

# Population Based Cancer Registry in Nepal

Interim Analysis of data from January-May 2018  
Progress Report, November, 2018

**Nepal Health Research Council**

Ramshah Path Kathmandu, Nepal

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Director	Bir Hospital	Member
Director	Tribhuvan University Teaching Hospital	Member
Director	Civil Hospital	Member
Director	Patan Hospital	Member
Director	Bhaktapur Cancer Hospital	Member
Director	Kanti Children Hospital	Member
Director	Nepal Cancer Hospital	Member
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Dr. Rajendra B.C	NHRC Consultant	Member
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The National Health Research Council, Nepal thankfully acknowledges the support, coordination and collaborations rendered by the following dignitaries' hospitals, laboratories, local authorities and other treatment centers for establishing population based cancer registry in Nepal.

SN	Name of Institution	Place
1	Paropakar Maternity Hospital	Kathmandu
2	Bir Hospital	Kathmandu
3	BirendraSainik Hospital	Kathmandu
4	Civil Service Hospital	Kathmandu
5	Grande International Hospital	Kathmandu
6	Green City Hospital	Kathmandu
7	Kanti Children Hospital	Kathmandu
8	Kantipur Hospital	Kathmandu
9	Kathmandu Medical Collage Teaching Hospital	Kathmandu
10	TU Teaching Hospital	Kathmandu
11	Om Hospital and Research Centre	Kathmandu
12	Nepal Medical College	Kathmandu
13	National Medicare and Research Centre	Kathmandu
14	Bhaktapur Cancer Hospital	Bhaktapur
15	Kathmandu Cancer Centre	Bhaktapur
16	Nepal Cancer Hospital and Research Centre	Lalitpur
17	Nepal Medi-city Hospital	Lalitpur
18	National Cancer Hospital	Lalitpur
19	Vayodha Hospital	Lalitpur
20	Patan Academy of Health Science	Lalitpur
21	KIST Medical College and Teaching Hospital	Lalitpur
22	Alka Hospital	Lalitpur
23	B&B Hospital	Lalitpur
24	National Public Health Laboratory	Kathmandu
25	MediQuest Laboratory Pvt. Ltd	Lalitpur

26	Samyak Diagnostic Pvt. Ltd.	Kathmandu
27	Thankot Hospice	Kathmandu
28	Hospice Nepal	Lalitpur
29	Divya Aayurvedic Aausadhalaya	Kathmandu
30	B.P Koirala Memorial Cancer Hospital	Chitwan
31	National Path Laboratory	Dang
32	Nepalgunj Medical College and Teaching Hospital	Banke
33	Sushil Koirala Prakhar Cancer Hospital	Banke
34	B.P. Koirala Institute of Health Sciences	Dharan
35	Nobel Medical College and Teaching Hospital	Biratnagar
36	Birat Medical College	Biratnagar
37	Saptakoshi Nursing Home	Biratnagar
38	Lifegaurd Hospital	Biratnagar
39	ShreeRam Diagnostic	Biratnagar
40	Neuro Hospital	Biratnagar
41	Golden Hospital	Biratnagar
42	National Medical College	Birjung
43	Mangalam Diagnostic	Birjung
44	Vision Diagnostic	Birjung
45	Tata Memorial Cancer Hospital	India
46	Rajeev Gandhi Cancer Institute	India
47	Department of Civil Registration	Nepal
48	Department of Health Service, Bipanna Section	Nepal
49	Other Centers (Municipalities/ Rural Municipalities, Urban Health Centers, Health Posts)	Kathmandu, Bhaktapur, Lalitpur, Siraha, Saptari, Mohattari, Dhanusha and Rukum

**Prof. Dr. Anjani Kumar Jha**  
Executive Chairman  
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## LIST OF ABBREVIATIONS

PBCR	: Population Based Cancer Registry
MoHP	: Ministry of Health and Population
NHRC	: Nepal Health Research Council
FCHV	: Female Community Health Volunteer
NCD	: Non-Communicable Disease
LMICs:	: Low and Middle Income Countries
WHO	: World Health Organization
IARC	: International Agency of Research on Cancer
HBCR	: Hospital Based Cancer Registry
BoD	: Burden of Disease

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## EXECUTIVE SUMMARY

### Background

Nepal Health Research Council (NHRC), a national apical body of Government of Nepal, responsible for promoting scientific study and quality health research in the country, has started Population Based Cancer Registry (PBCR) in Nepal since January 1, 2018. Starting with Kathmandu Valley, PBCR has been expanded to other districts as well in order to have representative information throughout the country. Kathmandu valley cancer registry covers the population of Kathmandu, Bhaktapur and Lalitpur districts of Province 3, cancer registries in Siraha, Saptari, Dhanusha and Mahottari covers the population of four districts of province 2, and eastern and western Rukum districts cancer registry covers the population of Rukum district of Province 5 and 6. NHRC is making close collaboration with Ministry of Health and Population (MoHP) and WHO to establish the registry in Nepal, which has been technically supported by International Agency for Research on Cancer (IARC). The objective of the registry is to generate evidence on cancer incidence, patterns and trends of disease and mortality related to cancer in the defined population, and also to enhance national capacity for sustainable PBCR in Nepal. The cancer registry data will be useful in planning cancer control activities and to strengthen cancer care services by the government of Nepal. The registry office is located in NHRC, Ramshah Path, Kathmandu.

### Population Covered

According to the census 2011, the total population of Nepal is 2,64,94,504. Population Based Cancer Registry in Nepal which includes registry in province no. 2, 3 and 6 covers 20.3% (53,84,523) of the total population as shown in the table below.

Cancer Registry	Province	Metropolitan City / Municipalities	Rural Municipalities	Population
PBCR Kathmandu valley	3	21	3	2,517,023
PBCR Siraha, Saptari, Dhanusha and Mahottari	2	39	28	2,658,933
PBCR Rukum	5 and 6	3	6	2,08,567
<b>Total</b>		<b>63</b>	<b>37</b>	<b>53,84,523</b>

### Methodology

The methodology of data collection by the registry is both active and passive surveillance depending upon the data sources. There are two major ways through which data are obtained for the registry. One is from the facilities which include hospital, pathology laboratory, hospice, department of health service bipanna section and civil registration. The registry personnel visit these sources at regular intervals and actively collect cancer cases data available there. The data is collected from the records of the sources since January 2018 and recorded in the standard format. Other is from the community in which orientation is given to the Health Coordinators at each Municipality/Rural Municipality, Health In-charges and even the Female Community Health Volunteers (FCHVs) wherever necessary. Data is then obtained

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by FCHVs from the population through home visit submitted to the Health In-charges. The Health In-charges submit data to the Health Coordinators and the Health Coordinators to the NHRC office on monthly basis. The obtained data from all these sources is verified for the completeness, accuracy and residence and then entered into CanReg5 Software at the NHRC office.

For the Kathmandu Valley cancer registry, there are many cancer diagnostic and treatment facilities in Kathmandu valley. Thus, most of the cases can be obtained from these facilities within Kathmandu, Bhaktapur and Lalitpur districts. However, people sometimes visit B.P. Koirala Memorial Cancer Hospital (BPKMCH), Bharatpur, Chitwan around 200 km away from the valley. So we collect the data of the cases of our selected districts from there as well. Since people also visit India for cancer treatment, we have coordinated to some renowned cancer hospitals in India to collect data of cancer patients. Nevertheless, for other two registries of Province no. 2 and 6, there are not any diagnostic and treatment facilities within Siraha, Saptari, Dhanusha, Mohattari, and Rukum districts. Thus, besides the data from the communities through Female Community Health Volunteers, health post incharge and health coordinators of these districts, PBCR has coordinated with different diagnostic and treatment facilities inside and outside Kathmandu valley such as Banke, Bardiya, Nepalgunj, Dharan, Birgunj, Biratnagar, Chitwan and even with India.

## **Result**

The data collection of cancer cases from all the sources has been completed till August, 2018. Out of total 5260 cases (new and old) checked by PBCR from various sources, 2612 cases have been found to be new cases.

The incidence (new case) was separated according to the date of diagnosis, and all the cases were contacted through the phone calls in order to confirm their residence. The verification and residence confirmation of the cases are completed till May 31<sup>st</sup> 2018, which shows a total of 702 cancer cases from Kathmandu Valley, 256 cancer new cases from Siraha, Saptari, Dhanusha and Mahottari and 23 new cases from East and West Rukum.

The Annual Report of PBCR 2018 is expected to be completed and published by September 2019. However, interim analysis of Kathmandu Valley registry until May 2018 has been completed. The major findings are summarized below

In 702 cases from Kathmandu Valley, cancer incidence is higher among females comparing to the males (379 Vs 323). The higher incidence is found among the age group of 70-74 years followed by the age group of 65-69 years and then 60-64 years with an age specific rate of 230.5, 203 and 185.3 per 100,000 respectively. In male the top leading cancer site is lungs followed by lip and oral cavity, colon and rectum, stomach, pharynx, bladder, larynx, pancreas, gall bladder and kidney. In females, breast, lungs, cervix uteri, thyroid, gall bladder, colon and rectum, ovary, stomach, lip and oral cavity, Non-Hodgkin's disease and brain are the leading cancer sites.

There might be under registration or under diagnosis of cancer cases as the pediatric cases are found very less. Similarly, we may have missed clinically diagnosed and radiological diagnosed cases. The cases which primary site is unknown are only 6.2% in males and 4% in females which signifies the quality of diagnostic information as well as proper documentation of health care providers.

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## CHAPTER 1 |

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## BACKGROUND

Of the estimated 56.9 million deaths globally, over 40.5 million deaths (71%) were due to Non-Communicable Diseases (NCDs) in 2016 (1). This is disproportionately high in Low and Middle Income Countries (LMICs) with over three quarters of NCD deaths (31.5 million) occurring in LMICs (1). The four major NCDs (cardiovascular diseases, cancer, chronic respiratory diseases and diabetes) are among the top 10 leading causes of death globally as well as for Nepal. More than 20 million new cases of cancer are estimated to occur worldwide in 2025, and a majority of them would be in LMICs (2). Cancer ranks number as the second globally and fifth leading cause of death for Nepal, accounting for an estimated 11,525 deaths in 2015 (3). This shows that cancer remains a major public health issue in Nepal. However, the estimation of the burden of disease, trends and the effectiveness of interventions carried out, depends unexceptionally on the continuous availability of robust surveillance data.

Registries have been shown to be a vital component of any logical cancer control programmes. Population-based cancer registry (PBCR) data provides information on the scale and profile of cancer that enables informed planning and monitoring. Governments have recognized this through the 2011 United Nations resolution on NCDs and the World Health Organization's (WHO's) Global Action Plan for the Prevention and Control of NCDs 2013–2020. The associated Global Monitoring Framework, used to track the implementation of the Global Action Plan through monitoring and reporting on voluntary targets includes among the 25 indicators one for 'cancer, by type per 100 000 population' (4).

A PBCR focuses on gathering information from all individuals with cancer in a defined population over a period of time. This implies that the registry must operate and comprise of people resident in a well-defined geographical area or region. PBCRs are the only means to support cancer control planning, documenting the scale and profile of cancer in a defined region to monitor trends over time.

