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# Cancer registries: data collection, challenges and steps to strengthen registries: Bangladesh

**Present by:**

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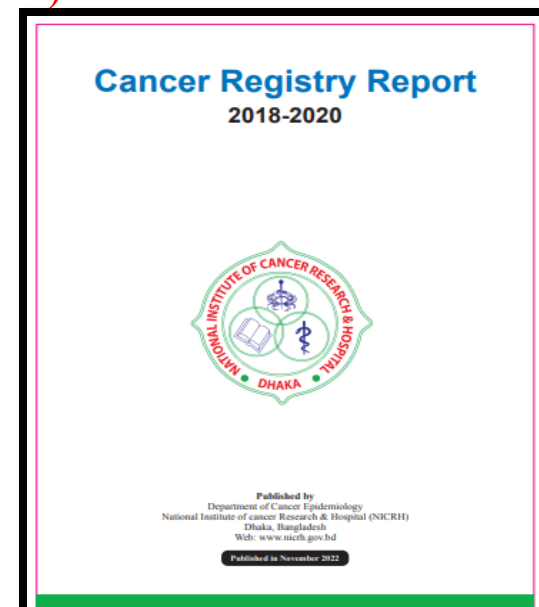
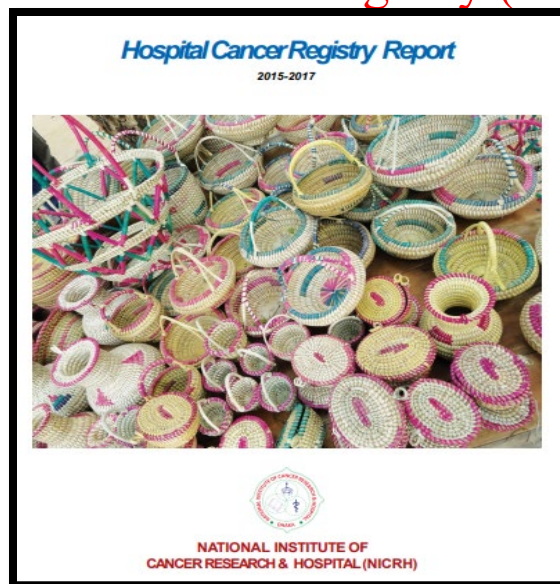
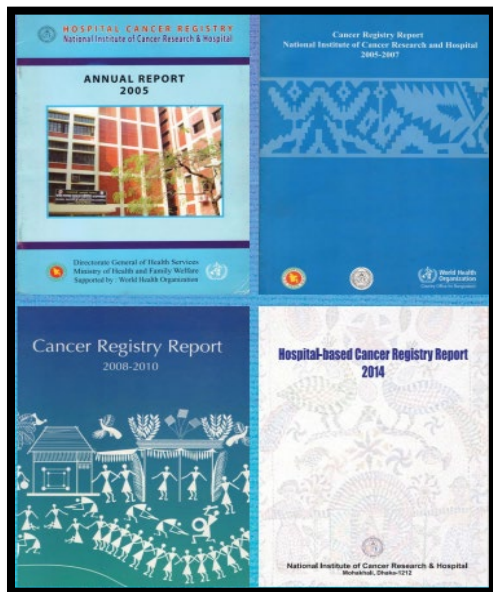
**South Asian Meeting**

**HPV Prevention and Control Landscape and the way forward.**

**13<sup>th</sup> , 14<sup>th</sup> and 15<sup>th</sup> - Dec 2022 – New Delhi, India.**

# Current cancer data collection strategy

Cancer registry was introduced first time in Bangladesh with development of **Hospital Based Cancer Registry (HBCR)**




# Cancer Registry of CMCH

গাইনিকোলজিক্যাল ক্যান্সার রেজিষ্ট্রি  
 এবং ক্যান্সার ফলোআপ রুম, ওয়ার্ড-৮০  
**Gynecological Cancer Registry &  
 Cancer Follow up Room, Ward-80**



## Cancer Registry Forms


**Department Of Obstetrics & Gynecology**  
 Chittagong Medical College & Hospital, Bangladesh  
 107, S.S. Vaidya Road, Chittagong-6200, Bangladesh  
 Phone: 880-31-6211111, 6211112, 6211113, 6211114, 6211115, 6211116, 6211117, 6211118, 6211119, 6211120, 6211121, 6211122, 6211123, 6211124, 6211125, 6211126, 6211127, 6211128, 6211129, 6211130, 6211131, 6211132, 6211133, 6211134, 6211135, 6211136, 6211137, 6211138, 6211139, 6211140, 6211141, 6211142, 6211143, 6211144, 6211145, 6211146, 6211147, 6211148, 6211149, 6211150, 6211151, 6211152, 6211153, 6211154, 6211155, 6211156, 6211157, 6211158, 6211159, 6211160, 6211161, 6211162, 6211163, 6211164, 6211165, 6211166, 6211167, 6211168, 6211169, 6211170, 6211171, 6211172, 6211173, 6211174, 6211175, 6211176, 6211177, 6211178, 6211179, 6211180, 6211181, 6211182, 6211183, 6211184, 6211185, 6211186, 6211187, 6211188, 6211189, 6211190, 6211191, 6211192, 6211193, 6211194, 6211195, 6211196, 6211197, 6211198, 6211199, 6211200

