Pathology Laboratory Based Cancer Surveillance

'Fighting Cancer with Information'

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National Cancer Control Programme
Ministry of Health

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Message of Secretary of Health

The cancer incidence data provides epidemiological information on cancers in Sri Lanka. This information assists in strengthening prevention & control of cancers including expansion of diagnosis and treatment services for cancers.

During last 30 years, National Cancer Control Programme conducts surveillance of cancers with the information collected from patients diagnosed and treated at all government cancer treatment centers.

Strengthening surveillance of cancers is a timely need to improve the coverage & validity of information and also the comprehensiveness of such data. Capturing data from all points of diagnosis would be important in this endeavor. During the process of surveillance the confidentiality of personal identification details has been maintained.

I would like to thank the membership of the College of Pathologists and College of Haematologists for their continuous support and enthusiasm extended to the National Cancer Control Programme in the surveillance of cancers for more than 10 years.

Dr. Ravindra Ruberu
Secretary/ Ministry of Health

Message of Director General of Health Services

Accurate and timely epidemiological information is important for observing disease patterns & trends, in planning, implementing, monitoring and evaluating activities conducted by any programme. This information will also be helpful in equitable resource allocation to combat such health problems.

As Sri Lanka is heading for an epidemic of Non communicable diseases (NCD), surveillance mechanisms of noncommunicable diseases need to be further strengthened. By strengthening pathology laboratory based cancer surveillance, it may improve the coverage and timeliness of cancer incidence data.

I appreciate the support extended by Consultant histopathologists, Consultant haematologists and the pathology laboratory staff despite their busy working schedules.

I would like to thank National Cancer Control Programme for coordinating this activity

Dr. Ajith Mendis
Director General of Health Services

Message of President, College of Pathologists of Sri Lanka

I have great pleasure in issuing this brief message to the national cancer surveillance programme.

Most of the cancers are diagnosed following the histopathological confirmation. Therefore relevant patient information and histopathology reports issued from pathological laboratories are the major source of information in cancer surveillance in Sri Lanka. Members of the College of Pathologists of Sri Lanka participate actively in cancer surveillance programme conducted by the National Cancer Control Programme.

The College of Pathologists of Sri Lanka will extend their support and cooperation to strengthen the cancer surveillance in Sri Lanka.

Dr. Janakie Fernando
President, College of Pathologists of Sri Lanka

Message of President, Sri Lanka College of Haematologists

I am delighted to send this message to the National Cancer Control Programme on behalf of the Sri Lanka College of Haematologiosts. Recent studies have shown that there has been increasing incidence in non communicable diseases like cancer all over the world. In this regard, collection of authentic data throughout the country is vital to fight this killer disease.

I hope this programme will be of immense help to all medical personnel, policymakers, scientists and researchers to combat this disease.

I must say that the haematologists are playing a major role in diagnosing and providing relevant data on haematological malignancies to the National Cancer Control Programme.

The Sri Lanka of College of Haematologists is whole heartedly supporting this programme and will extend its fullest cooperation to achieve the highest standard of health of our nation.

Dr. Sasikala Suresh
President, Sri Lanka College of Haematologists

Preface of Director, National Cancer Control Programme

Surveillance of cancer is an essential strategy for the implementation of evidence based cancer control programmes. The National Cancer Control Programmme (NCCP) has been monitoring trends of cancer in Sri Lanka since 1985 and has been publishing the national cancer incidence data. Current cancer surveillance is an exclusively hospital based registry and have published cancer incidence data up to 2005.

Sri Lanka College of Pathologists has actively participated in developing pathology based cancer surveillance during last 10 years and this surveillance mechanism of cancers needs to be further strengthened including the cancer related information from all pathology laboratories in Sri Lanka.

This booklet on cancer surveillance with special emphasis on pathology based cancer surveillance was developed to sensitize consultants and relevant laboratory staff to encourage them to participate in strengthening pathology based laboratory surveillance.

Ministry of Health also explores the possibility of making cancer a notifiable disease to strengthen cancer surveillance.

NCCP expects the active participation of Consultant Pathologists / Haematologists representing different parts of the country to identify ways of strengthening cancer surveillance including obtaining data from private hospitals / private pathology laboratories. NCCP would greatly appreciate the continuous collaboration of College of Pathologists of Sri Lanka, Sri Lanka College of Haematologists and their membership for the success of this activity.