The Global Initiative for Cancer Registry Development (GICR) was established by the International Agency for Research on Cancer (IARC) as collaboration with key international partners to accelerate improvements in the coverage, quality and use of PBCRs worldwide. An IARC/GICR Regional Hub has been established at the Tata Memorial Centre in Mumbai, India that serves South, Southeast and East Asia to help support countries with training, consultation and research.

In Nepal, a hospital based cancer registry (HBCR) programme was initiated in 2003, which currently incorporates 12 hospitals (B P Koirala Memorial Cancer hospital, Bhaktapur Cancer Hospital, Bir hospital, TU Teaching Hospital, Kanti Children Hospital, BP Koirala Institute of Health Science and Manipal Teaching Hospital, Shree Birendra Hospital, Civil Service Hospital, Patan Hospital, Paropakar Maternity & Women Hospital and Nepalgunj Teaching Hospital) operating throughout the country (5). However, PBCR data is currently unavailable in Nepal.

The existing HBCRs in Nepal is not generalizable to population, hence of limited significance in

formulating long term cancer plan and policies. Thus, a PBCR is crucial as it gives a systematic ascertainment of cancer incidence from multiple sources like health facilities, laboratories, cancer centers, hospice etc. which can provide an unbiased profile of the cancer burden in the defined population and its trend over time. Population registries in turn, can have a different role in planning and evaluating cancer control programmes thus proving more useful information than hospital or laboratory based registries. The advantages and basic difference between various registries is presented in table below.

**Table 1** Types of registries

Registry types	Characteristics	Purpose	Can this Registry be used in formulating cancer plans?
Hospital-Based Cancer Registry	Collects information on all cases of cancer treated in hospitals	Useful for administrative purposes and for reviewing clinical performance of particular Hospital	NO/An incomplete and inaccurate sample. Dataset is based on patient attendance at given hospital(s)
Pathology-Based Cancer Registry	Collects information from laboratories on morphologically-diagnosed cancers	Supports need for laboratory-based services and serves as quick 'snapshot' of cancer profile	NO/An incomplete and inaccurate sample Dataset is based on laboratory-based surveillance only
Population-Based Cancer Registry	Systematically collects information on all reportable neoplasms occurring in a geographically-defined population from multiple sources	Identifies incidence, mortality, patterns and trends of cancer.  Supports population-based actions aimed at reducing the cancer burden in the community	YES/Such a systematic ascertainment from multiple sources can provide an unbiased profile of the cancer burden, and how it is changing over time

## Rationale

According to WHO, PBCR is a core component of a national cancer control strategy. In Nepal, although HBCR, has generated some basic evidence on incidence of cancer cases by site, sex and age, it cannot be used to estimate cancer rates as it is not population-based. Not all the hospitals have initiated hospital based registry either(6). In addition, hospital based registry cannot provide measures of occurrence of cancer in a defined population and alone cannot be used to generate national estimates. In contrast, high-quality PBCR give an accurate picture of cancer burden in a defined population and data about national cancer burden (7). Data on the cancer burden in the population are necessary in the evaluation of current situation, identifying cancer control activities and defining priorities, monitoring and evaluating cancer control activities (8).

Evidence on cancer incidence, prevalence and mortality due to cancer from PBCRs are essential to produce accurate burden of disease (BoD) estimates for Nepal. BoD estimates currently are produced by such groups as IARC, WHO and Institute of Health Metrics and

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Evaluation (IHME) at a regular basis for countries across the globe, but in many instances, they are based on information from neighboring countries from the region. NHRC has also signed MOU with IHME and MOHP to estimate BoD of national and sub-national level in Nepal. One of the major challenges currently faced by Nepal to estimate the BoD is the lack of data on cancer incidence and deaths. The need to address this through improved data has been identified as a major priority task for Nepal. Cancer being the fifth leading cause of mortality in Nepal, it accordingly poses a high priority for initiating PBCR.

## Objective

### General objective:

To initiate National Population Based Cancer Registry to identify the incidence, trends, pattern and mortality of cancer cases in Nepal

### Specific objectives:

- To enhance national capacity for sustainable PBCR in Nepal
- To generate evidence on cancer incidence, patterns and trends of disease and mortality related to cancer in the defined population, including data quality indicators

A high level Steering Committee (SC) with representation from NHRC, MoHP, WHO, and other stakeholders such as hospital directors, clinical oncologist and epidemiologists was formed so as to guide the entire process of PBCR in close co-ordination with the MoHP.

A Technical Working Group (TWG) was then formed under the Steering Committee to manage operational task. The TWG is responsible for the implementation of cancer registry programme. The TWG consists of Registry coordinator/director, Consultant oncologist, Research officers, Medical record officer, Representatives from WHO, Health Management Information System (HMIS), Civil Registration, Technical assistant personnel and non-technical assistant personnel. The PBCR is being operated following the principles set out in "Cancer Registration: Principles and Methods.

The government of Nepal, MoHP has given an approval for NHRC to conduct Population Based Cancer Registry Program and issued an administrative order (Annex 1) to all the hospitals to help and support cancer registry program done by NHRC. Because of this order, good cooperation from all the public and private hospitals has been obtained. Similarly, Ministry of Federal Affairs and Local Development has issued an order (Annex 1) to the all Metropolitan City/Municipalities/Rural Municipalities to obtain all the cancer cases from the communities and to put the data in their respective website and provide a copy to NHRC, which made us easy to obtain cooperation from the local levels.

## 2.1 Source of Data

The sources of information for the PBCR are all public and private hospitals (especially tertiary centers), health posts, histopathology laboratories, imaging centers, cancer screening units, cancer centers, hospice, death registry, municipalities and/or rural municipalities.

A preliminary list of all available sources is obtained from the Ministry of Health and Population (MoHP), National Public Health Laboratory (NPHL), District Public Health Office (DPHO). Consultation with the Oncologist is also done to identify the Cancer diagnosing and treating health facilities. Meeting with the key leadership group from the selected facilities is conducted to explain the role of the registry and to seek their cooperation.

Currently, in Nepal, all patients diagnosed with cancer have to register with Department of Health Services, to be eligible to receive the cancer treatment fund provided by the government. This is also taken as one of the sources for the registry data.

In addition, Department of civil registration and the death certificates obtained from the death registry in ward offices are the other sources. However, in Nepal the death certificate does not provide adequate information. For the completeness and quality of the data, the information is obtained by 'traced back procedure' i.e. through the patients family members and/or their medical record obtained via the address of the death record. Similarly, the community related data is obtained through health coordinators at local levels.

## 2.1.1 Data Collection of cancer cases from Different Hospitals

The registry staffs/data enumerators regularly visit these hospitals/centers in order to collect data from the respective places. The following table shows the different sources of data collection on cancer cases.

Table 2 Sources of Data Collection

SN	Name of Institution	Place
1	Paropakar Maternity Hospital	Kathmandu
2	Bir Hospital	Kathmandu
3	BirendraSainik Hospital	Kathmandu
4	Civil Service Hospital	Kathmandu
5	Grande International Hospital	Kathmandu
6	GreenCity Hospital	Kathmandu
7	Kanti Children Hospital	Kathmandu
8	Kantipur Hospital	Kathmandu
9	Kathmandu Medical Collage Teaching Hospital	Kathmandu
10	TU Teaching Hospital	Kathmandu
11	Om Hospital and Research Centre	Kathmandu
12	Nepal Medical College	Kathmandu
13	National Medicare and Research Centre	Kathmandu
14	Bhaktapur Cancer Hospital	Bhaktapur
15	Kathmandu Cancer Centre	Bhaktapur
16	Nepal Cancer Hospital and Research Centre	Lalitpur
17	Nepal Medicity Hospital	Lalitpur
18	National Cancer Hospital	Lalitpur
19	Vayodha Hospital	Lalitpur
20	Patan Academy of Health Science	Lalitpur
21	KIST Medical College and Teaching Hospital	Lalitpur
22	Alka Hospital	Lalitpur
23	B&B hospital	Lalitpur
24	National Public Health Laboratory	Kathmandu
25	MediQuest Laboratory Pvt. Ltd	Lalitpur
26	Samyak Diagnostic Pvt. Ltd.	Kathmandu
27	Thankot Hospice	Kathmandu
28	Hospice Nepal	Lalitpur
29	Divyam Ayurvedic Aausadhalaya	Kathmandu
30	B.P Koirala Memorial Cancer Hospital	Chitwan
31	National Path Laboratory	Dang
32	Nepalgunj Medical College and Teaching Hospital	Banke
33	Sushil Koirala Prakhar Cancer Hospital	Banke
34	B.PKoirala Institute of Health Sciences	Dharan

35	Nobel Medical College and Teaching Hospital	Biratnagar
36	Birat Medical College	Biratnagar
37	Saptakoshi Nursing Home	Biratnagar
38	Lifegaurd Hospital	Biratnagar
39	ShreeRam Diagnostic	Biratnagar
40	Neuro Hospital	Biratnagar
41	Golden Hospital	Biratnagar
42	National Medical College	Birjung
43	Mangalam Diagnostic	Birjung
44	Vision Diagnostic	Birjung
45	Tata Memorial Cancer Hospital	India
46	Rajeev Gandhi Cancer Institute	India
47	Department of Civil Registration	Nepal
48	Department of Health Service, Bipanna Section	Nepal
49	Other Centers (Municipalities/ Village Council, Urban Health Centers, Health Posts)	Kathmandu, Bhaktapur, Lalitpur, Siraha, Saptari, Mohattari, Dhanusha and Rukum

## 2.1.2 Community Involvement in the Cancer Registration Process

Community involvement for the cancer registration is highly important. This increases the ownership and the awareness among the community people so that we can collect genuine information on newly diagnosed cancer and cancer deaths.

In close coordination with Ministry of Federal Affairs and Local Development, collaboration has been established with the mayors and the health coordinators in the Rural/Municipalities in the program implemented districts. Orientation is given to the health coordinators and health in-charges and also to FCHVs if necessary and the data is collected through them. In addition, other approaches like interactions with the ward chairpersons and community leaders, different groups such as mothers groups, women's groups were followed in order to collect information on newly diagnosed cancer cases and mortality cases.

## 2.2 Data Collection Method

The methodology of data collection by the registry is both active and passive depending upon the data sources. There are two major ways through which data are obtained for the registry. One is from the facilities which include hospital, pathology laboratory, hospice, department of health service bipanna section and civil registration. The registry personnel visit these sources at regular intervals and actively collect cancer cases data available there. The data is collected from the records of the sources since January 2018 and recorded in the standard format. Other is from the community in which orientation is given to the Health Coordinators at each Municipality/Rural Municipality, Health In-charges and even the Female Community Health Volunteers (FCHVs) wherever necessary. Data is then obtained by FCHVs from the population through home visit submitted to the Health In-charges. The Health In-charges submit data to the Health Coordinators and the Health Coordinators to the NHRC office on monthly basis. The obtained data from all these sources is verified for the completeness, accuracy and residence and then entered into CanReg5 Software at the NHRC office.

