

Steps for establishing Cancer Registry

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Planning a Cancer Registry

- Advisory committee
- Identify geographical area , criteria for defining residential status
- Physical location and space
- Get the population by five year age group and gender
- Identify sources of registration
- Identify personnel
- Training of personnel
- Data entry software
- Rules for variable to be collected
- Method of data collection
- Finance

Advisory committee

Identify members

Members help to identify location of registry

Suggest methods of data collection

Networking with high level officials

Help in getting support from various sources of registration

Identify geographical location and residential status procedures

Identify region for population based cancer registries.

Set up the rules for defining residential status.

Physical location and space

Identify location of registry

Identify space for the registry

Population estimates

Obtained population estimates by 5 years age group and gender from Census.

Estimate population of the year for which data is being collected.

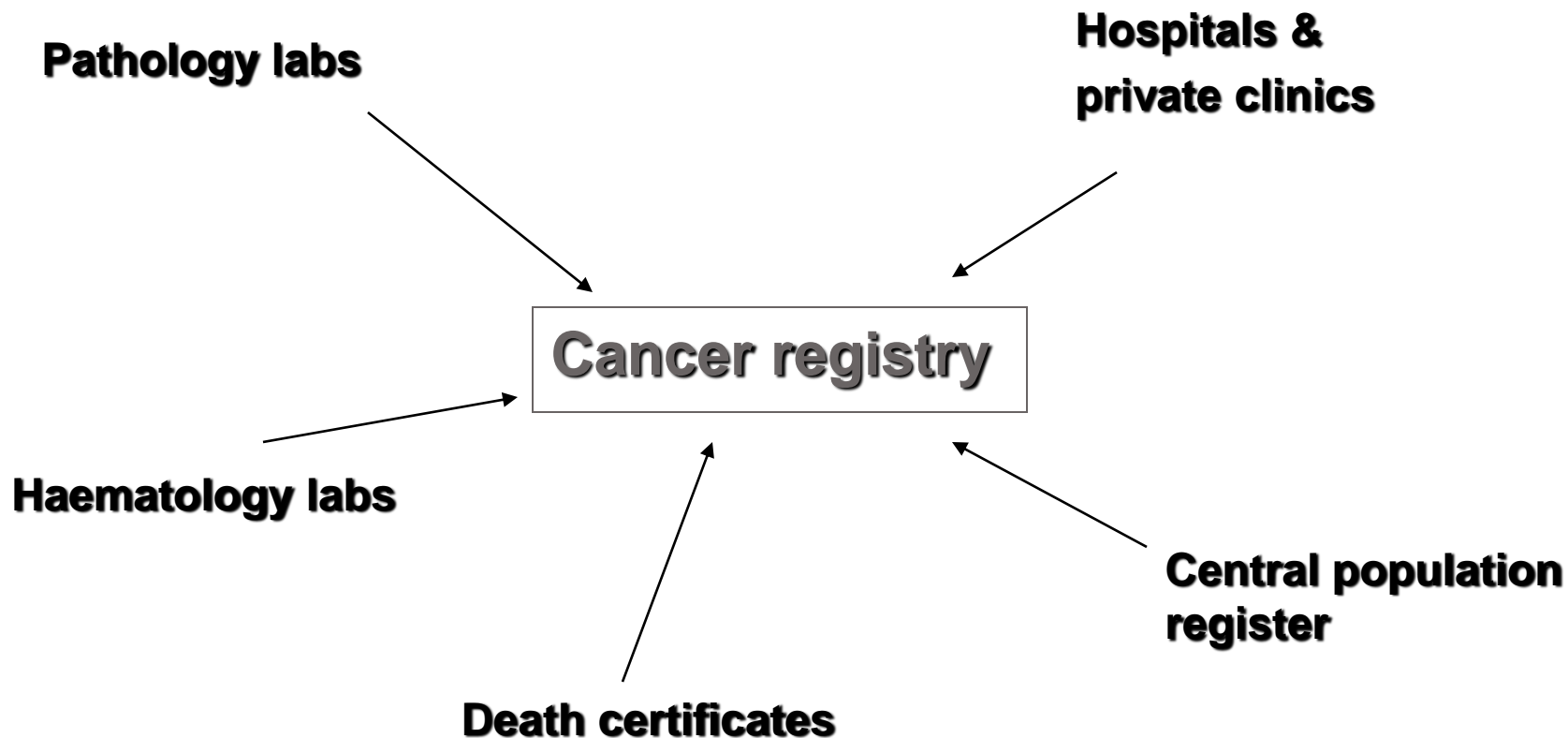
Identify source of registration and method of data collection

Prepare list of all sources of registration in the region where cancer case can be diagnosed and treated.

