.
- PBSR webpage hosts the Data entry module, Search features, Follow up module and Procedure manual for the use of the PBSR centres.
- Quality check module developed containing checks on:
 - a) Missing date
 - b) Consistency
 - c) Unknown value

Review of PBSR Centres:

Site visit to each of the PBSR centre for review of methodology of data abstraction, process of quality checking and completeness of coverage has been planned. Site visit to PBSR Varanasi was completed on 6th and 7th January 2019.

Review meeting of PBSR centres was held on February 28th 2019. Coverage of sources of registration including the civil registration system, completeness of follow up information, identification and cooperation of new sources, challenges in data abstraction were discussed.

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

The National Stroke Care Registry Programme for development of Hospital Based Stroke Registries in different regions of India (duration 5 years) has been funded under the Health Technology Assessment projects of Department of Health Research, Ministry of Health and Family Welfare.

The objectives are to generate reliable data on pattern of stroke and pattern of care and treatment for stroke. The centres to be selected are the hospitals providing treatment for stroke patients. Every year 10 centres will be selected to initiate the HBSR. In the first year, 5 hospitals that house the PBSR would also start the HBSR. This study will help in identifying and developing indicators for quality of care in stroke, in different treatment settings.

Meeting on the Hospital Based Stroke Registry was held on 29th May, 2018 at NCDIR, Bengaluru to discuss the objectives of the Hospital Based Stroke Registry (HBSR), and to review the core form of the HBSR. Experts have provided the comments and the Core form was revised.

Review meeting of ICMR – NCDIR National Stroke Registry Programme was held on 28th February 2019 at NCDIR, Bengaluru with a focus on update of PBSR, followed by a discussion on the Hospital Based Stroke Registry (HBSR) core form and framework of Hospital Based Stroke Registry for understanding quality of care for stroke in India. Core form for HBSR has been revised as per the suggestions given by the experts and a procedure manual has been developed for the same.



Review meeting of ICMR – NCDIR National Stroke Registry Programme held on 28th February 2019

A sensitization workshop was held on ICMR - National Stroke Care Registry Programme: Development of HBSR at the XIII Indian National Stroke Conference, Ahmedabad on 17th March 2019.

Development of HBSR data entry software module in open source Java platform has commenced. Data entry page template has been designed in html format. The functionalities of the form need to be implemented.

CARDIOVASCULAR DISEASES

Ongoing Project

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 with the objective to understand the patterns of causes, care and outcomes of heart failure patients along with assessing the feasibility of establishing the heart failure registry in different geographies of India.

Following centres are collecting the data under the project.

Sl. No	Name of the Institution	City and State	Geography
1	Indira Gandhi Medical College and Hospital	Shimla, Himachal Pradesh	North
2	JLN Medical College and Associated Group of Hospital	Ajmer, Rajasthan	North West
3	Sri Jayadeva Institute of Cardiology	Mysore, Karnataka	South West
4	Tirunelveli Medical College (TMC)	Tirunelveli, Tamil Nadu	South
5	All India Institute of Medical Sciences (AIIMS)	Bhubaneswar, Odisha	East

The software has been tested on live webpage and deployed in the centres.



MORTALITY

Ongoing Projects

NCDIR electronic mortality (NCDIR e-Mor) software has been developed for reporting, recording and improving cause of death by hospitals. It records all causes of deaths with ICD-10 coding as per National list of Office of Registrar General of India to generate medical certificate of cause of death (MCCD) and Death report (Form 4 and 2 respectively) to aid in death registration. The software aims to strengthen MCCD reporting through training, quality checks to avoid mode of dying and guide doctors in recording the underlying cause of death and report deaths.

Software development- Improvements in the application have been made.

.Net version

- i. A 128-bit encryption algorithm has been implemented to encrypt and store the data.
- ii. A local monitoring module to monitor centre's data has been developed for NCDIR.
- iii. Modifications in the proforma were done.
- iv. Modifications in cause of death intellisense, Form4/4A and Form2 and death report was done.
- v. Login credentials for the registered centres were developed and shared.

Java version

- i. SNOMED CT was integrated in the application for recording the cause of death as per the updated SNOMED International release in July 2018. The SNOMED CT mapping to ICD10 is being incorporated in the application.
- ii. Cause of death module for Tamil Nadu CRS was developed and shared. Testing of the module is in progress by the Tamil Nadu CRS team.