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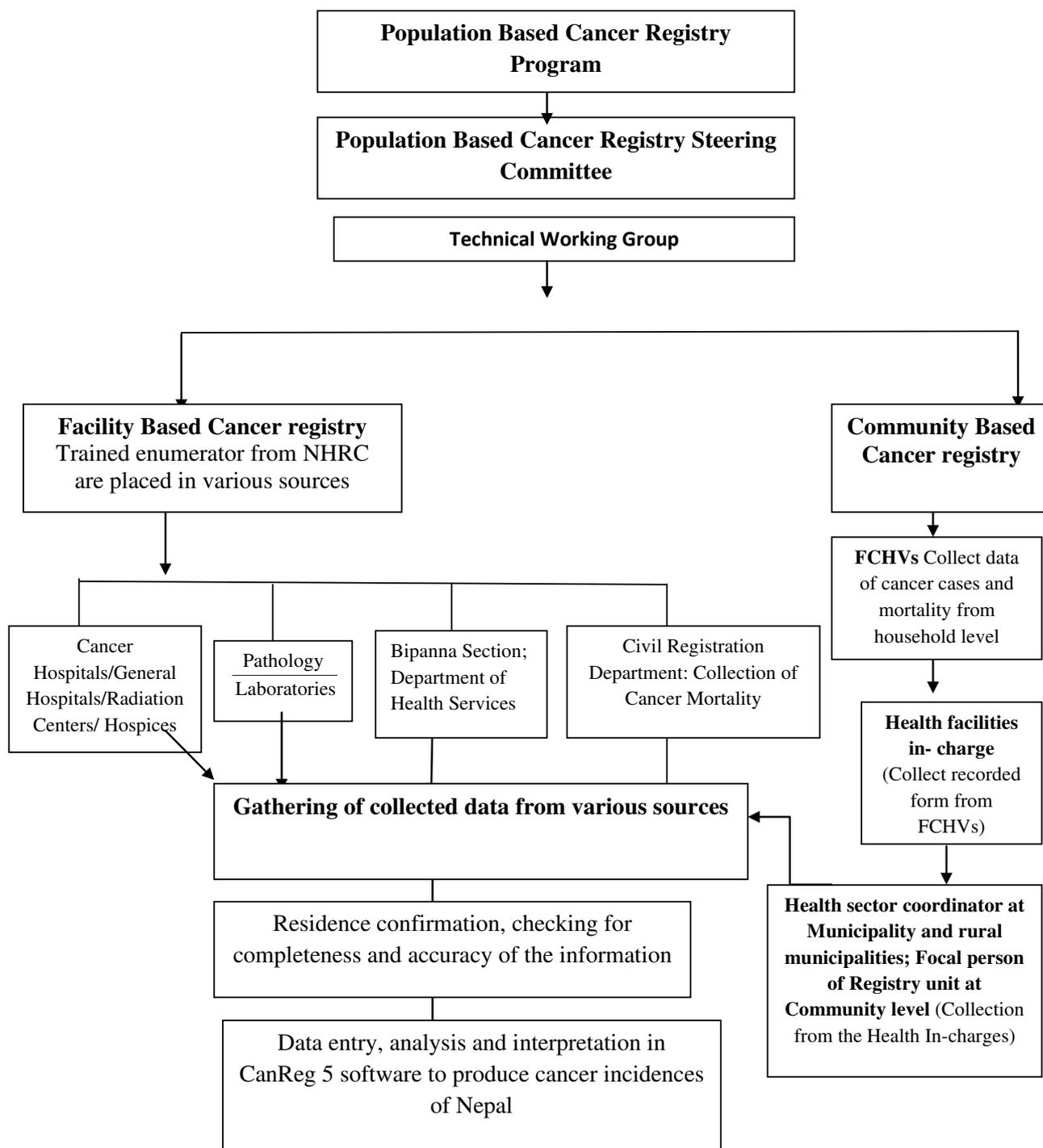
For the Kathmandu Valley cancer registry, there are many cancer diagnostic and treatment facilities in Kathmandu valley. Thus, most of the cases can be obtained from these facilities within Kathmandu, Bhaktapur and Lalitpur districts. However, people sometimes visit B.P. Koirala Memorial Cancer Hospital (BPKMCH), Bharatpur, Chitwan around 200 km away from the valley. So we collect the data of the cases of our selected districts from there as well. Since people also visit India for cancer treatment, we have coordinated to some familiar cancer hospitals in India to collect data of cancer patients.

Nevertheless, for other two registries of Province no. 2, 5 and 6, there are not any oncology related diagnostic and treatment facilities within Siraha, Saptari, Dhanusha, Mohattari, and Rukum districts. People have to move Kathmandu valley, Banke, Bardiya, Nepalgunj, Dharan, Birgunj, Biratnagar, Chitwan and even India for the investigation and treatment of cancer. Thus coordination and collaboration has been made with the diagnostic and treatment facilities of these areas, and data are being obtained from there, besides the data from the communities through Female Community Health Volunteers, health post incharge and health coordinators of these districts.

Records are then checked and verified for the completeness and accuracy of the information. Patient or the contact person is contacted for residence confirmation and for any missing information. After completing all these, data are electronically entered from the paper forms into CanReg5 software. CanReg5 is software specially designed for cancer registry to enter, check, store and analyze the registry data. The unique feature of CanReg5 is it identifies the potential duplicates based on the assigned variables and patient duplication can be easily identified from the software which is a common issue in cancer registry.

Confidentiality of each individual is maintained throughout. The details of the patient are known to data enumerator, research coordinator and the data entry person. However, they are fully responsible for maintaining the confidentiality of the patient. The collected forms are being stored in separate cabinet and the sole responsibility retains within Cancer Registry Unit at Nepal Health Research Council.

## 2.2.1 Flow Chart for Data Collection Process on Cancer Registry



## 2.3 Population Covered by the different Cancer Registry

### 1. Kathmandu Valley Cancer Registry

The PBCR has covered the entire population of the Kathmandu valley (Kathmandu, Lalitpur and Bhaktapur districts). These three districts have many public and private cancer diagnostic and treatment centers. The valley has 21 municipalities/rural municipalities including metropolitan with a total of 246 wards. According to 2011 census, the total population of the valley was 2,517,023. Of the total population, 1,305,967 are males and 1,211,056 are females. Table below shows the total population in the three districts.

**Table 3 Total Population of the Valley (Kathmandu, Lalitpur & Bhaktapur)**

SN	Districts	Population			Remarks
		Male	Female	Total	
1	Kathmandu	913,001	831,239	1,744,240	
2	Lalitpur	238,082	230,050	468,132	
3	Bhaktapur	154,884	149,767	304,651	
	<b>Total</b>	<b>1,305,967</b>	<b>1,211,056</b>	<b>2,517,023</b>	

Source: CBS, 2011

### 2. Siraha, Saptari, Dhanusha and Mahottari Cancer Registry

Province 2 covers the 8 districts of eastern tarai of Nepal which is also pronounced as Madhes/ Mithila/ Bhojpura. It is Nepal's second most populous province but smallest province by area. Siraha, Saptari, Dhanusha and Mahottari cancer registry has been searching cancer incidence and mortality of following four districts which covers 2,658,933 populations. Table below shows the total population in the four districts.

**Table 4: Population of Siraha, Saptari, Dhanusha and Mahottari district**

S.N.	District	Population			Remarks
		Male	Female	Total	
1	Siraha	310,101	327,227	637,328	
2	Saptari	313,846	325,438	639,248	
3	Dhanusha	378,538	376,239	754,777	
4	Mahottari	311,016	316,564	627,580	
	<b>Total</b>	<b>1,313,501</b>	<b>1,345,468</b>	<b>2,658,933</b>	

Source: CBS, 2011

### 3. Rukum Cancer Registry

Rukum district (both east and west Rukum) is a hill and mountain district nearly 280 Km west from Kathmandu. It partially belongs to province 5 and partially to province 6 (Karlani Pradesh). Rukum covers an area of 2,877 km<sup>2</sup> with population of 208,567. Table below shows the total population of Rukum district.

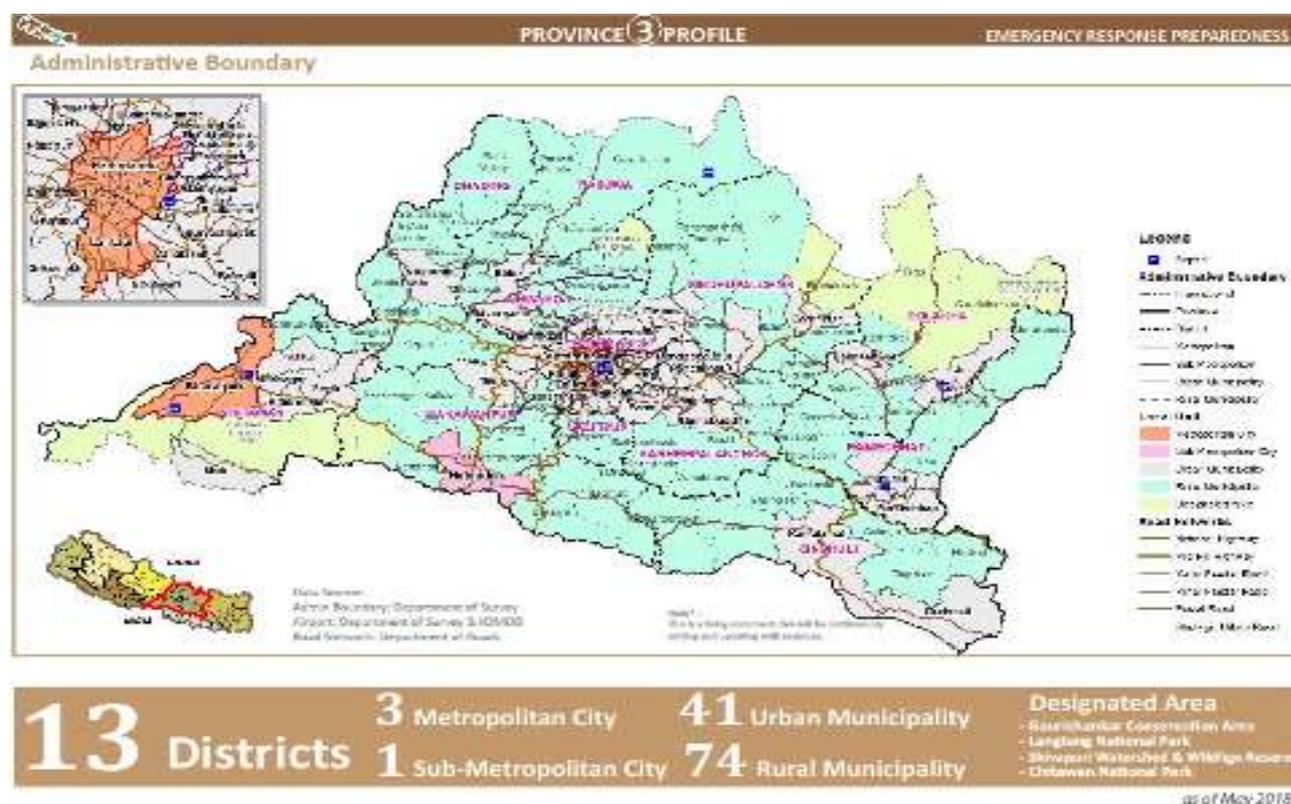
**Table 5: Population of Rukum district**

Source: CBS, 2011

S.N.	District	Population			Remarks
		Male	Female	Total	
1.	East Rukum	24,980	28,204	53,184	
2.	West Rukum	74,179	81,204	1,55,383	
	<b>Total</b>	<b>99,159</b>	<b>1,09,408</b>	<b>2,08,567</b>	

Since the report represents the findings of interim analysis from Kathmandu Valley Cancer Registry, it's very important to understand background information on administrative structure and health system within the valley. Thus, the following paragraphs briefly describe the profile of the three districts of the Kathmandu valley aiming to provide their geographical structures, boundaries, administrative divisions, and non/public health facilities.