List frequency of the visits to these hospitals.

Explore if data can be collected passively

Sources of information



Cancer registry – sources of information

Pathology labs
haematology labs

Specialized hospital:
Cancer centres, children’s hospitals

General & teaching hospitals

Provincial/district hospitals

Private clinics

GPs

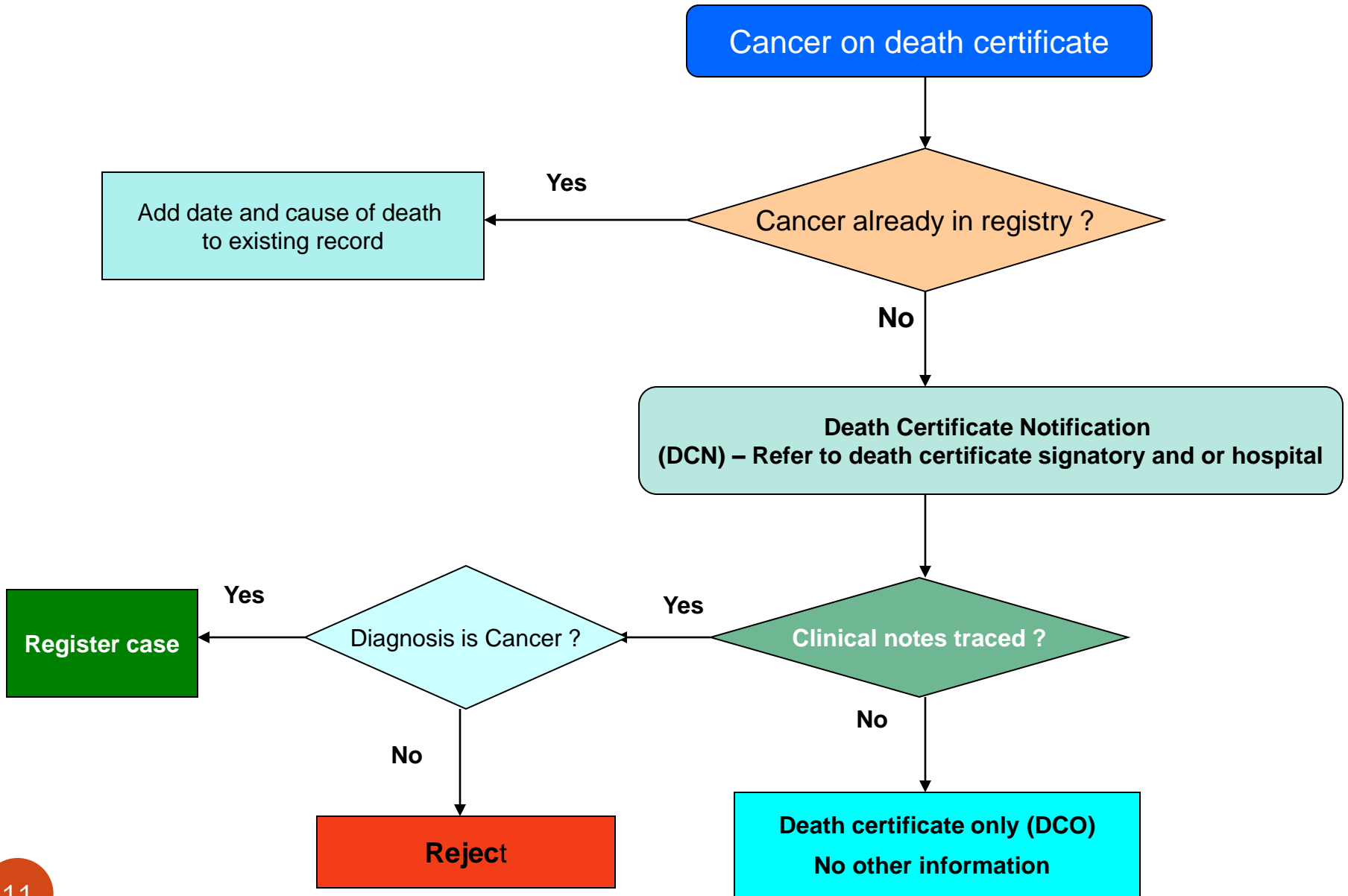
Death certificates

Primary care units

House survey

Death certificates

- All death certificates with mention of cancer (not just as underlying cause of death)
- Try to see original (or copies of original) death certificates
- Even if the diagnosis is not very accurate identifying information and date of death are (important for survival)



Identify personnel

Decide level of staff required from the registry.

Decide minimum criterion for different levels of registry staff

Training of staff

Ensure regular training.

Training in data collection procedures, software, coding and analysis.

Different types of training fro different levels of staff

Data entry software

Decide upon software to be used for the registry
CANREG-5

Define rules for various variable collected

Rules for residential status.

Rules for date of Diagnosis.

Rules for reportable neoplasm.

Rules for eliminating duplicates.

Rules for defining Multiple primaries

Methods of data collection

Active vs. Passive.

Develop logistics of data collection.

Develop quality control procedures

Finance

Cancer Registry is a regular activity.

Ensure regular allocation of funds for registry activities.

Report preparation

Define report format.

Prepare annual/Biannual reports.

Ensure distribution of reports ..

Phases in Cancer Registration

Phase 1 (first two years)

- Start registry with collection of minimum variable
- Establishing contact with sources.
- Build co-operation and establish the modus operandi for data capturing.
- Prepare preliminary report.

Phase 2 (third year)

- Demonstrate quality of cancer registration.
- Identify the gaps and try to resolve them
- Prepare report with indicator of quality (both process indicator as well as indicator of outcome)

Phases in cancer Registration

Phase 3 (third year onwards)

- Look into feasibility of adding additional variables.
- Utilization of data for descriptive Epidemiology purpose.
- Utilization of data for cancer control activities.
- Collaborate with clinicians to develop further studies.
