Continuing Medical Education:
Cancer registration: Principles & methods

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Definitions :
Cancer Registration

The process of continuing, systematic collection of data on the occurrence and the characteristics of reportable neoplasms, with the purpose of helping to assess and control the impact of malignancies on the community is known as cancer registry.

Hospital-based cancer registry:

Record all cases in a given hospital "without" knowledge of the background population. The emphasis is on clinical care and hospital administration

Population based cancer registry:

Records all new cases in a defined population (most frequently a geographical area) General: records all cancers Specialized: records specific cancers, e.g. childhood cancer, lymphomas etc.
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The emphasis is on epidemiology and public health.

The task of the registry

Collection of data serving as basis for Individual follow-up of patients.

Reliable morbidity statistic with a view to accurate estimate of therapeutic results

Accurate evaluation of variation in incidence of malignant neoplasms, secular, geographical, occupational etc.

Establish nothing but a basis for research

Methods of data collection work

Active : Collection at source- visit, abstraction, copying.

Passive : Self-reporting by source staff copies, discharge letters etc.

Linkage :Computer assisted linkages to files containing   the   information

Table: 1

Relative Frequency of Cancer Cases: Population based Vs Hospital Registry
(The Gujarat Cancer & Research Institute 2001)

ICD10	SITE	Population Based (1998)		Hospital Based (2001)	
		M	F	M	F
COO C 14 C 01	Buccal Cavity& Pharynx (Tongue)	10.63 6.26	3.22 2.53	33.96 10.95	10.69 2.41
C 15 C 26 C 15	Digest. Org & Peritoneum (Oesophagus)	11.11 7.89	6.77 3.81	14.85 5.21	9.22 3.41
C 30 C 3b & C 39 C 34	Respiratory Organs (Lung)	0.11 7.37	3.39 2.97	15.49 11.61	3.80 2.23
C 40 C 41 C 42	Bone Bone marrow	1.04	0.53	1.73 0.02	1.18 0.00
C43 C44	Skin	1.77	1.19	1.35	1.14
C45 C49	Soft Tissue			1.71	1.43
C 50	Breast	0.18	23.76	0.38	19.96
C 53	Cervix	----	13.54	----	1.14
C 61	Prostate	2.50	----	1.42	----
C 67	Bladder	2.19	0.68	1.63	0.44
C 81- C 96	Lymhoma & Leukaemia	8.34	6.95	11.75	8.30

The Leading Sites in men were Lung, Oesophagus and Base of Tongue. In Women they were Breast, Cervix, Oesophagus & Lung.

Breast and Cervix cancer constituted 37% of all female Cancers.