## 2.4 Province 3 Profile



Province no 3 is one of the 7 provinces of Nepal established by the New Constitution of Nepal adopted on 20 September 2015. Most of the parts of this province are hilly and mountainous. The capital city of Nepal, Kathmandu also lies in this province. The temporary capital of this province is Hetauda. It covers an area of 20,300 square kilometers, about 14% of the total area of the country. It borders to Tibet Autonomous Region of China to the north, Province No. 1 to the east, Gandaki Pradesh to the west, and the Province No. 2 and Bihar province of India to the south. The total population of the province is 5,529,452 out of which 50.31% are male and 46.69% are female. The population density of province no.3 is 270/square



## Lalitpur District Profile

Lalitpur district is a part of Kathmandu valley located in Province no 3 of the country. The district covers an area of 385 km<sup>2</sup> and has a population of about 468,132 as per 2011 census of Nepal. The district is surrounded by Dhading district in the west, Makwanpur in the south, Kavreplanchok in the east, and Sindhupalchok and Nuwakot districts in the north. The district has 6 Municipalities/Rural Municipalities as Lalitpur, Godawari, Dakshinkali, Mahalaxmi Municipalities and Kojeshom, Bagmati, Mahankal Rural Municipalities. The district has many rural areas and semi-urban areas that it is comparatively less accessible for health and educational services than two other districts of the valley.



**Fig. 2 Lalitpur District**

## Bhaktapur District Profile

Bhaktapur is the smallest district of Nepal. It falls under Province 3 of Nepal. According to the 2011 census of Nepal, Bhaktapur district covers maximum population of about 304,651. It covers the total area of 123.79 square kilometers. It is surrounded by Kavrepalanchowk district in the east, Kathmandu and Lalitpur districts in the west, Kathmandu and Kavrepalanchowk districts in the north and Lalitpur district in the south. The geographical features of the districts are almost same as that of Kathmandu and Lalitpur districts, the two other districts of Kathmandu valley. The entire eastern region and nearly half of the northern and southern region of district is covered with hills, which are part of the Mahabharat series.

The district has been divided into 4 municipalities as Bhaktapur, Changunarayan, MadhyapurThimi and Suryabinayak municipalities. Bhaktapur lags behind to when it comes to medical service. Bhaktapur does not have enough hospitals rendering qualitative medical facilities. However, some of the major cancer hospital Bhaktapur Cancer Hospital and Kathmandu Cancer Centre are located in Bhaktapur.

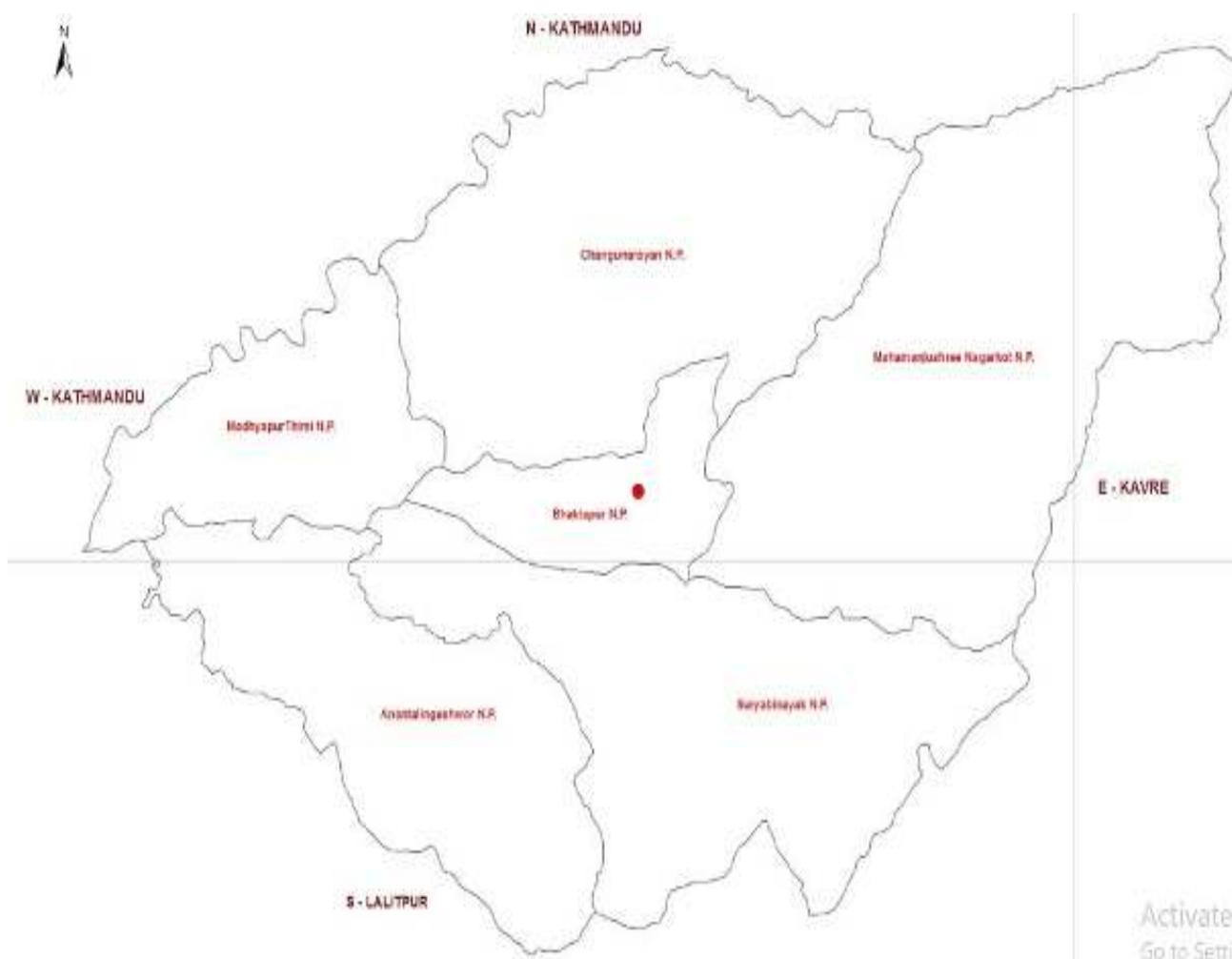


Figure 3 Bhaktapur District

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## CHAPTER 2

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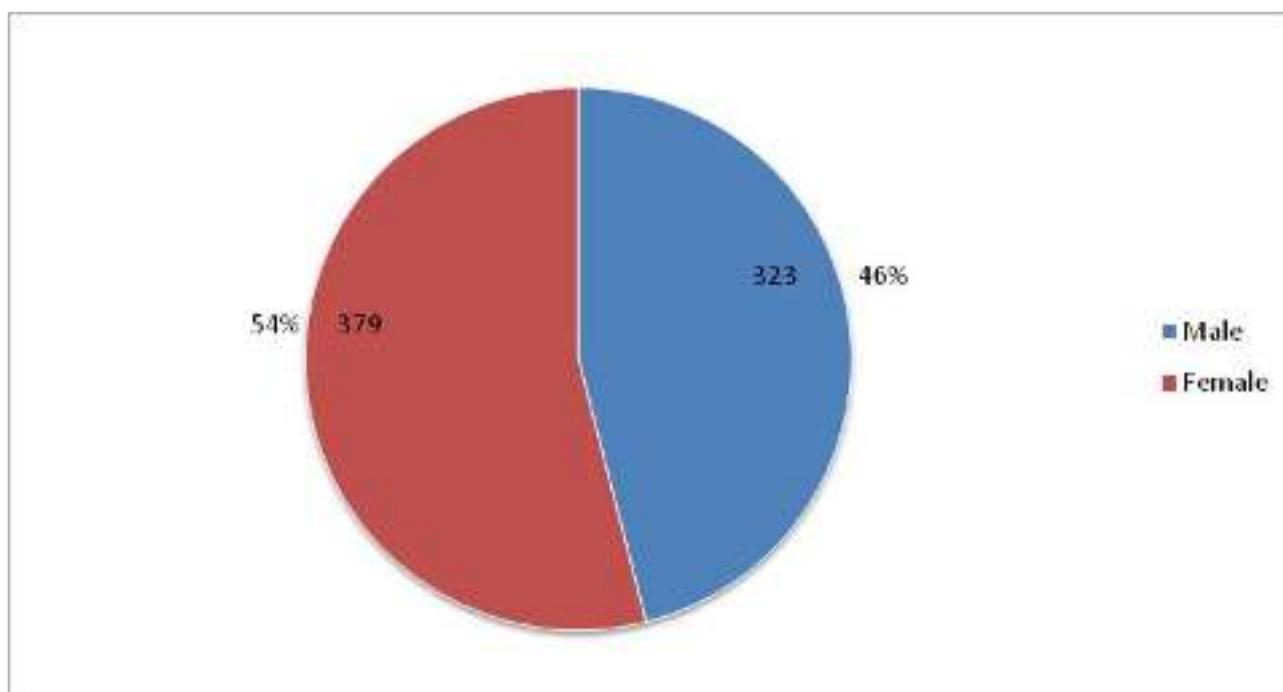
## RESULTS/FINDINGS

The data collection of cancer cases and cancer mortality from all the sources has been completed till August, 2018. Out of total 5260 cases (new and old) checked by PBCR from various sources, 2612 cases are found to be the newcases.

The incidence was separated according to the date of diagnosis, and all the cases were contacted through the phone calls in order to confirm their residence. The verification and residence confirmation of the cases are completed till May 31<sup>st</sup> 2018, which shows a total of 702 cancer cases from Kathmandu Valley including 256 cancer incidences from Siraha, Saptari, Dhanusha and Mahottari and 23 incidences from Rukum.

The Annual Report 2018 has been planned to get published by September 2019. However interim analysis of Kathmandu Valley registry till May 2018 was done and the major findings are highlighted here. Kathmandu Valley Cancer Registry has collected a total of 702 new cancer cases until May 2018. There are few number of male cancer cases i.e. 323 than female cancer cases i.e. 379 in the valley. The proportion distribution of cancer incidence cases among females is 54% whereas it is 46% in males. The cancer incidence of all sites for males and females are presented in figure below.