Dr. Neelamani Paranagama
Director / National cancer Control Programme

1. Introduction

1.1 Surveillance of Cancers

Surveillance of cancers is a process of systematic, continuous collection, storage, analysis, interpretation and dissemination of epidemiological information on cancer cases occurring in a particular geographic area.

Surveillance of cancers provides the information about the occurrence (incidence) of cancer, the types of cancers (morphology / histology) that occur and their locations (site / topography) within the body and the extent of cancer at the time of diagnosis (disease stage).

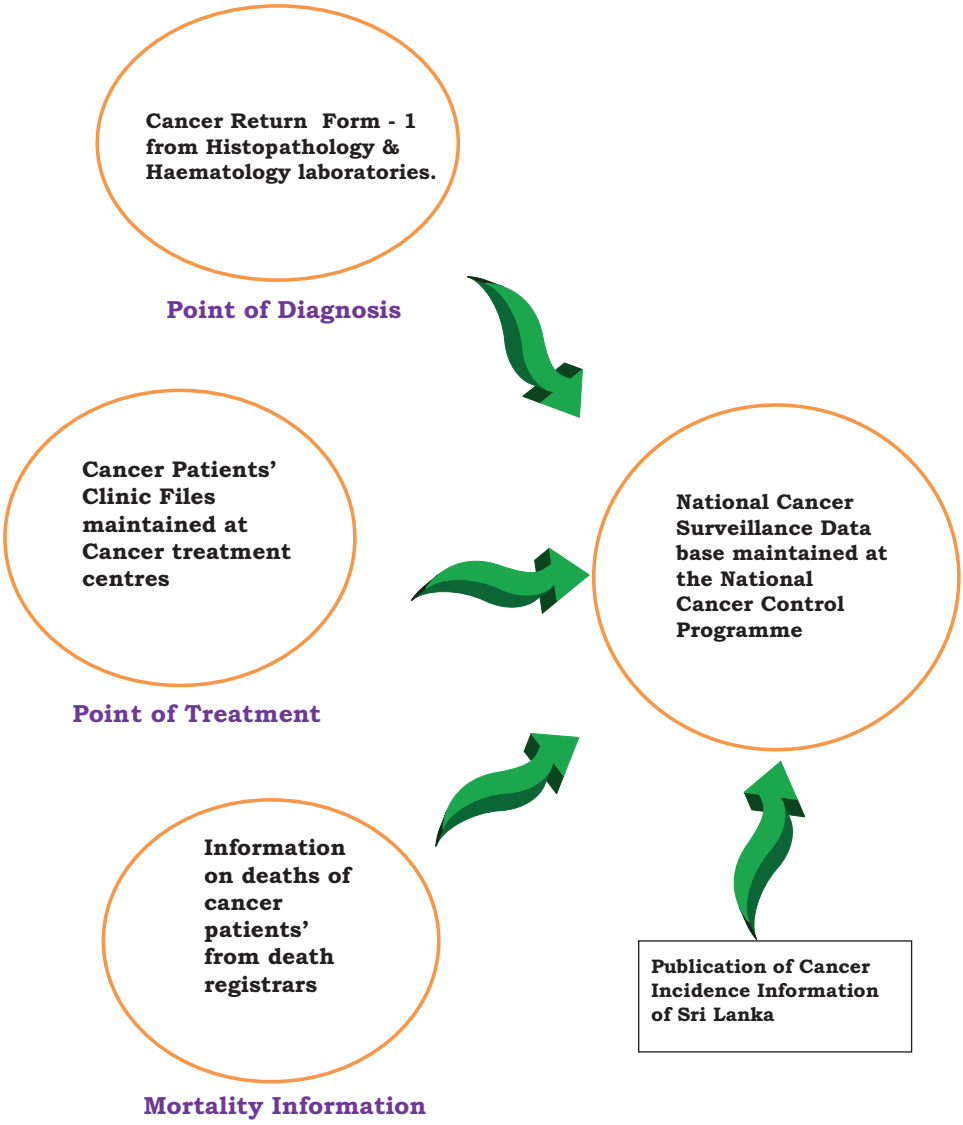
1.2 Importance of Surveillance of Cancers