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

A Training workshop on NCDIR e-Mor software for registered hospitals in North East India was conducted on 22nd June 2018 at Dr. B. Borooah Cancer Institute, Guwahati. Doctors, social investigators and data entry operators of 9 registered Hospitals in the North East states attended the workshop.



Training workshop on NCDIR e-Mor software on 22nd June 2018 at Dr. B. Borooah Cancer Institute, Guwahati.

During 2018-19, the following centres have been registered for the project.

Sl. No.	State	Name of the Hospital
1-3	Nagaland	Zion Hospital and Research Centre, Dimapur
		Christian Institute of Health Sciences & Research, Dimapur
		Eden Medical Centre, Dimapur
4	Mizoram	Mizoram State Cancer Institute, Aizawl
5	Sikkim	Central Referral Hospital, Gangtok

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

Tamil Nadu:

NCDIR is working with Dept. of Health and Family Welfare, Tamil Nadu to develop Cause of Death software for integration with CRS software of Tamil Nadu. A webpage in Java as plug in has been developed based on the intelligence of e-Mor software, with the technical documentation. Procedure manual and software user manual have been shared with the State bureau of Health Intelligence (SBHI), Dept. of Public Health (DPH), Govt. of Tamil Nadu for further testing. SNOMED CT integration for recording cause of death is under development.

3. Implementation of NCDIR electronic Mortality software (NCDIR e-Mor) – strengthen Medical Certification of Cause of Death

The project was initiated on 1st December 2018. Six hospitals have registered to implement the NCDIR e-Mor software.

Sl. No.	State	Name of the Hospital
1	Punjab	Government Medical College & Rajindra Hospital, Patiala
2	Andhra Pradesh	Andhra Medical College, Visakhapatnam
3	Kerala	Malabar Cancer Centre
4	Telangana	MNJ Institute of Oncology & Regional Cancer Center, Hyderabad
5	West Bengal	Peerless Hospitex Hospital and Research centre limited, Kolkata
6	Karnataka	St. John's Medical College Hospital, Bengaluru

NONCOMMUNICABLE DISEASES

Ongoing Projects

1. National NCD 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 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 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 and health facility responses to NCDs, which 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 which 20 households were selected from each PSU by random sampling method. 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.

Current status

The survey was implemented during October 2017 - May 2018. The data collected has been synced

and cleaned for quality checks. The quality data thus obtained was subjected to analysis and the results of the factsheet and the final report have been presented to the TWG members following a 3-day workshop on “Data analysis and Report writing” was conducted for all the survey implementing agencies PI’s and Co-PI’s. The factsheet of 21 NCD indicators and the final factsheet of NNMS 2017 - 18 have been submitted to the Ministry of Health and Family Welfare, Govt of India. The Technical working group meeting scheduled on 24th of January 2019 discussed the final draft report with results, executive summary and recommendations for approval. The final NNMS – 2017 - 18 report is in finalization process.

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 (YLL= No of deaths * life expectancy). For Years lived with disability (YLD), the incidence and prevalence methods (YLD=Incidence*DW*Remission or prevalent *DW) were used. From the calculated YLL and YLD, the burden of cancer by DALYs for overall cancer, site wise, gender wise and region wise was calculated by adding both YLL and YLD.

Current status

The draft report has been submitted to the TAC committee. The suggested recommendations following the submission were implemented and the same was resubmitted and discussed in the National Technical Advisory Committee meeting held in March 2019.

BIOETHICS UNIT

Ongoing Projects / Activities

1. Brainstorming meeting on Multicentre Research

A brainstorming meeting was held at NCDIR, Bengaluru on 10th May 2018 to discuss the process for a common ethics review of multicentre research in order to streamline the review process and improve coordination in a multicenter research. The experts discussed the major issues with multicentric research such as duplication of efforts, wastage of time and communication between ECs. The need to develop specific guidelines and standard operating procedures (SOPs) on multicentre research was deliberated upon by the experts. It was suggested to develop a guidance document for the mechanism for common ethics review for multicentric research and to improve the conduct of research by saving time, preventing duplication, streamlining and improving the ethics review process. It will also enhance communication and networking between the EC's. This will raise the quality of ethical review and save resources, while maintaining the highest ethical standards for the protections of human research participants.