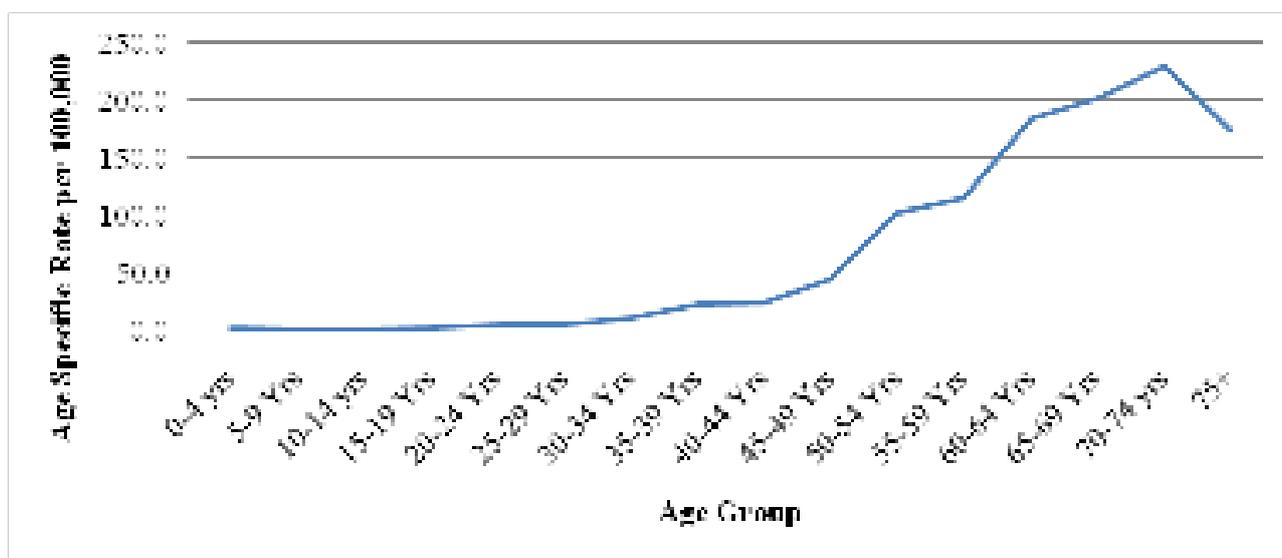
**Fig. 4 All Sites Cancer Incidence Rate by Sex (Total N=702)**



### 3.1 Cancer Incidence Rate by Age Group

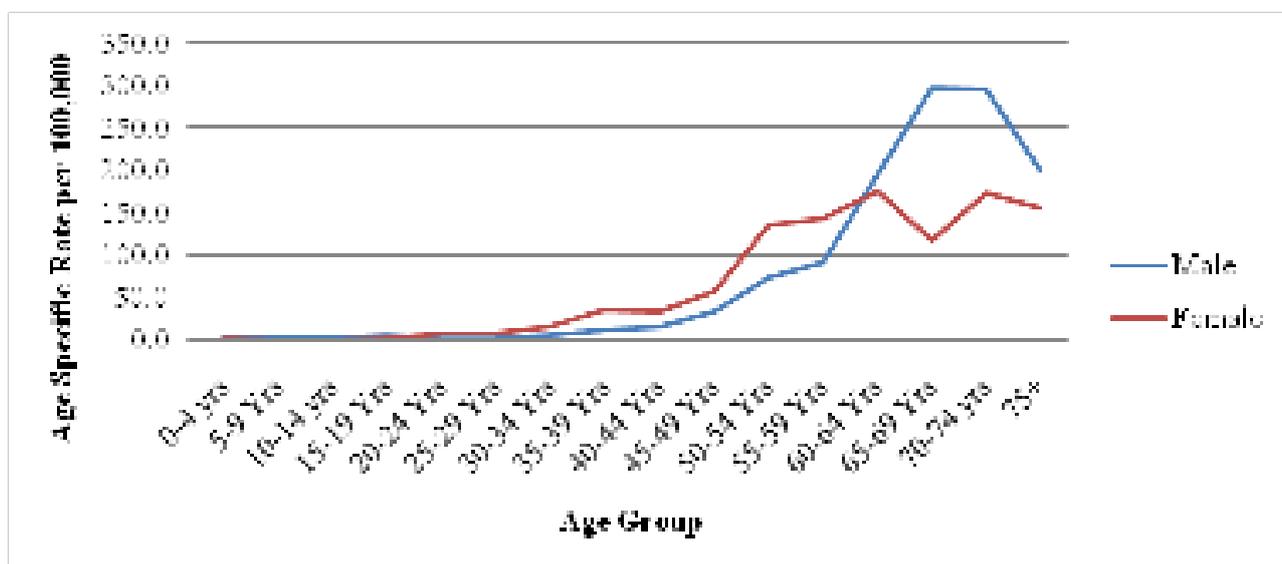
The peak cancer incidence is found among the age group of 70-74 years followed by 65-69 years and then 60-64 years with an age specific rate of 230.5, 203 and 185.3 per 100,000 respectively. The following figure shows cancer incidence rate by age group.

**Fig 5 Age Specific Rate per 100,000 (Total N=702)**



While comparing with male and female incidence rate according to age, in Males the peak incidence age is 65-69 and 70-75 years followed by 60-64 years and 75+ and the least incidence is among the age group of 25-29 years and 10-14 years. Whereas, in Females the peak incidence age is 60-64 years followed by 70-74 years and the least incidence is among the age group of 5-9 years followed by 10-14 years.

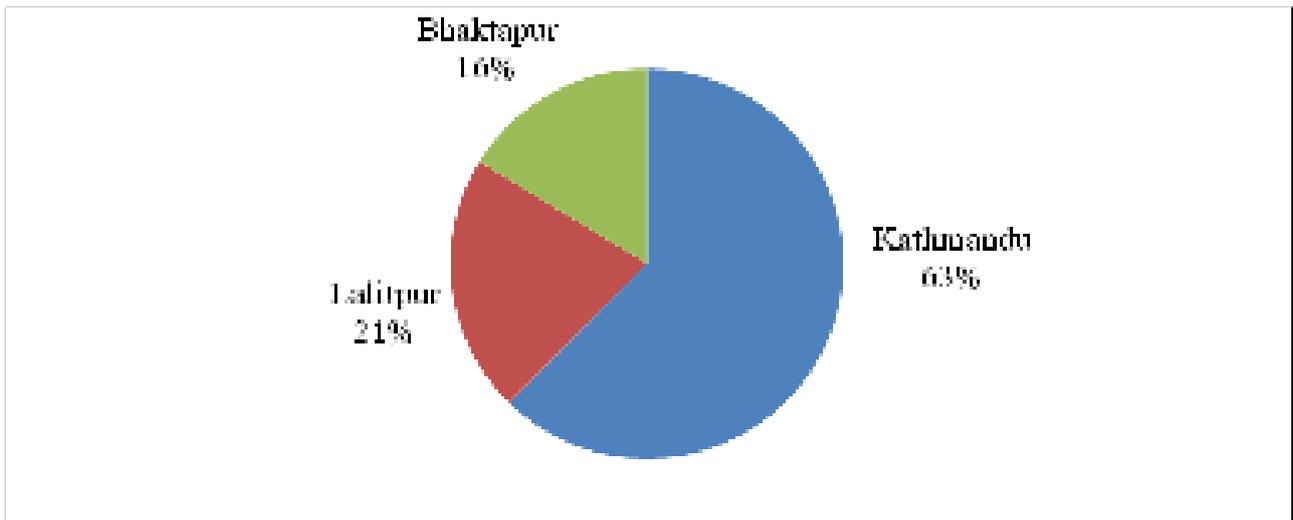
**Fig. 5 Cancer Incidence Rate by Age Group among Male and Female (Male n=323, Female n=379)**



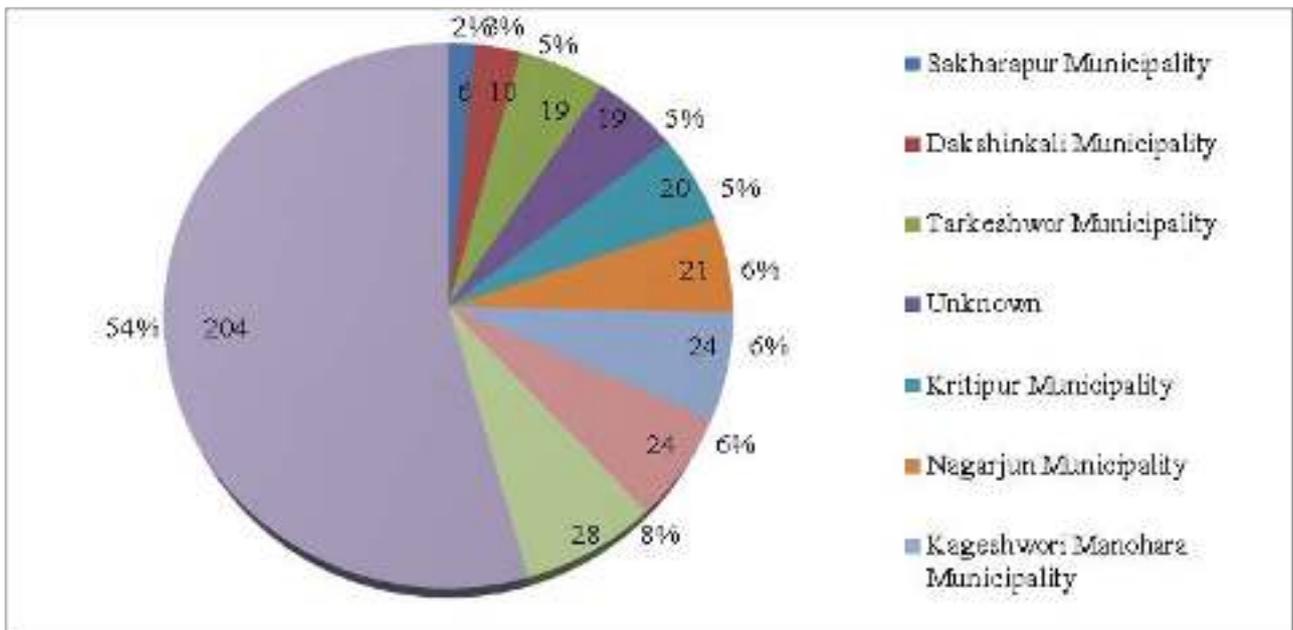
### 3.2 Distribution of cancer cases according to administrative area

Among the three districts in Kathmandu Valley, out of 702 cases, more than half cases were found to be in Kathmandu district 63% (n=438). Remaining 21% are found in Lalitpur district (n=150) and only 16% of the new cases are found in Bhaktapur district (n=114) as shown in the figure below.