Figure: 1 REGISTRY LINKS
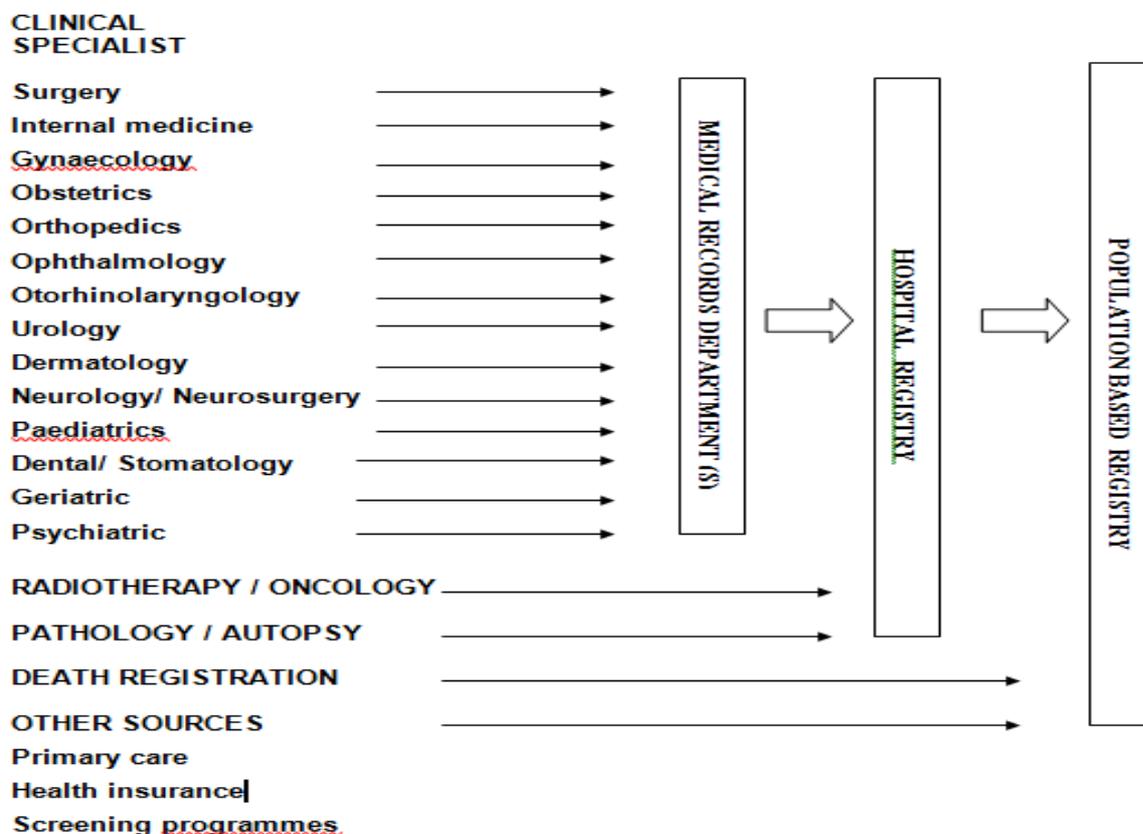
CANCER REGISTRY:
Source Documents :

Hospital:
(1) Specifically designed registration (notification/reporting) forms- completed by hospital staff, or registry staff.
(2) Copies of radiotherapy notes or summaries.
(3) Copies of discharge letters or case summaries.
(4) Hospital patient information systems.

Laboratory:
(1) Pathology department: histopathology + autopsy reports
(2) Other laboratories: hematology, clinical chemistry, imaging- must be sorted at source.

Death certificate: Mentioning cancer in part I or II

Other

Table 2 :Basic information for cancer registries

Item no	Item	Comments
The person	Personal identification	
3	Name	According to local usage
4	Sex	
5	Date of birth or age Demographic	Estimate if not known
6	Address	Usual residence
11	Ethnic group	When population consists of two or more groups
The tumor		
16	Incidence date	
17	Most valid basis of diagnosis	
20	Topography (site)	Primary tumor
21	Morphology (histology)	
22	Behavior	
35	Source of information	E.g. hospital record no name of physician

The minimum information collected is to ensure that if the same individuals are reported again to the registry, they will be recognized as being the same person. This could also be a personal identification number.

Table 3 :Details of information in the registry

| Item	DATA ITEM
Personal identification	
1	Index Number
2	Personal Identification number
3	Names
Demographic and cultural	
4	Sex
5	Date of Birth
6	Address
7	Place of Birth
8	Marital Status
9	Age at Incidence Date
10	Nationality
11	Ethnic Group
12	Religion
13	Occupation and Industry
14	Year of Immigration
15	Country of Birth of Father and or/ Mother
Tumor, investigations and treatment	
16	Incidence Date
17	Most Valid Basis of Diagnosis
18	Certainty of Diagnosis
19	Method of Detection
20	Site of Primary Tumor: Topography (ICD-O)
21	Histological Type: Morphology (ICD-O)
22	Behavior
23	Clinical Extent of Disease before Treatment
24	Surgical-cum-pathological Extent of Disease before Treatment
25	TNM Code
26	Site(s) of Distant Metastases
27	Multiple Primaries
28	Laterality
29	Initial Treatment
Outcome	
30	Date of Last Contact
31	Status at Last Contact
32	Date of Death
33	Cause of Death
34	Place of Death

SOURCES OF INFORMATION

(35.1)   Type of Source:
Whether death certificate only, doctor, laboratory, hospital or other.
(35.2)   Actual Source:
 Identity of laboratory or Hospital

MULTIPLE CANCER RULES:
Although every tumor registry has the prerogative to set its own rules, it should pay attention to the comparability of its data with those of other registries as well as consistency over time. For international comparative purposes, the IARC has suggested a rather simple set of rules, In brief, these rules state the following:

(1)   The recognition of the existence of two or more primary cancers doesn't depend on time.

