

Cancer data collection:

Collaboration between data system to improve (data) coverage and quality

Collaborating to improve cancer-related data collection and use with other health programs and data systems

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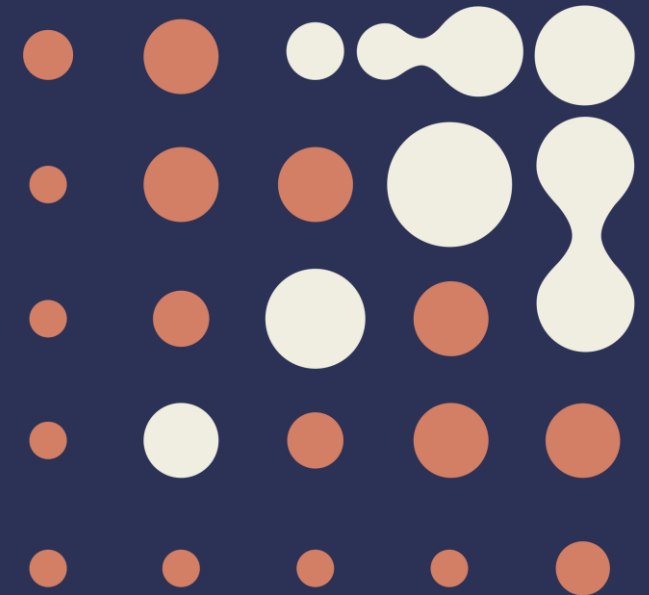
Cancer Surveillance Branch, IARC

International Agency
for Research on Cancer



ICCP ECHO Virtual Program

20 July 2022



Outline

Cancer Control

Goals: Cancer Surveillance

Descriptive burden
Prevention strategy
Quality of Care
Provision of services

Data collection

Disease Surveillance approaches

Communicable
versus
Non-Communicable Diseases

Case study

Interaction to improve data collection

Harnessing technology

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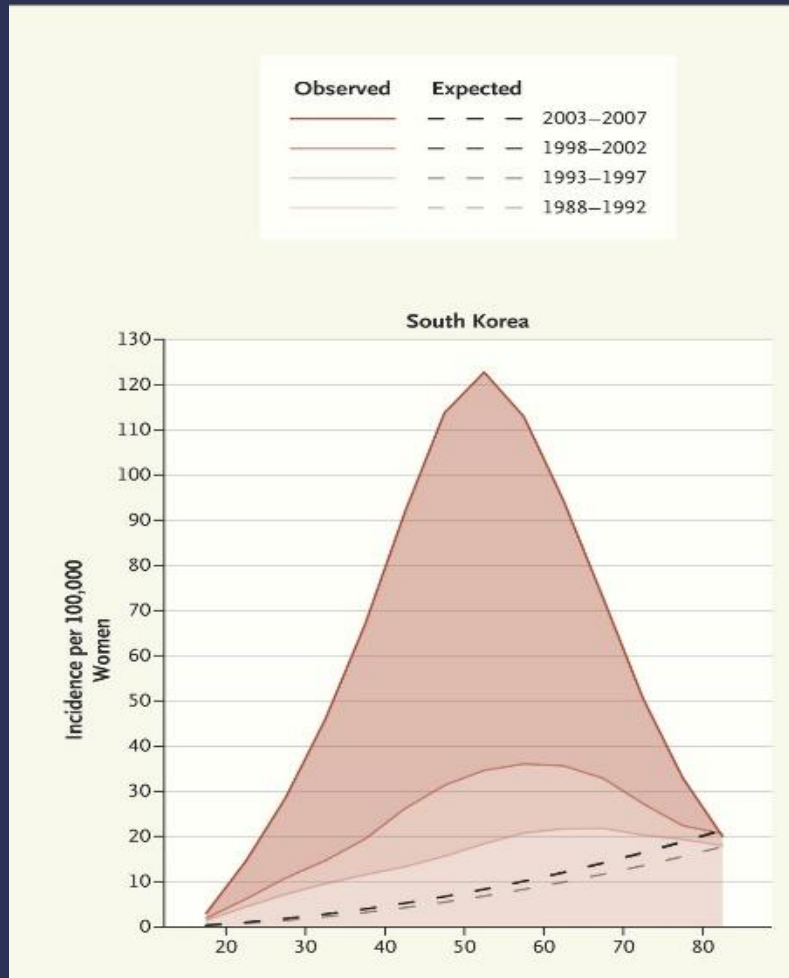
Case study