- Determine cancer patterns in various sub populations.
- Guide planning, implementation and evaluation of cancer control programmes (eg. determine whether prevention, screening and treatment efforts have made sufficient impact).
- Identify priorities for allocating health resources.
- Provide evidence for advanced clinical, epidemiologic and health services research.
- Provide information for a national database of cancer incidence (National Cancer Registry) for national and international comparisons

1.3 Surveillance of Cancers in Sri Lanka

National Cancer Control Programme of Ministry of Health conducts surveillance of cancers in Sri Lanka. Cancer incidence data are extracted from cancer patients' clinic files by the staff of National Cancer Control Programme and the respective staff of each cancer treatment centre in Sri Lanka. In addition cancer incidence data are reported from pathology laboratories throughout the country to supplement the cancer incidence data. In addition it is planned to obtain cancer mortality data from Registrar General Department.

Data Flow of Cancer Surveillance System in Sri Lanka



2. Pathology Laboratory Based Cancer Surveillance

2.1 Collection of data

Pathology laboratory based cancer surveillance is the quickest method of surveillance of cancer. Since most of the cancers are diagnosed following histopathogy or haematology reports, it is essential to obtain at least basic data for cancer surveillance from pathology laboratories as shown in table 1.1.

Table 1.1 Basic data items for pathology laboratory based cancer surveillance

Variable	Remark
Patient details	
Name	Full Name
Address	Patients' usual residential address
Sex	Male/ Female
Age	In years
NIC No.	National Identity Card Number
Tumour details	
Site of Cancer **(Topography)**	Mention the anatomical site with subsite
Histology **(Morphology)**	Exact histology type with behavior & differentiation
Incidence date	Date of the first pathology report (Date of Biopsy)
Basis of Diagnosis	Cytology/ Haematology Histology of primary Histology of metastasis Autopsy with concurrent histology
Source of information	From histopathology laboratory / haematology laboratory

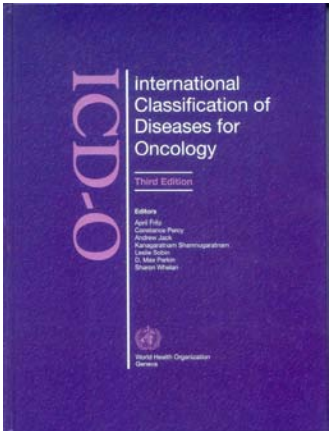
These details of diagnosed each cancer are entered into the Cancer Return Form - 1 and monthly the certified copy is send to the National Cancer Control Programme.

2.2 Coding of data

When Cancer Return Form is received by the National Cancer Control Programme, cancer registry staff code the relevant data items before entering to the data base. Coding will enable the uniformity of the classification of cancers for the storage and retrieval of information for clinical, epidemiological and research purposes.

The 10th revision of International Classification of Diseases (ICD - 10) is used for the classification of diseases and health problems in general epidemiological, clinical & health management purposes. ICD coding system is a single axis coding system as behavior & anatomic site is only used for disease classification.

Eg. Benign lung tumour D 14.3
Malignant lung tumour C 34.9



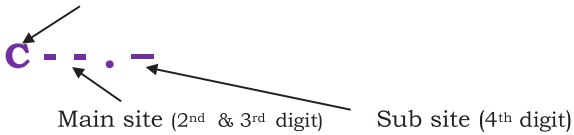
In cancer epidemiology, the International Classification of Diseases for Oncology (ICD-O) is used for coding since this coding system is a multi-axial classification of the site, morphology, behaviour and grading of neoplasms.

The International Classification of Diseases for Oncology 3rd edition (ICD-O 3) is used for coding the site (topography) and the histology (morphology) of cancers.

Topography Axis

Topography axis consists of four digit codes. This code indicates the point of origin of tumour. This is the most important data item collected and it provides the main basis of tabulation of cancer incidence data.