**Fig.6 Cancer case distribution among the districts of Kathmandu Valley(Total N=702)**

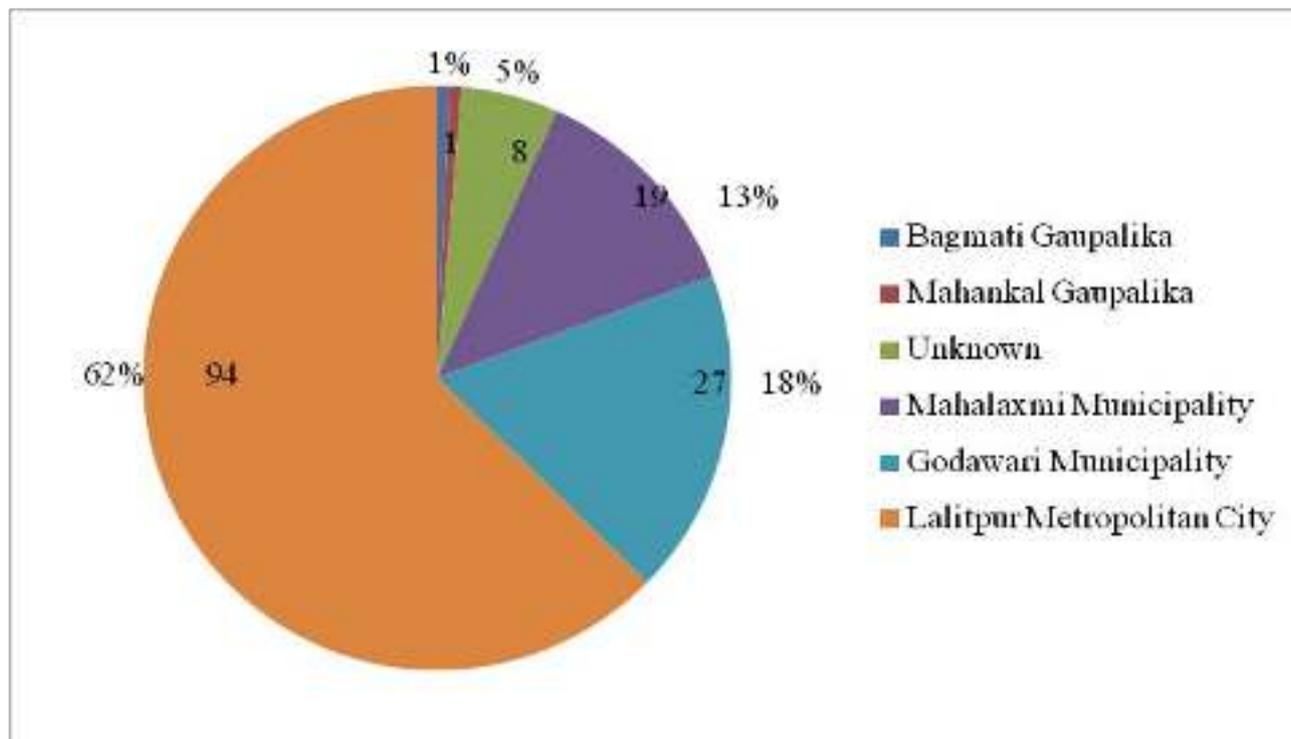


Within Kathmandu district, the cancer cases are found to be highest in Kathmandu Metropolitan city and least in Sakharapur Municipality. Similarly, in Lalitpur district cases are high in Lalitpur metropolitan city and lowest in Bagmati Village Council. In Bhaktapur, the cancer cases are maximum in Bhaktapur Metropolitan city and Suryabinayak Municipality and minimum number of cases in Chagunarayan Municipality.

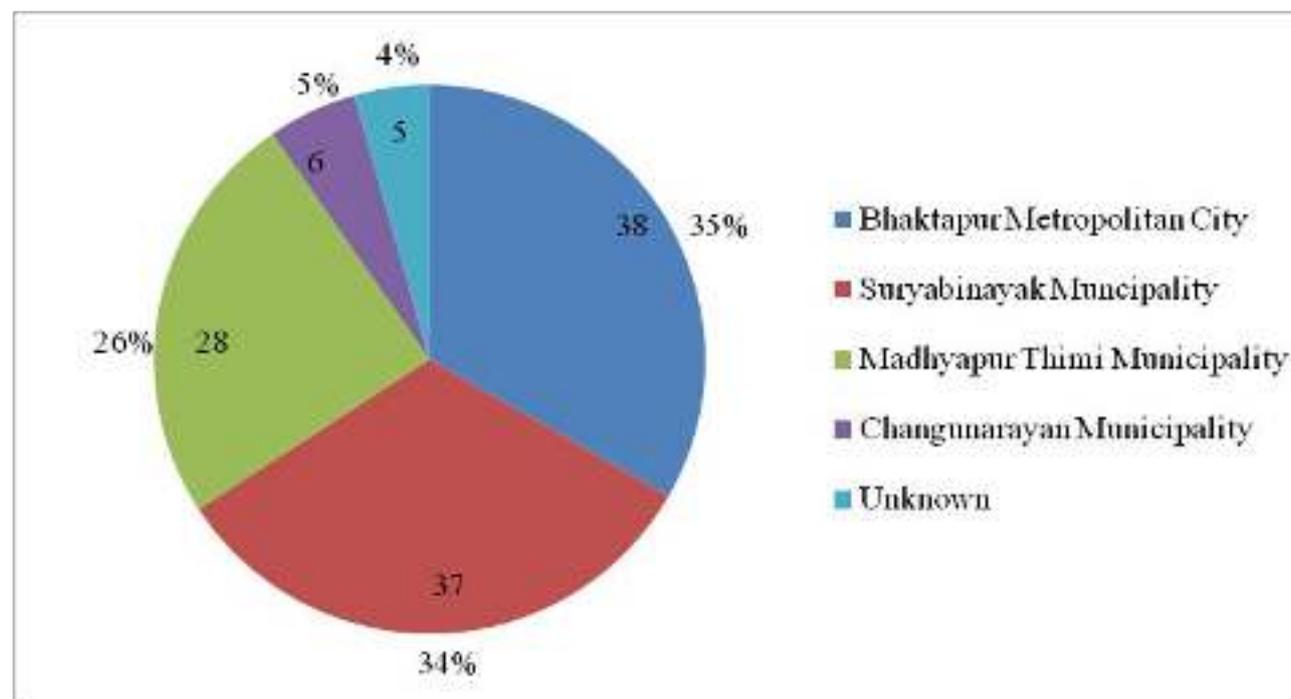


**Fig.7 Distribution of cases within the local government of Kathmandu district (n=438)**

**Fig. 8 Distribution of cases within the local government of Lalitpur district (n=150)**



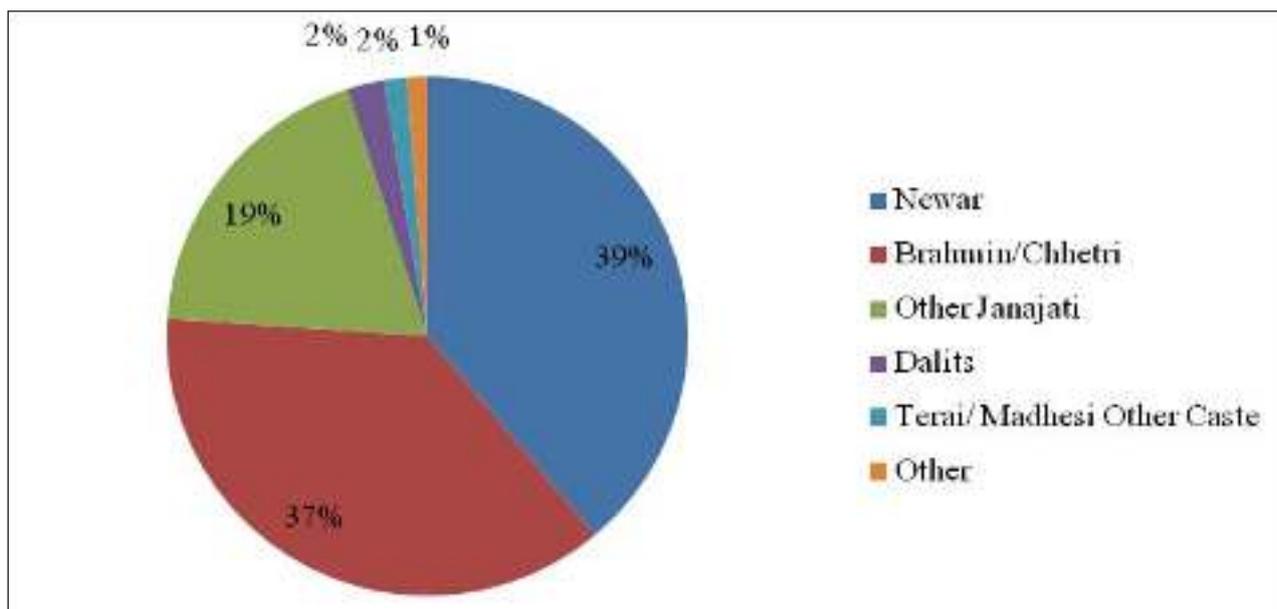
**Fig.9 Distribution of cases within the local government of Bhaktapur district (n=114)**



### 3.3 Distribution of cases according to Ethnicity

Among the 702 cases, the proportion of Newar was highest (39%), Brahmin/ Chhetri were 37%, followed by other Janajati i.e. 19%. Dalits and Terai/Madhesi Other caste were only 2% and remaining Others were found to be 1%.

**Fig 10 Distribution of cases by Ethnicity (Total N=702)**



### 3.4 Distribution of cases according to Marital Status

The table below shows the cancer incidence based on the marital status. Among the total 702 new cases, there were 524 married cases (74.6%), 43 (6.1%) single referring to widow men and women, 19 (2.7%) were unmarried and among 100 (14.2%), the marital status is not identified. It refers to either the information is not recorded or patients did not respond to this question during the phone calls.

**Table 6 Distribution of Cases by Marital Status**

Marital Status	Number of Cases (n)	Percentage
Married	524	74.6
Unknown	100	14.2
Single	43	6.1
Unmarried	19	2.7
Not Applicable	13	1.9
Divorced	3	0.4
<b>Total (N)</b>	<b>702</b>	<b>100.0</b>