Interaction to improve data collection

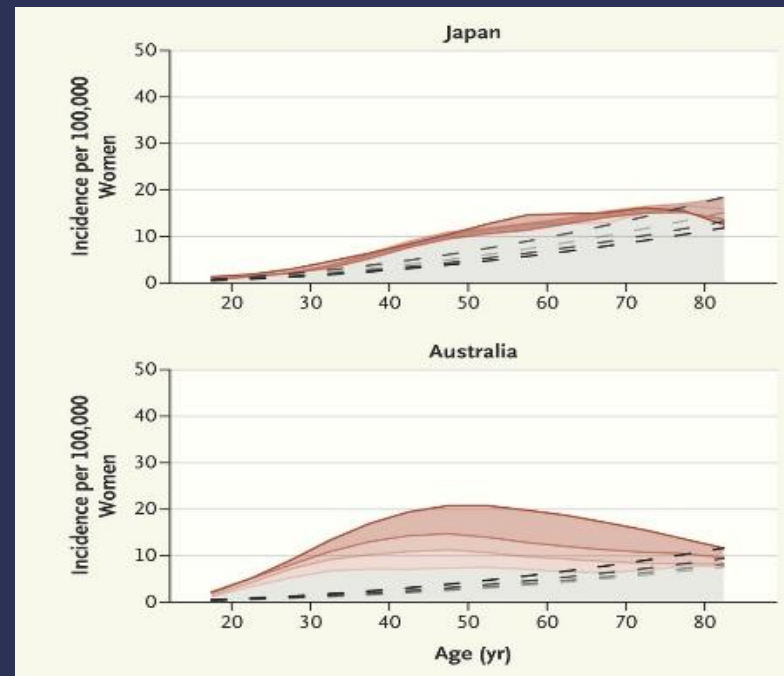
Harnessing technology

Cancer data for cancer control

(1) Describing the cancer burden



Observed versus expected changes in age-specific incidence of thyroid cancer per 100,000 women, 1988–2007.



Basic data from population-based cancer registry

- Long-standing
- Comparable (geographical and temporal)

Basic data sources:

- Pathological reports
- Imaging centres
- Hospital/Medical records
- Mortality registration

Cancer data for cancer control

(2) Quality of care, health system

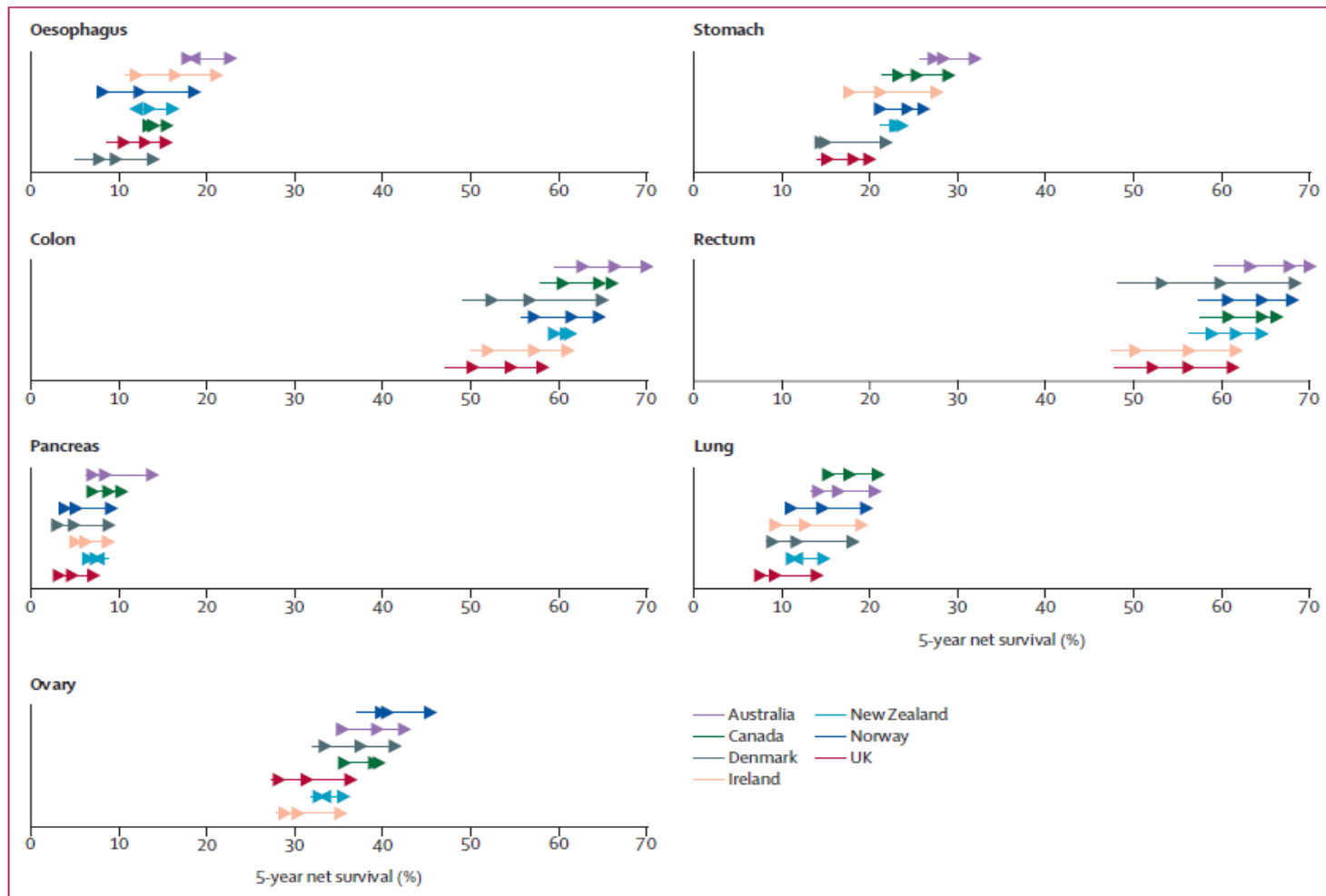


Figure 1: Age-standardised 5-year net survival by site, country, and period of diagnosis, 1995–2014