Brainstorming meeting for Common Review of Multicentric Research by Ethics Committees held on 10 May 2018

2. Consultation on Reuse of cardiovascular catheters

Reuse of catheters is commonly done in India and it is important that there are clear-cut guidelines on when and how this reuse can be permitted. To take this step forward ICMR proposed to prepare a guidance document to clarify issues related to reuse of cardiovascular catheters while considering the various issues related to patient autonomy and safety on one hand and considering the scientific, economic, legal, regulatory and ethical framework on the other hand so that careful reuse and monitoring can be carried out and patients can be adequately protected. In this regard, a brainstorming meeting on “Reuse of cardiovascular catheters: Scientific, Ethical & Legal Implications” was held at National Centre of Disease Informatics and Research, Bengaluru, on 26th June, 2018. Based on the suggestions from the meeting a draft guidance document was drafted. In order to further discuss this, a meeting was held at ICMR Headquarters, New Delhi on

19th July, 2018 under the chairmanship of DG ICMR and Secretary DHR to explore the ethical reuse of cardiovascular catheters and provide a direction while considering the existing scientific knowledge, regulatory and ethical framework in India. The issues related to current practices in India as well as international, Legal/ Regulatory Issues, Ethical Issues, Economics Issues, Sterilization and repackaging were reviewed and discussed.



Brainstorming Meeting on Reuse of Cardiovascular Catheters: Scientific, Ethical & Legal Implications held on 26th June 2018

3. ICMR Common EC Forms

Based on the feedbacks received followed by the discussions and deliberations by the expert group and the Ethics Advisory Committee, the draft common forms were revised and approved by the Ethics Advisory Committee. The printed final version of Common forms for EC review consisted of 34 pages with an Application form for Initial Review and 13 associated annexures relevant to EC submissions. The annexures include formats for other types of EC reviews, adverse events, protocol violations, reporting formats. Additional forms focussing on clinical trials, socio-behavioural, public health research and human genetics testing/research. The application form for initial review is divided in to 5 sections including the required checklist for submission and a self-declaration. The common forms for EC review was released during the CECHR meeting held on 7th December 2018 at NCDIR, Bengaluru.

Reference: ICMR, 2018 Common Forms for Ethics Committee Review – available at http://ethics.ncdirindia.org/Common_forms_for_Ethics_Committee.aspx



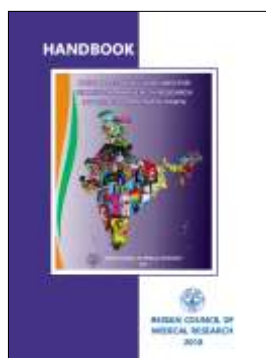
Release of Common forms for Ethics Committee review

4. Handbook on ICMR National Ethical Guidelines for Biomedical and Health Research Involving Human Participants

Under the direction of DG ICMR, an initiative was taken to draft a handbook for the National Ethical Guidelines for Biomedical and Health Research Involving Human Participants that provides quick reference to all 12 sections of the guidelines. The draft was prepared in very simple language that captures the essence of the source document and provides ready and easy reference material and safeguard the dignity, rights, safety and well-being of the human participants involved in biomedical and health research. The handbook would serve as an easy reference document to students, researchers and ECs. The Handbook was released at ICMR Headquarters, New Delhi on 26th March, 2019.

Reference: - Handbook on National Ethical Guidelines for Biomedical and Health Research Involving Human Participants – available at

http://ethics.ncdirindia.org//asset/pdf/Handbook_on_ICMR_Ethical_Guidelines.pdf



Release of the Handbook on National Ethical Guidelines for Biomedical and Health Research Involving Human Participants by Dr. Shekhar C Mande, Secretary, DSIR & DG, CSIR during the Symposium on Gandhi & Health @150 at ICMR Headquarters, New Delhi on 26th March, 2019

5. Creation of Bioethics Webpage as a resource

A webpage has been developed to improve the access of various stakeholders and other national and international agencies to ICMR Bioethics Unit. Webpage is also being served as a means to disseminate the tools and instruments developed by ICMR Bioethics Unit to relevant stakeholders and public. The ICMR National Ethical Guidelines, Common Ethics committee forms and other relevant policy documents are freely available to download which will benefit multiple stakeholders. The webpage also acts as a resource center providing access to various national and international bioethics guidelines, readings, activities related to field of bioethics and resource material expected to be useful to ECs, researchers, students, nurses as well as faculty involved in biomedical and health research across the country. The webpage would also have SOPs, FAQs, updates regarding training programs etc. The website is being updated on regular basis and new contents are added.