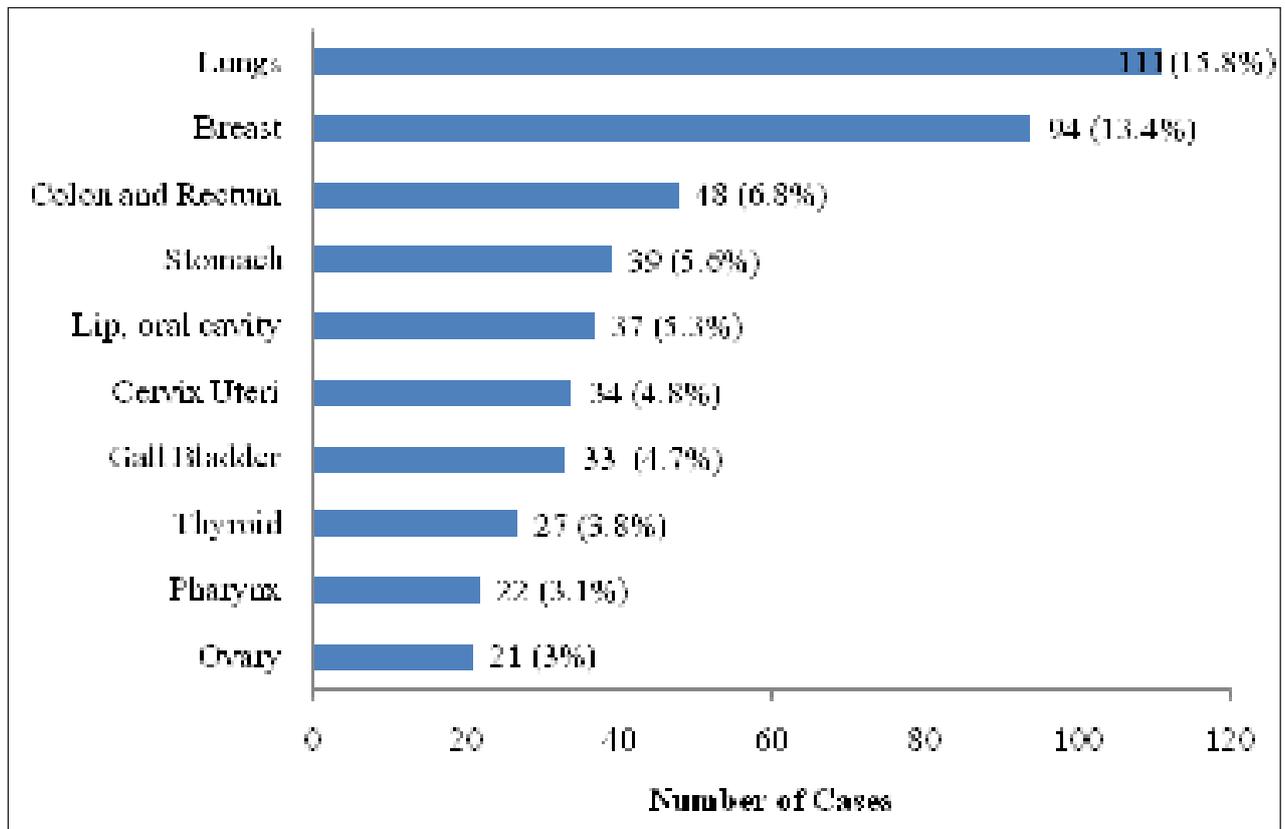
### 3.4 Leading Cancer Sites

Irrespective of sex, the leading cancer site was found to be Lungs, Breast, Colon and rectum, Stomach, Lip and Oral cavity, Cervix Uteri, Gall Bladder, Thyroid and Pharynx. Among the total 702 cases, Lungs cancer is among 111 i.e. 16% cases are of lungs cancer. However, the distribution among Male and Female showed that it is highly prominent among Males 64% Vs Females 36%.

Similarly for second most leading cancer, Breast cancer is among 13% of the total cases. However it is predominantly in Females i.e. among the total 97% in females and only 3% in males. Followed by Breast cancer, third most common carcinoma was found to be colon and

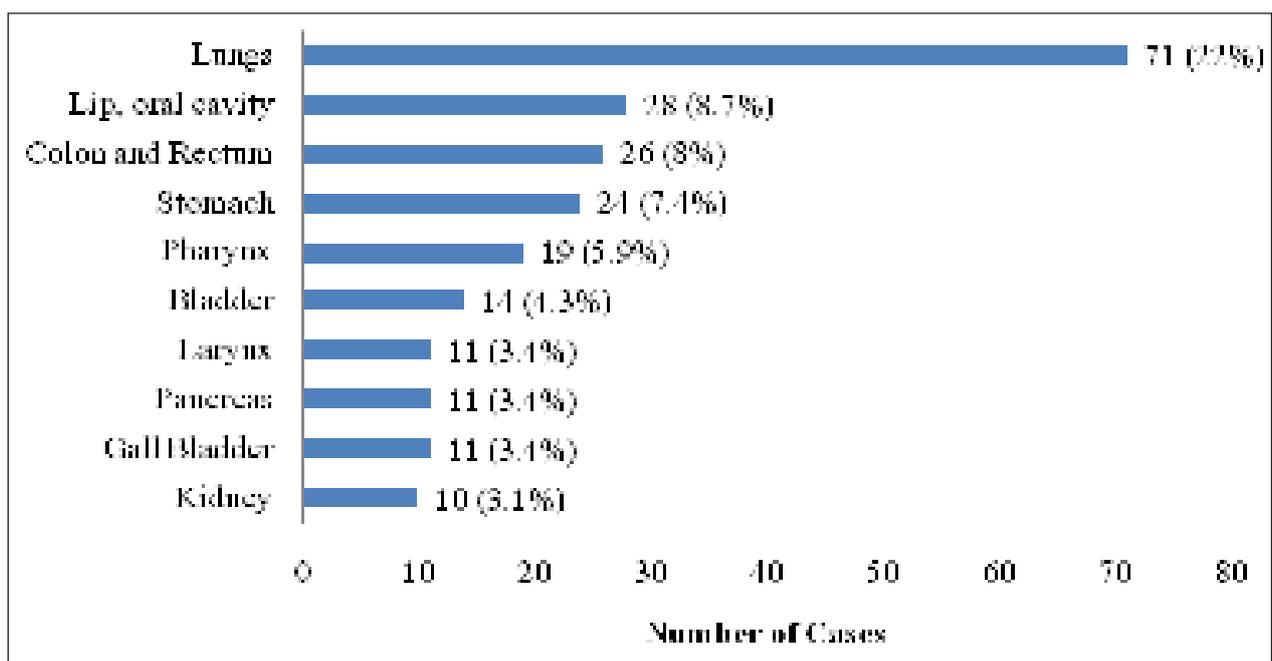
Rectum i.e. 7% of the total cases and distributed equally among both sexes.

**Fig. 10 Leading Cancer Sites(Total N= 702)**



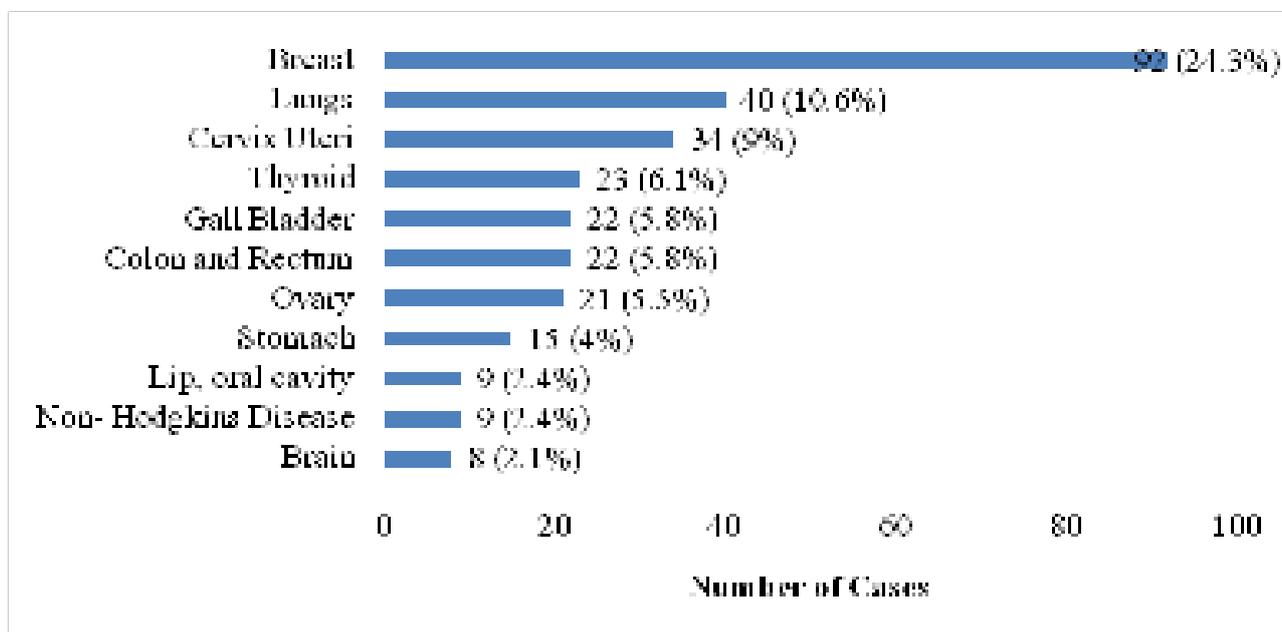
In male, the top leading cancer site is lungs followed by lip and oral cavity, colon and rectum, stomach, pharynx, bladder, larynx, pancreas, gall bladder and kidney as shown in the figure below.

**Fig. 11 Leading Cancer Sites in Males (n=323)**



In female's breast, lungs, cervix uteri, thyroid, gall bladder, colon and rectum, ovary, stomach, lip and oral cavity, Non-Hodgkin's disease and brain are the leading cancer sites.

**Fig. 12 Leading Cancer Sites in Females (n=379)**



### 3.5 Childhood Cancer Cases

Out of total 702 cancer cases, only 5 cases are pediatric cancer cases. There are 4 cases of boys and only a case of girl as shown in table below. We may have missed the pediatric cancer cases.

**Table 7 Pediatric Cancer Cases**

Age Group	Male		Female	
	Number	Percentage	Number	Percentage
0-4 yrs	2	0.6	1	0.3
5-9 Yrs	2	0.6	0	0.0

### 3.6 Microscopic Verification of cases:

Out of 323 male cases, 304 (94.1%) are diagnosed on microscopic verification, 1.2% are diagnosed on the basis of radiological investigation. Only 0.3% cases are diagnosed on the basis of clinical investigation. Similarly, in females, out of 379 cases, 361 (95.3%) are diagnosed on microscopic verification. Only 0.8% is diagnosed on radiological investigation and 0.3% on the basis of clinical investigation.

In male 13 cases (4%) and in females 12 cases (3.2%) were registered under Death Certificate Only (DCO). The death cases have been registered on the basis of death certificate found on the hospital file and also according to the relative's remark. The valid basis of diagnosis has been summarized in the table below.

**Table 8 Most Valid Basis of Diagnosis among Male and Females**

Most Valid Basis of Diagnosis	Male		Female	
	Number	Percentage	Number	Percentage
Microscopic ( Histology of Primary/ Histology of metastasis/ Cytology/ Bone Marrow Aspiration)	304	94.1	361	95.3
Death Certificate only	13	4.0	12	3.2
Clinical Investigation	4	1.2	3	0.8
Specific Tumor Marker	1	0.3	2	0.5
Clinical only	1	0.3	1	0.3
<b>Total</b>	<b>304</b>	<b>94.1</b>	<b>379</b>	<b>100.0</b>

### 3.7 Other and Unspecified Sites

The other and unspecified sites are C26- Other and ill-defined Digestive Organ, C48- Retro Peritoneum and Peritoneum, C77- Lymph Nodes and C80- Unknown Primary. In males out of 323 cases, 22 cases are of other and unspecified sites. The predominant cases Primary Unknown (6.2%), followed by Lymph nodes (0.3%) and Retro Peritoneum and Peritoneum (0.3%). Whereas in case of females the other and unspecified cases are only 19 out of 379 total female cases in which Primary Unknown is the predominant (4%) followed by other and ill-defined Digestive Organs (0.5%), Lymph nodes (0.3%) and Retro Peritoneum and Peritoneum (0.3%).

The Primary Unknown case is the indicator of the health infrastructure and also awareness and utilization of health facilities. It also indicates proper documentation of the health care service provider and the quality of diagnostic information. As Kathmandu Valley is an area with availability of comprehensive cancer treatment facilities and also the sophisticated diagnostic facilities, the predominant number of Primary Unknown cases in both sexes is due to poor maintenance of the record. In addition, after going through the medical records, discharge summary, mostly, it's mentioned lungs metastasis, liver metastasis, bone metastasis etc. and usually the patient are found to be of old age. As the disease reaches to metastatic stage, most of the cases prefer to take alternative medicine. The following table shows the other and unspecified percentages between males and females.