Common code for malignant neoplasms as in ICD -10 (1st digit)



Eg. Carcinoma in upper third of oesophagus C 15.3

Table 1.1 Codes of main sites

Code	Main Site
C00 –C14 Lip, Oral Cavity & Pharynx	
C00	Lip
C01	Base of Tongue
C02	Other & unspecified parts of tongue
C03	Gum
C04	Floor of mouth
C06	Other & unspecified parts of mouth
C07	Parotid gland
C08	Other unspecified major salivary glands
C09	Tonsils
C10	Oropharynx
C11	Nasopharynx
C12	Pyriform sinus
C13	Hypopharynx
C14	Other and ill defined sites in Lip, oral cavity and Pharynx
C15 – C26 Digestive Organs	
C15	Oesophagus
C16	Stomach
C17	Small Intestine
C18	Colon
C19	Recto sigmoid Junction
C 20	Rectum
C 21	Anus & Anal canal
C 22	Liver & Intrahepatic bile ducts
C23	Gall bladder
C 24	Other unspecified parts of biliary tract
C 25	Pancreas
C 26	Other & ill defined digestive organs
C 30 – C39 Respiratory system & intra thoracic organs	
C 30	Nasal cavity & middle ear
C 31	Accessory sinuses
C 32	Larynx
C 33	Trachea
C 34	Bronchus & lung
C 37	Thymus
C 38	Heart, mediastinum & pleura

C 39	Other and ill defined sites within respiratory system and intrathoracic organs
C 40 –C 41 Bones, joints and articular cartilage	
C 40	Bones, joints and articular cartilage of limbs
C 41	Bones, joints and articular cartilage of other and unspecified sites
C 42	Haematopoetic and Reticulo endothelial systems
C 44	Skin
C 47	Peripheral nerves and autonomic nervous system
C 48	Retroperitoneum & peritoneum
C 49	Connective, subcutaneous & other soft tissues
C 50	Breast
C 51 – C 58 Female genital organs	
C 51	Vulva
C 52	Vagina
C 53	Cervix uteri
C 54	Corpus uteri
C 55	Uterus not otherwise specified
C 56	Ovary
C 57	Other & unspecified female genital organs
C 58	Placenta
C 60 – C 63 Male genital organs	
C 60	Penis
C 61	Prostate
C 62	Testis
C 63	Other & unspecified male genital organs
C 64 – C 68 Urinary tract	
C 64	Kidney
C 65	Renal pelvis
C 66	Ureter
C 67	Bladder
C 68	Other & unspecified urinary organs
C 69 – C 72 Eye, brain & other parts of central nervous system	
C 69	Eye & adenexa
C 70	Meninges
C 71	Brain
C 72	Spinal cord, cranial nerves & other parts of central nervous system

C 73 – C 75 Thyroid & other endocrine glands	
C 73	Thyroid gland
C 74	Adrenal gland
C 75	Other endocrine glands & related structures
C 76	**Other & ill defined sites**
C 77	**Lymph nodes**
C 80	**Unknown primary site**

Morphology Axis

The morphology axis consists of 5 digit codes ranging from M-8000/0 to M-9989/3. The first four digits indicate the specific histological term.

Table 1.2 Codes of main histology types

Code	**Main histological type**
8000 - 8005	Neoplasms NOS
8010 - 8046	Epithelial neoplasms NOS
8050 - 8084	Squamous cell neoplasms
8090 - 8110	Basal cell neoplasms
8120 - 8131	Transitional cell papillomas and carcinomas
8140 - 8384	Adenomas & adenocarcinomas
8390 - 8420	Adenexal and skin appendage neoplasms
8430	Mucoepidermoid neoplasms
8440 - 8490	Cystic, mucinous and serous neoplasms
8500 - 8543	Ductal & lobular neoplasms
8550 - 8551	Acinar cell neoplasm
8560 - 8576	Complex epithelial neoplasms
8580 - 8589	Thymic epithelial neoplasms
8590 - 8671	Specialized gonadal neoplasms
8680 - 8713	Paragangliomas and glomus tumours
8720 - 8790	Naevi and melanomas
8800 - 8806	Soft tissue tumours and sarcomas NOS
8810 - 8836	Fibromatous neoplasms
8840 - 8842	Myxomatous neoplasms
8850 - 8881	Lipomatous neoplasms
8890 - 8921	Myomatous neoplasms
8930 - 8991	Complex mixed and stromal neoplasms
9000 - 9030	Fibroepithelial neoplasms
9040 - 9044	Synovial like neoplasms