(2)   A primary cancer is one of which originates in a primary site or tissue and is thus neither an extension, a recurrence nor a metastasis.

(3)   Only one tumor shall be recognized in an organ or pair of organs or tissue (as defined by the three - digit rubric of the ICD). (This rule may have to be reviewed when ICD -10 comes into effect, for bone, for example, which has been divided between two three-digit rubrics).

(4)   Rule 3 does not apply if tumors in an organ are of different histology. Table 3 (adapted from Berg, 1982) lists eight major groups of carcinomas and non-carcinomas. The specific histologies (the groups numbered 1,2,3,5,6, and 7) are considered different for the purpose of defining multiple tumors; groups 4 and 8 include tumors, which have not been satisfactorily   typed histologically and cannot therefore be distinguished from the other groups.
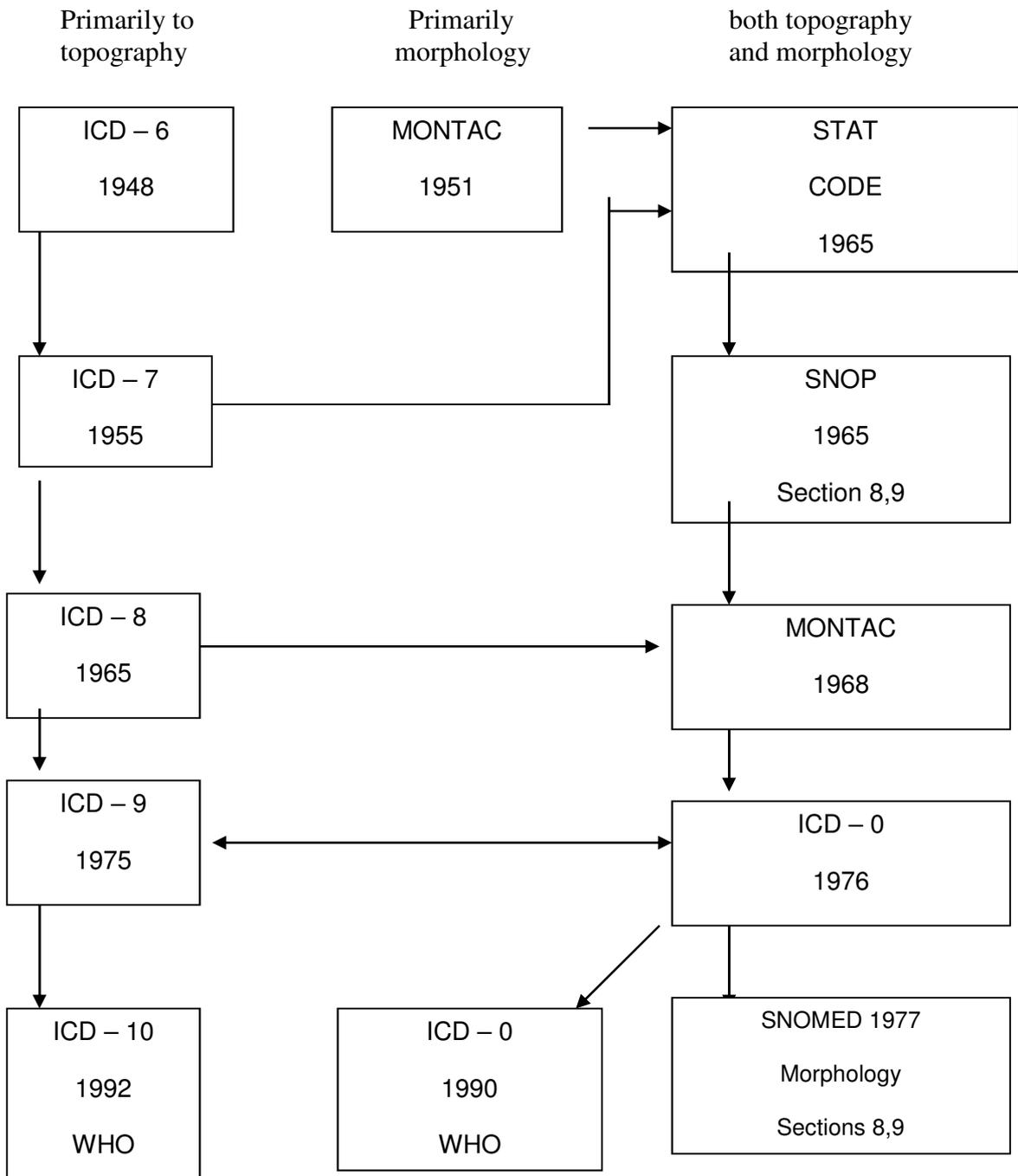
Figure 2 : RECORD LINKAGE
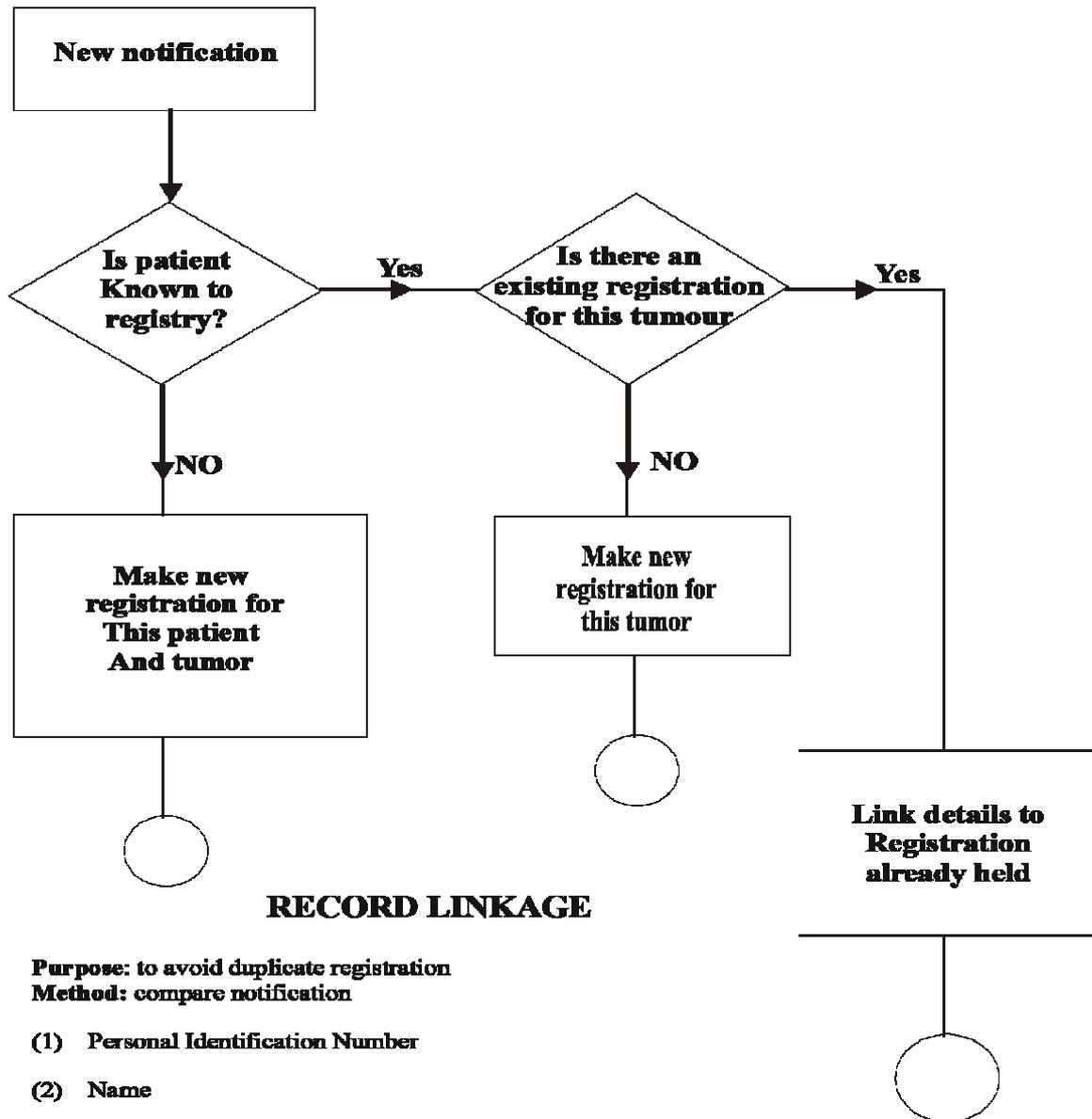
RECORD LINKAGE