- Collaborate with state govt. to design cancer control activities.

Indicators of well functioning registries : Phase 1

S. N.	Process indicators	Outcome indicators
1	Data capture permitted from major sources	Case finding evenly distributed over the years
2	Access to case records	Primary unknown cases minimum
3	% of cases with direct interviews	Confirmed residence for majority of cases
4	Clinicians interact with registries	
5	Govt. official support registry activity	Preparation of report and its distribution to various sources and govt. officials

Indicators of well functioning registries : Phase 2

S.N.	Process indicators	Outcome indicators
1	High % of number of cases per source	Minimum missing information
2	Re-abstraction and recoding done	Minimal error rate
3	Assessment of completeness done	Minimum cases are missing
4	Timeliness	Reports prepare in timely manner

Indicators of well functioning registries: Phase 3

S.N.	Process indicators	Outcome indicators
1	Follow up of registered cases possible	Population based survival studies initiated
2	Information on clinical variables obtained	Rates by histological type, stage etc provided
3	Identify cancer sites for primary, secondary and tertiary prevention	Government initiate cancer control measures, registry data utilized for evaluation
4	Shift from active to passive registration for some sources	Data quality improves
5	Data provided back to clinicians/sources	Clinicians analyze data according to there need.
6	Increased Interactions with all stakeholders	Advisory committee established. Report disseminated in timely manner

Report format

Executive summary

1. State profile
2. Cancer Registration and procedures
3. History and background (including description of health system, legal framework etc)
4. Cancer registration structure (Staff, location financing etc)
5. Registry procedures (population, sources of data, method of data collection, instructions for reporting, data management, confidentiality, quality control procedures, data analysis and software used, description of statistical terms, dissemination of results)
6. Results
7. Data quality (Review of comparability, completeness, accuracy and timeliness)
8. Discussions (Factors to consider while interpreting results)
9. Minimum tables (No, crude and age adjusted incidence rates by site , age and sex, cumulative incidence rates, tables for subset of populations, tables for indices of validity of diagnoses)
10. References
11. Acknowledgement

Thank you