ICMR Bioethics webpage is available from: - <http://ethics.ncdirindia.org/>



Snapshot of the ICMR Bioethics webpage

6. Consultation on Conflict of Interest (COI) Policy for Health Research in India

A consultation meeting was organized by ICMR Bioethics Unit on 12th February 2019 and was attended by various stakeholders including institutional heads, policymakers, clinicians, patient representatives, social scientists, representatives from funding agencies and industries etc. The lack of clarity in the process required for the identification and management of COI in biomedical and health research at various levels (e.g. researchers, patients, ECs, academic institutions, donor/agencies and journals/publications) was highlighted as a major concern. The disclosure of individual and institutional financial relationships is a critical but limited first step in the process of identifying and responding to COI. A mechanism has to be framed to encourage and improve wilful self-declaration of potential COI at all the above mentioned levels. Various international guidelines published in this regard such as Institute of Medicine (IOM), International Committee of Medical Journal Editors (ICMJE), World Association of Medical Editors (WAME), and Committee on Publication Ethics (COPE) can be referred. It was decided to establish a standard content, format and procedures for COI policy for Health research in India that will address all aspects of COI arising during the conduct of a biomedical and health research study.

A subcommittee has been formed involving multi stakeholders for drafting the COI policy for health research in India.



Consultation meeting on Need for Conflict of Interest Policy for Health Research in India held at NCDIR, Bengaluru

7. Short term Training for Ethics Committee Members

ECs have a key responsibility of protecting the dignity, rights, safety and well-being of the research participants. Therefore, ECs must be competent and well-resourced in order to fulfil their role. This requires basic and continuous research ethics training and an understanding of the research review process.

Formal and educational updates in research ethics can help increase stakeholders' knowledge, sensitivity to new and emerging ethical concerns in the conduct of research. Training and continuing education sensitize scientists to the ethical issues arising from rapid advances in science and technology such as research into genome, multicentric studies/trials, research involving vulnerable populations and research during humanitarian emergency and disasters. Therefore, the short-term trainings are being organized by ICMR Bioethics Unit, NCDIR, Bengaluru to strengthen the stakeholder's expertise in the design, review and conduct of research involving human participants. In this regard, 2-days Workshop on Ethical Guidance for Biomedical Research was held on 17-18th January 2019 at NARI, Pune to provide basic and advanced levels training on research ethics, identify ethical dilemmas and provide practical interactive exercises to solve such dilemmas researchers or EC members encounter during the conduct or review of research. Total 60




 Workshop On
Ethical Guidance for Biomedical Research
(17th - 18th January, 2019)

participants (EC members and faculty) from ICMR-NARI, ICMR-NIV, AFMC, Pune attended the program.

SOFTWARE DEVELOPMENT AT NCDIR

1. New website of NCDIR

New revamped website for NCDIR was launched on 28th January 2019 during the Scientific Advisory Committee meeting.



2. Population Based Cancer Survival in cancers of Breast, Cervix and Head & Neck Cancers

The image shows a web form for cancer registration. The form is titled 'Follow-up Case' and includes a search bar for 'Incidence Registration Number'. The form is divided into several sections: '1. Disease Registration Number', '2. Hospital Registration Number', '3. State of Registration at Source of Registration', '4. Full Name of Patient', '5. Method of Follow-up', '6. Vital Status Date', '7. Date of Death', '8. Change in Phone Number', and '9. Change in Address'. The '9. Change in Address' section is highlighted with a red box and contains sub-sections for 'Urban Area (Town / City)' and 'Rural Area / Rural Area'. The form includes various input fields, dropdown menus, and checkboxes. At the bottom, there are 'Previous' and 'Next' buttons.