**MOLAR CARD**  
**MANAGEMENT OF GESTATIONAL TROPHOBLASTIC DISEASE**

Patient: \_\_\_\_\_ Hospital: \_\_\_\_\_  
 1. Name of the Patient \_\_\_\_\_ Age \_\_\_\_\_  
 2. Address \_\_\_\_\_  
 3. Blood group \_\_\_\_\_  
 4. Date of admission \_\_\_\_\_  
 5. Date of discharge \_\_\_\_\_  
 6. M.M. - Duration of Antenatal Care \_\_\_\_\_  
 7. F/U Monitoring/Discharge/Other Finding \_\_\_\_\_  
 8. Mode of diagnosis - By U.S.G. \_\_\_\_\_  
 9. Serum Beta HCG before Evacuation/Date / not done \_\_\_\_\_  
 10. Problems - Ectopic pregnancy / Molar pregnancy, Date \_\_\_\_\_  
 11. Interval between diagnosis and procedure \_\_\_\_\_  
 12. Staging System \_\_\_\_\_  
 13. Check in & out - Date / not done \_\_\_\_\_  
 14. Date of discharge \_\_\_\_\_  
 15. Address \_\_\_\_\_  
 16. Return to \_\_\_\_\_  
 17. Follow up - 24 hrs.

**Carcinoma Cervix Registry Form**

**Section (I) - (Particulars of Patient)**  
 Name: \_\_\_\_\_ Age: \_\_\_\_\_ Occupation: \_\_\_\_\_  
 Residential: \_\_\_\_\_  
 Date of Admission: \_\_\_\_\_ Date of Discharge: \_\_\_\_\_  
 Contact No: \_\_\_\_\_  
 Marital Status:  Single  Married  Divorced  Widowed  
 Educational Status:  Illiterate  Primary  up to  Secondary  
 Socio-Economic Condition:  Lower Class  Middle Class  Upper Class  
 Husband's Name (if applicable): \_\_\_\_\_  
 Father's Name: \_\_\_\_\_ Mother's Name: \_\_\_\_\_  
 Address: \_\_\_\_\_  
 Hospital No: \_\_\_\_\_ Hospital: \_\_\_\_\_  
 F.I.D. \_\_\_\_\_  
 P.I.D. \_\_\_\_\_  
 S.I.D. \_\_\_\_\_

**Section (II) - (Specimen Examination Method)**  

Sl. No.	Method
1	Smear
2	Smear with Papanicolaou stain
3	Smear with Pap-Haematoxylin stain
4	Smear with Pap-Haematoxylin stain with Papanicolaou stain
5	Smear with Pap-Haematoxylin stain with Papanicolaou stain and special stain
6	Smear with Pap-Haematoxylin stain with Papanicolaou stain and special stain and special stain
7	Smear with Pap-Haematoxylin stain with Papanicolaou stain and special stain and special stain and special stain
8	Smear with Pap-Haematoxylin stain with Papanicolaou stain and special stain and special stain and special stain and special stain
9	Smear with Pap-Haematoxylin stain with Papanicolaou stain and special stain and special stain and special stain and special stain and special stain
10	Smear with Pap-Haematoxylin stain with Papanicolaou stain and special stain and special stain and special stain and special stain and special stain and special stain

**Section (III) - (Short Comments)**  
 1. \_\_\_\_\_  
 2. \_\_\_\_\_  
 3. \_\_\_\_\_  
 4. \_\_\_\_\_

## How data is collected?

- Data collected by cancer registration form following International guidelines with some modification as per social context
- Data on demography, system-wise-distribution, leading sites, residential status, smoking habit, method of diagnosis, pediatric care, geriatric care, treatment received- are included
- Data compiled by electronic database (SPSS) and is published

## Electronic Data Tracking with Population Based Cervical and Breast Cancer Screening Programme (2018-2022)



**200 Upazilas / 5,500 CC**



NID is required for Unique registration number



**Awareness creation activity-** through face to face communication, BCC material



CHCPs have necessary ICT equipment and they can generate electronic data for DHIS2

VIA and CBE facilities initiated use of DHIS 2 to collect data since 2013 and upgraded for each individual women since 2018

- ✓ Women's motivation and registration are being initiated at the community level
- ✓ One CC serves about 6,000 population, which include about 600 to 800 women of the target group (30-60 years)
- ✓ One CC staffed with one CHCP/ HA/ FWA/ multipurpose health care volunteers (MHCV) also helps