9050 - 9055	Mesothelial neoplasms
9060 - 9091	Germ cell neoplasms
9100 - 9105	Trophoblastic neoplasms
9110	Mesonephormas
9120 - 9161	Blood vessel tumors
9170 - 9175	Lymphatic vessel tumours
9180 - 9243	Oseous and chrondrmatous neoplasms
9250 - 9252	Giant cell tumours
9260 - 9262	Miscellaneous bone tumours
9270 - 9342	Odontogenic tumours
9350 - 9373	Miscelleneous tumours
9380 - 9480	Gliomas
9490 - 9523	Neuroepitheliomatous neoplasms
9530 - 9539	Menigiomas
9540 - 9571	Nerve sheath tumours
9580 - 9582	Granular cell tumours & alveolar soft part sarcomas
9590 - 9729	Hodgkin & Non Hodgkin Lymphomas
9731 - 9734	Plasma cell tumours
9740 - 9742	Mast cell tumours
9750 - 9758	Neoplasms of histiocytes and accessory lymphoid cells
9760 - 9769	Immunoproliferative diseases
9800 - 9948	Leukaemias
9950 - 9964	Chronic myeloproliferative disorders
9970 - 9975	Other haematologic disorders
9980 - 9989	Myelodysplastic syndrome

The fifth digit after the slash (/) is the behaviour code as shown in table 1.3.

Table 1.3 Behaviour codes of tumours

Code	Behaviour type
0	Benign
1	Uncertain whether benign or malignant
2	Carcinoma in situ
3	Malignant
6	Metastatic site
9	Uncertain whether primary or metastatic site

A separate one-digit code (6th digit) is also provided for histologic grading of tumour (differentiation) as shown in table 1.4.

Table 1.4 Codes for differentiation of tumour

Code	Differentiation
1	Grade I – Well differentiated / differentiated not otherwise specified
2	Grade II – Moderately differentiated / moderately well differentiated / Intermediate differentiation
3	Grade III – Poorly differentiated
4	Grade IV – Undifferentiated / anaplastic
9	Grade or differentiation not determined, not stated or not applicable

Eg. Poorly differentiated infiltrating ductal carcinoma of left breast
Morphology code - 8500 / 33

2.3 Data Entering & Verification

The cancer incidence data obtained from pathology returns is entered into the tailor made software for cancer registration named 'CANREG 5' which is developed by the International Agency for Research on Cancer (IARC). This software is an open source software in which input, store, check and analyse cancer incidence data. This software contains modules to data entry, quality control, consistency checks and basic analysis of the data.

2.4 Analysis of cancer incidence data

Cancer incidence data from various sources is analyzed using 'CANREG 5' and SPSS software. The main objective of data analysis is to provide a descriptive overview of the incidence & pattern of cancers.

2.5 Dissemination of Information

Pathology laboratory based cancer incidence data will be included for the publication of National Cancer Incidence Data and will be distributed through electronic & printed format. In addition Summary of pathology laboratory based cancer surveillance will be published.

3. Limitations of existing cancer surveillance in Sri Lanka

It is estimated that current cancer surveillance system in Sri Lanka provides about 80% of incident cancer cases in Sri Lanka due to following reasons. Majority of cancer incidence data derived from cancer patients' clinic files eventhough most of the cancers are diagnosed at non cancer treatment centres. To overcome this limitation, pathology based cancer surveillance was initiated. But cancer notifications are not received from all pathological laboratories including private sector laboratories. Some early stage cancers are totally managed at non cancer wards or clinics in other hospitals. Some cancer patients seek treatment from private sector or from overseas. Those cancer patients may not be counted for incidence of cancers.

A study was conducted in Jaffna district to assess the completeness of cancer incidence data reported to national cancer surveillance system during 2006 – 2008 period from cancer treatment centre, Jaffna. In that study, it was revealed that the completeness of reporting of cancer incidence in Jaffna district was 69% (95% CI 65% - 73%). Hospital Indoor Morbidity Mortality Register (IMMR), hospital histopathology reports, information from a cancer rehabilitation & palliative care home managed by a NonGovernmental Organization and death certificate information from Registrars of births & deaths were the other sources used to extract cancer incidene data (Surenthikumaran et al, 2010).

4. Strengthening Pathology Laboratory Based Cancer Surveillance

National Cancer Control Programme in collaboration with the Sri Lanka College of Pathologists established the pathology laboratory based cancer surveillance system from year 2000. Data on cancer cases diagnosed in government (Ministry of Health units and University units) and private histopathology and haematology laboratories in the country are passively reported to the National Cancer Control Programme using 'Cancer Return Form -1' monthly.