3. A Study on the Magnitude and Pattern of Causes of Heart Failure – A Feasibility Study

NCDIR National Centre for Disease Informatics and Research
 (Indian Council of Medical Research)
 A Study on the Magnitude and Pattern of Causes of Heart Failure - A Feasibility Study

September 10 2018 15:20:30 User Logged in as: **medir**

A Study on the Magnitude and Pattern of Causes of Heart Failure - A Feasibility Study

September 18 2018 15:27:23 User Logged in as: **medir**

Reference Number: **100000004**

IDENTIFYING INFORMATION

1. Name of Participating Centre: Centre Code:

2. HF Registration Number: (First 2 digits are for year of registration and the next 5 digits for actual registration number)

3.1 Name of the Source of Registration (OPD/ICU/Ward Name):

3.2 Hospital Registration Number:

4. Date of Hospital admission / attendance:

5. Full Name of the Patient:

6. Place of Residence:

Urban / Semi-Urban Areas (Town / Market / Block) **Rural Areas** (Gram Panchayat / Panchet)

House No. and Ward:

Road / Street Name:

Area / Locality:

Name of City / Town:

Name of District:

Mobile Number:

Postal Pin Code:

Vehicle Number:

4. ICMR Bioethics Unit Webpage

ICMR Bioethics Unit

About Us

The Indian Council of Medical Research (ICMR) is the apex body for the formulating, coordinating and promoting all research in medical and health sciences in the country. ICMR Bioethics Unit (ICMR Bioethics Unit) is the central body for the formulating, coordinating and promoting all research in medical and health sciences in the country. ICMR Bioethics Unit is the central body for the formulating, coordinating and promoting all research in medical and health sciences in the country. ICMR Bioethics Unit is the central body for the formulating, coordinating and promoting all research in medical and health sciences in the country.

Recent ICMR Guidelines / Publications

Contact Us

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 National Centre for Disease Informatics and Research
 Indian Council of Medical Research, 15, Block 1, Sector 15, Connaught Place, New Delhi - 110 054, India
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 Website: www.icmr.gov.in

5. Software for 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 Kolkata

a. Gynaecological Cancers

NCDIR NATIONAL CENTRE FOR DISEASE INFORMATICS AND RESEARCH
NATIONAL CANCER REGISTRY PROGRAMME
Indian Council of Medical Research

PATTERNS OF CARE AND SURVIVAL STUDIES
Proforma for Gynecologic Cancers (Except Cervix)

DIAGNOSTIC DETAILS

20. Diagnostic Status at Registration at Source of Registration / Reporting Institution (RI):

21. Method of Diagnosis (Must valid final basis):

22. Anatomical Site of Specimen / Biopsy / Streak:

23. Complete Pathological Diagnosis (Use Complete Description of Primary Site of Tumour (PST), and Topographic Diagnosis (PTD))

23.1 Primary Site of Tumour – Topography:

23.2 Morphology:

23.3 Pathology Slide No.:

Date:

24. Coding according to ICD-O-3: Auto Coding Required

24.1 Primary Site of Tumour – Topography: L45.0 M85.0 C 51 1

24.2 Primary Histology – Morphology: M 85001

24.3 Secondary Site of Tumour: C 1 1

24.4 Morphology of Metastasis: M 85001

b. Lymphoma and Leukaemia Cancers

NATIONAL CENTRE FOR DISEASE INFORMATICS AND RESEARCH
NATIONAL CANCER REGISTRY PROGRAMME
Indian Council of Medical Research

PATTERNS OF CARE AND SURVIVAL STUDIES
Patient Information Form – Lymphoma & Leukemia

DIAGNOSTIC DETAILS

20. Diagnostic Status at Registration at Source of Registration / Reporting Institution (RI):

21. Method of Diagnosis (Must valid final basis):

22. Anatomical Site of Specimen / Biopsy / Streak:

23. Complete Pathological Diagnosis (Use Complete Description of Primary Site of Tumour (PST), and Topographic Diagnosis (PTD))

23.1 Primary Site of Tumour – Topography:

23.2 Morphology:

23.3 Pathology Slide No.:

Date:

24. Coding according to ICD-O-3: Auto Coding Required

24.1 Primary Site of Tumour – Topography: M85.0 M85.0 C 1 1

24.2 Primary Histology – Morphology: M85.0 M85.0 M 85001

24.3 Secondary Site of Tumour: C 1 1

24.4 Morphology of Metastasis: M 85001

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4. Tandon N, Anjana R.M, Mohan V, Kaur T, Afshin A, Ong K, Mukhopadhyay S, Thomas N, Bhatia E, Krishnan A, **Mathur P.**, et al. The increasing burden of diabetes and variations among the states of India: the Global Burden of Disease Study 1990–2016. *Lancet Glob Health*[Internet] 2018, 14 September 2018 (IF: 18.7).
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