**Table 9 Other and Unspecified Percentage between Male and Females**

ICD	Male		Female	
	Number (n)	%	Number (n)	%
C80 (Unknown Primary)	20	6.2	15	4.0
C77(Lymph Nodes)	1	0.3	1	0.3
C48(Retro peritoneum and Peritoneum)	1	0.3	1	0.3
C26 (Other and ill-defined digestive organs)	0	0.0	2	0.5
Total Cancer Cases (N)	323	100.0	379	100.0

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## Hurdles in Establishing the Population Based Cancer Registry in Nepal

It's challenging to establish population based cancer registry in Nepal as people use multiple locations to diagnose cancer and for treatment. People even visit many cancer hospitals in India as well as abroad for treatment. So it's hard to keep exact record of cancer cases within a certain territory. However, coordination has been made with some of the familiar cancer hospitals in India to obtain data of cancer patients.

Since there are not fully/partially dedicated staffs available at the data source locations, it is difficult to obtain data on periodic basis. Reporting may not be mandatory in such cases. Similarly, there is no budgetary provision for cancer by the rural/municipalities hindering coordination with the stakeholders and access to cancer cases at the locations. Since the FCHVs have already their own roles and responsibilities in the communities, they are overburdened to collect data on cancer cases and submit on timely basis. They haven't been given any additional incentives for this work. In such cases, they might be de-motivated to collect data on cancer cases in future.

Though the country has entered into federalism and started administration via provincial and local governments, there is no PBCR coordination body at the respective provinces and local governing bodies (municipalities) to work effectively and efficiently.

Some hospitals (government and private) are not willing to share detail information of cancer patients as well as they are unlikely to make coordination to provide cancer data from their hospitals. So, NHRC has also signed MOU with some hospital/s to make collaborative efforts on PBCR in future.

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## Annexure

### Annex 1: Administrative Order by the Ministry of Health and Population for the Cancer Registration Process



प.सं: २०७४।०७५(यो)

च.नं. ११०

नेपाल सरकार  
स्वास्थ्य मन्त्रालय  
(नीति, योजना तथा कार्यक्रम शाखा)



बि ४२६२६४३

रामशाहपथ,

काठमाण्डौ

मिति: २०७४।११।२३

विषय: स्वीकृत वार्षिक कार्यक्रम पठाइएको सम्बन्धमा।

✓ श्री नेपाल स्वास्थ्य अनुसन्धान परिषद्  
रामशाहपथ, काठमाण्डौ।

घालु आ.ब. २०७४।७५ मा तर्हवाट सञ्चालन हुने व.उ.शि.नं. ३७०१२७ स्वास्थ्य करकोषको कार्यक्रम र तर्हवाट पेश भएको नेपालमा जनसंख्यामा आधारित क्यान्सर रजिष्ट्रि (Population based Cancer Registry-PBCR) सम्बन्धी विस्तृत परियोजना प्रस्ताव (Detail Project Proposal) नेपाल सरकार (सचिबस्तर) मिति २०७४।११।२१ को निर्णयानुसार स्वीकृत भएकोले आवश्यक कार्यार्थ यसैसाथ संलग्न गरी पठाइएको छ। सकेसम्म कार्यक्रम संशोधन नगर्नु हुन र कथकदाचित संशोधन गर्नु पर्ने अवस्था आएमा त्यसबाट पर्ने असरहरु तथा संशोधन गर्नुपर्नाको पर्याप्त पुष्ट्याई सहितको विवरण उपलब्ध गराउने व्यवस्था गर्नुहुन तथा कार्यक्रम संचालन गर्दा प्रचलित कानून एवं अख्तियारीको पालना गर्नुका अतिरिक्त वित्तीय पारदर्शिता, जवाफदेहिता र अनुगमन सम्बन्धी व्यवस्था अनुरूप नियमानुसार प्रगति विवरण यस मन्त्रालयको जनस्वास्थ्य प्रशासन, अनुगमन तथा मूल्यांकन महाशाखामा पठाउनु हुन समेत निर्देशानुसार अनुरोध गर्दछु।

  
2074/11/23  
(हरिकृष्ण फुर्याल)  
शाखा अधिकृत

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सिंहदरवार।



आ.व. ०७४/७५  
च.न.२/६२१

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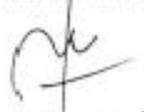
मिति: २०७४/११/३०

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२०. सम्यक डायग्नोस्टिक प्रा. लि., जाबलाखेल, ललितपुर,
२१. मेडिसिटी ल्याबोरेटरी प्रा. लि., पुल्चोक, ललितपुर \*
२२. बयोधा अस्पताल, बल्जु, काठमाण्डौं
२३. अल्का अस्पताल, जाबलाखेल, ललितपुर
२४. कान्तिपुर अस्पताल, तीनकुने, काठमाण्डौं

२५. ओम अस्पताल, चाबहिल, काठमाण्डौं
२६. काठमाण्डौं मेडिकल कलेज शिक्षण अस्पताल, सीनामंगल, काठमाण्डौं
२७. स्टार अस्पताल, धोबीघाट, ललितपुर
२८. किस्ट मेडिकल कलेज शिक्षण अस्पताल, इमाडोल, ललितपुर
२९. नेपाल प्रहरी अस्पताल, पानीपोखरी, काठमाण्डौं
३०. ग्रीनसिटी अस्पताल, धापासी, काठमाण्डौं
३१. श्री मनमोहन मेमोरियल अस्पताल, ईचयम्मु, काठमाण्डौं
३२. नेपाल मेडिकल कलेज शिक्षण अस्पताल, अत्तरखेल, जोरपाटी
३३. काठमाण्डौं मेडिकल कलेज शिक्षण अस्पताल, सिनामंगल
३४. वि.पि कोइराला मेमोरियल क्यान्सर अस्पताल, भरतपुर, चितवन
३५. शुसिल कोइराला प्रखर क्यान्सर अस्पताल, खजुरा, बाँके
३६. मनिपाल शिक्षण अस्पताल, पोखरा, कास्की
३७. पोखरा स्वास्थ्य विज्ञान प्रतिष्ठान, पोखरा, कास्की
३८. कोशी अञ्चल अस्पताल, विराटनगर, मोरङ
३९. वि.पि. कोइराला स्वास्थ्य विज्ञान प्रतिष्ठान, धरान, सुनसरी

प्रस्तुत विषयमा नेपाल स्वास्थ्य अनुसन्धान परिषदले नेपाल सरकार, स्वास्थ्य मन्त्रालयद्वारा कार्यक्रम स्वीकृत गरी आ.व. २०७४/७५ देखि "नेपालमा जनसंख्यामा आधारित क्यान्सर रजिष्ट्री (Population Based Cancer Registry (PBCR) in Nepal) सम्बन्धी परियोजना" कार्यान्वयन गरिरहेको व्यहोरा जानकारी गराउदै सो कार्यको सिलसिलामा त्यस अस्पतालमा आउनुहुने अनुसन्धानकर्ता तथा कर्मचारीहरूलाई परियोजना अर्वाधिभर आवश्यक सहयोग र समन्वय गरिदिनु हुन आदेशानसार अनुरोध गर्दछु ।

  
कृष्ण प्रसाद सुवेदी  
शाखा अधिकृत

Annex 2: Administrative order to the all rural/municipalities by the Ministry of Federal Affairs and Local Development for the Cancer Registration Process.



नेपाल सरकार  
सङ्घीय मामिला तथा सामान्य प्रशासन मन्त्रालय

सिंहदरवार, काठमाडौं  
(स्थानीय तह, सामान्य प्रशासन शाखा)



पत्र संख्या: २०७५/०१६  
चलानी नं. २१५

मिति: २०७५।०२।१३

विषय: आवश्यक सहयोग गरिदिने सम्बन्धमा ।

श्री महा/उपमहा/नगरपालिका सवै,  
श्री गाउँपालिका सवै ।

नेपाल स्वास्थ्य अनुसन्धान परिषद्को प. सं. ०७४/७५, च. नं. २६२२, मिति २०७५।०१।२० को पत्रवाट नेपाल सरकारको स्वीकृत कार्यक्रम अनुसार नेपाल स्वास्थ्य अनुसन्धान परिषद्ले आ. व. ०७४/७५ मा सञ्चालन गर्ने "जनसंख्यामा आधारित क्यान्सर रजिष्ट्री" (Population Based Cancer Registry, PBCR) सम्बन्धी कार्य गर्न हरेक नगरपालिका तथा गाउँपालिकावाट क्यान्सर रोग लागेका विरामीहरू तथा क्यान्सर रोग लागी मृत्यू भएका मानिसहरूको सम्पूर्ण विवरण आवश्यक पर्ने भएकाले प्रत्येक स्थानीय तहले सो सम्बन्धी अभिलेख तयार गरी website मा राख्ने व्यवस्था गर्नुहुन, उक्त विवरण तयार गरी नेपाल स्वास्थ्य अनुसन्धान परिषद्लाई उपलब्ध गराई दिनुहुनका साथै नेपालमा जनसंख्यामा अधारित क्यान्सर रजिष्ट्री सम्बन्धी परियोजना सञ्चालनमा आवश्यक समन्वय गरिदिनुहुन मिति २०७५।०२।१३ को नेपाल सरकार (सचिबस्तरीय) निर्णयानुसार अनुरोध छ।

  
केशवराज पाठे  
(शाखा अधिकृत)

बोधार्थ:

श्री नेपाल स्वास्थ्य अनुसन्धान परिषद्, रामशाहपथ, काठमाडौं ।  
श्री सूचना तथा प्रविधि शाखा, website मा upload गर्नुहुन ।

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### Annex 3: Photos of Major Events/Activities



Workshop Formal Launching of PBCR in Nepal



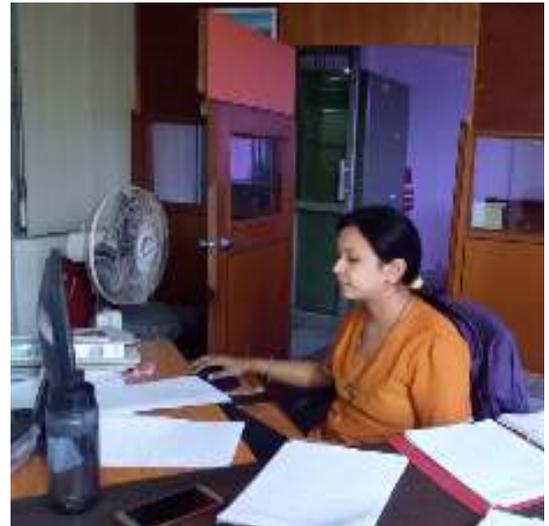
Coordination and Collaboration with Private/Public Hospitals



PBCR Interaction with Oncologists, Nursing Officers and Medical Recorders of Kathmandu Valley



Interaction with Oncologist and Nursing Officers



Coding and Entering Data in CanReg5 Software



PBCR Orientations with Female Community Health Volunteers



Data Collection from Health Facilities



Checking and Verification of Data