Both government sector and private sector histopathology and haematology laboratory services were expanded during last 10 years. As regular sensitization programmes for administrators, consultants and laboratory staff were not conducted, relevant cancer incidence information was not received from newly established pathology laboratories and from laboratories with new senior staff.

Since completeness of coverage and quality of data are prime requisites for a good cancer surveillance system, pathology laboratory based surveillance of cancers also need to be expanded to include all histopathology & haematology laboratories in the country. In this regard National Cancer Control Programme of Ministry of Health is collaborating with College of Pathologists of Sri Lanka, Sri Lanka College of Haematologists Consultant histopathologists, Consultant haematologists and laboratory staff to improve the coverage and quality of pathology laboratory based cancer surveillance data.

Existing Cancer Return Form - 1 (Annex 1) which was used for pathology based cancer surveillance was updated with consultations of histopathologists and haematologists. A column on 'Address of the patient' was included in the new form (Annex 2) as this information is helpful to search duplicate at main cancer surveillance database. In addition existing partnership with private sector laboratories will be strengthened by coordinating with Consultant histopathologists, Consultant haematologists, laboratory staff and hospital administration.

Also pathology laboratory based cancer surveillance data will be incorporated to the proposed Population Based Cancer Registry which will be commenced in year 2012 (Annex 3).

Regular dialogue between Consultant Histopathologists, Consultant Haematologists and National Cancer Control Programme will be maintained to monitor, evaluate & strengthen the pathology laboratory based cancer surveillance in Sri Lanka.

5. Confidentiality of cancer incidence data

Cancer is not a notifiable disease in Sri Lanka. Therefore currently case reporting is based primarily on an administrative order issued by the Secretary of Ministry of Health. National Cancer Control Programme has conducted surveillance of cancers in Sri Lanka for more than 30 years maintaining the confidentiality of personal identification data.

Eventhough the personal details of cancer patients are collected, it will be known to designated surveillance staff of the National Cancer Control Programme only. Serial numbers for each cancer case which is known only to the data coder, will be used during the stage of data entry. By that, identification of persons is protected at data analysis stage. Access to main data base will be restricted to authorized officials only.

All data containing files both in printed and electronic formats are being kept securely at the NCCP till 5 years after the publication of cancer incidence data and will be disposed under strict supervision.

Confidentiality of all records is guaranteed and no information by which respective patients can be identified would not be released or published. These data will never be used in such a way that the patients could be identified in any public presentation or publication without the express permission of respective patients.

All research projects based on cancer surveillance data will be allowed only if personal identification data is not required.

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Annex 1

P= primary S=secondary U=unknown

Cancer Return Form

Lab no. 008

20..11/.....July..... Histology/~~FNAC~~

Lab.ref.no	District	Name	Age	Gender M/F	Identification		Site	Details of diagnosis			Previous malignancy	Previous malignancy if yes			
~~2846~~					NIC	BHT		Date	p/s/u	Diagnosis		Diagnosis	place	Date	ref
2846		[redacted]	34	F		[redacted]	R/S breast	08/07/11	P	Invasive ductal Ca					
2847.		[redacted]	75	F		[redacted]	R/S breast	08/07/11	P	Invasive ductal Ca					
2848 -		[redacted]	68	F		[redacted]	L/S ~~R/S~~ breast	05/07/11	P	Invasive ductal Ca					
2850.		[redacted]													
2857.		[redacted]	67	F		[redacted]	L/S breast	11/07/11	P	Invasive ductal Ca					
2885		[redacted]	46	F		[redacted]	L/S breast		P	Invasive ductal Ca					
2888		[redacted]	48	F		[redacted]	colon	13/07/11	P	moderately differentiated adeno Ca.					
2933		[redacted]	73	F		[redacted]	Oesophagus	19/07/11	P	well to mod. differentiated squamous cell Ca.					

Annex 2

CANCER RETURN FORM - 1

Lab Number

…… *(Month & Year)*

	Patient Details						Tumour Details				H/O Previous Malignancy	
Lab.ref.no	Name	Address	Age	Sex M / F	Identification		Site	Details of Diagnosis			Yes / No	Diagnosis
					NIC No.	BHT No.		Date	Primary / Secondary/ Unknown	Histology / Morphology		

Prepared ----------

Certified ----------

Consultant Histopathologist / Consultant Haematologist

Annex 3

Data Flow of Proposed Population Based Cancer Registry in the Colombo District