# Registration form should be used liberally

ইলেকট্রনিক ডাটা ট্র্যাকিংসহ জনসংখ্যা ভিত্তিক জরায়ু-মুখ ও স্তন ক্যান্সার ক্রিনিং কর্মসূচি  
জরায়ু-মুখ ও স্তন পরীক্ষার মাধ্যমে ক্যান্সার প্রতিরোধ  
VIA & CBE রেজিস্ট্রেশন এবং রেফারাল ফর্ম

কেন্দ্রের নাম: \_\_\_\_\_ তারিখ: DDMMYYYY

ইলেকট্রনিক কোড: \_\_\_\_\_ সেবা প্রদানকারীর ডায়েরি নং: \_\_\_\_\_

নাম: \_\_\_\_\_  
 মাতার নাম: \_\_\_\_\_  
 স্বামীর নাম: \_\_\_\_\_  
 জাতীয় পরিচয়পত্রের নম্বর: \_\_\_\_\_  
 জন্ম তারিখ: DDMMYYYY বয়স (বছর): \_\_\_\_\_  
 পেশা: \_\_\_\_\_ শিলা: \_\_\_\_\_  
 বিয়ের সঙ্গী বয়স: \_\_\_\_\_ এমন সঙ্গী প্রদানের বয়স: \_\_\_\_\_  
 সন্তানের সংখ্যা: \_\_\_\_\_ মেসাইল নম্বর: \_\_\_\_\_

সেবার তারিখ: \_\_\_\_\_ পল্লী: \_\_\_\_\_  
 ক্রমিক: \_\_\_\_\_

**Front Side**

পরিচালিত করে

স্বামী বর্তমান অবস্থা: একত্রে বাস করেন  বিবাহ ভাঙা অবস্থায়  প্রবাসী  বিবাহ বিচ্ছেদকার  মৃত   
 পরিবারে থাকার স্থান: পরিবারে মেসাইল নম্বর: \_\_\_\_\_

মুঠি ত্রিকাল

তারিখ: \_\_\_\_\_ গ্রাম/রোড নং: \_\_\_\_\_  
 পোষ্ট: \_\_\_\_\_ ইউনিয়ন/পৌরসভা: \_\_\_\_\_  
 উপজেলা/থানা: \_\_\_\_\_ জেলা: \_\_\_\_\_

সংশ্লিষ্ট স্বাস্থ্যকর্মীর নাম এবং কেন্দ্রের নাম: \_\_\_\_\_ মেসাইল নম্বর: \_\_\_\_\_

VIA পরীক্ষা: VIA (-ve)  CBE পরীক্ষা: CBE (-ve)   
 VIA (+ve)  CBE (+ve)

অল্পে অল্পে করা হয়েছে কিনা: হ্যাঁ  না  তরল: \_\_\_\_\_ ২০ ই.  
 করেছেন কিনা: \_\_\_\_\_

**Back Side**

**It has two similar parts.**  
 Both parts are filled up by HA/FWA during home visit/ awareness meeting

**1**

One is for patients used as referral card

**2**

Other one is given to CHCP for e-registration

Women aged **30-60 years** are registered with **NID (National Identification)** number and an automatically system-generated **unique registration number** are used for identification of each registered woman

# Gaps and challenges for Cancer Registries

Development of the PBCR is the major challenge

## Lack of awareness

- Scarcity of knowledge
- Fear, stigma and superstition
- Religious barrier
- Ignorance about referral system

## Unequal access to care

- Lack of decentralization of care
- Unequal distribution of health care providers
- Disproportionate patients load

## Inadequate reporting

- Avoidance of notification
- Incomplete data collection
- Inadequate follow-up

## Resource constraints

- Cost of treatment and follow-up
- Lack of skilled manpower
- Lack of infrastructure
- Lack of ICT/software facilities



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# Challenges for Cervical Cancer Registry and Electronic Data Tracking

Position of women in the society and cultural barrier

Lack of resources for electronic data tracking

Slow internet connectivity

Different type of database and software system often create problem in data harmonization

Inadequate reporting by private health facilities to national HMIS



# Steps to strengthen data collection system

- Boost up of cancer **awareness** program
- Establishment of user friendly and robust **referral system**
- Making cancer **notifiable and registriable** disease through govt rules
- Proper maintenance of birth, death and other **vital statistics**
- Improvement of **electronic data tracking** and software
- **Linkage** between different registries
- Developing **equitable access** to cancer care
- Making diagnosis, treatment and follow-up **cost** affordable
- Investment in **skill development** and capacity building

# Lastly

GoB is kind enough to allocate budget for cancer care

A visionary project is now in implementation phase for establishment of eight 100-bedded comprehensive cancer centers

These centres will work as hubs for all cancer control activities, hospital based and population based registries

Financial and technical support needed from International Organizations and private sector for implementation of PBCR in Bangladesh

**Thank you**