Purpose: to avoid duplicate registration
Method: compare notification

(1)   Personal Identification Number

(2)   Name

(3)   Sex

(4)   Date of birth (age/date of diagnosis)

(5)   Diagnosis (consider second cancers)

(6)   Other: Address
       Place of Birth
       Etc.

Figure 3: Codes for neoplasms 1948 – 1985

Primarily to topography   Primarily morphology   both topography and morphology

ICD – 6 1948		MONTAC 1951		STAT CODE 1965

ICD – 7 1955

SNOP 1965 Section 8,9

ICD – 8 1965 → MONTAC 1968

ICD – 9 1975 ↔ ICD – 0 1976

ICD – 10 1992 WHO

ICD – 0 1990 WHO

SNOMED 1977 Morphology Sections 8,9

WHO = World Health Organization,
ACS = American Cancer Society,
CAP = College of American Pathologies,
ICD = International Classification,
MOTNAC = Manual of Turner Nomenclature and Coding,
STAT = Statistical Code for Human Tumors,
SNOP = Systematized Nomenclature of Pathology,
SNOMED = Systematized Nomenclature of Medicine

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Table 3: Groups of malignant neoplasms considered to be histologically 'different' for the purpose of defining multiple tumours (adapted from Berg, 1982)

I	Carcinomas	
(1)	A.	Squamos 805-813
(2)	B.	Adeno carcinomas 814, 816, 818-823, 825-855, 857,894
(3)	C.	Other specific carcinomas 803-804, 815,817, 824, 856. 858-867
(4)	D.	Unspecified (Carcinomas NOS) 801-802
(5)	II.	Lymphomas 959-974
(6)	III.	Sarcomas and other soft tissue 868-871, 880-892, 904-905, 912-934, 937, 949-950, 954-958.
(7)	IV.	Other specified (and site-specific) types of cancer 872-879, 893,895-898, 900-903,906-911, 935-936, 938-948, 951-953
(8)	V.	Unspecified types of cancer 800,999

The numbers refer to the first three digits of the ICD-O morphology code

QUALITY CONTROL IN CANCER REGISTRATION

(1) **Comparability of Definitions**:

    1. Classification and coding

    2. Definitions of incidence

        (i)   Multiple primaries

        (ii)   Incidental diagnosis

(2) Completeness:

1. Death certificate method

Proportion of cases <u>not</u> first notified by DC

2. Independent case ascertainment method

(i) Comparison with independent source(s)

(ii) Mortality data: the M/I ratio

(3) Historic data method

(4) **Validity**:

(5) Diagnostic criteria method

Percentage histologically verified (HV%)

Percentage registered from death certificate only (DCO%)

Percentage with unknown primary site (PSU%)

Percentage with unknown age

(6) **Reabstracted record method**

(7) **Internal consistency method**

Internal Validity checks

Invalid codes or combinations

Unlikely combinations

References:

(1)   "Cancer Registration, Principles & Methods International Agency for Research on Cancer (WHO), M. Parkin, 1992.

(2)   International Course on Cancer Epidemiology with Emphasis on Occupational Cancer and Cancer Registration., O. M. Jensen, D. M. Parkin, R. Maclennan, C. S. Mair and R.G. Skeet NIOH, Ahmedabad, India. 9-20 NOV 1992 (Training Programme)

(3)   Report of Hospital & Population based Cancer Registry (1999-2000-2001) The GCRI,*A*hmedabad**.**