Extended data from population-based cancer registry

- Long-standing
- Comparable (geographical and temporal)
- Linkage to death register or active follow-up of cases

Basic data sources:

- Pathological reports
- Imaging centres
- Hospital/Medical records
- Mortality registration

Cancer data for cancer control

(2) Quality of care, health system

Article

Adherence to Clinical Practice Guidelines and Colorectal Cancer Survival: A Retrospective High-Resolution Population-Based Study in Spain

Population:

1050 incident CRC cases from the **PBCR** of Granada and Girona, 5-year follow-up.

Results:

Overall adherence significantly reduced the excess risk of death.

Extended data from population-based cancer registry

- Extended clinical data
- Linkage to death register or active follow-up of cases
- Detailed treatment-related information

Basic data sources:

- *Pathological reports*
- *Imaging centres*
- *Hospital/Medical records*
- *Mortality registration*

Cancer data for cancer control

(3) Provision of resources

Estimating equipment and human workforce in radiation oncology - Colombia

TABLE 1. Workforce Needs in Radiation Oncology

Criteria	Estimate for 2018	Relative Deficit of Radio-Oncologists, 2018	Estimate for 2040
Current demand (new cancer cases)	101,893		136,000 ^a
Current supply			
Radiation oncologists	101		145 ^b
Megavoltage machines	67	47 ^c	125 ^c
Radiation oncology centers ^d	53	NA	NA
Workforce needs based on international standards			
Cancer incidence (per new cancer cases) ^e	653	149	567
Megavoltage machines (per megavoltage machine)	1.5	67	1.2
Radiation oncology services ^f (per machine and per center), %	84.1	19	81.5

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Disease surveillance features:

Communicable, non-communicable disease and cancer

Surveillance aspects	Communicable Diseases	Other NCDs (CVD, Diabetes and COPD)	Cancers
Core purpose	Interruption of transmission of disease	Estimate of burden/ focus on prevalence	Estimate of burden/ focus on risk (incidence)
Main system of classification	Based on causal agent	Based on organ and function	Based on organ and morphology
	ICD-10	ICD-10	ICD-10; ICD-O-3
Aim of follow-up of cases	Identification of carrier status, Establishment of case fatality	Identification of chronic complications / Vital status	Identification of spread & recurrence / Identification of multiple primaries /Vital status
Target population	Nationwide	Regional and/or national	Regional and/or national
	including non-residents	(all residents in defined area)	(all residents in defined area)

Measures and strategies: cancer surveillance as input for national cancer control plans

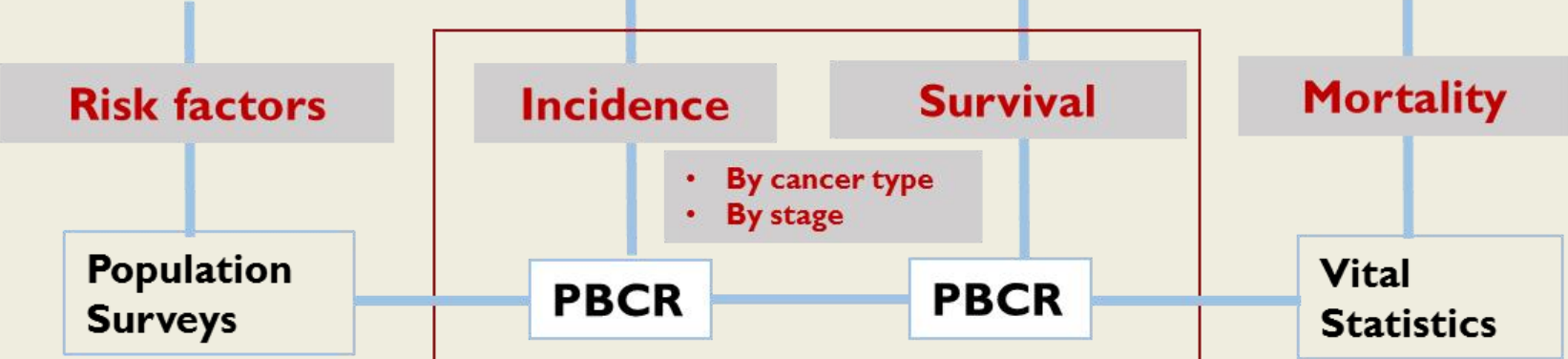
Cancer Control Measures



Population



Basic Surveillance measures



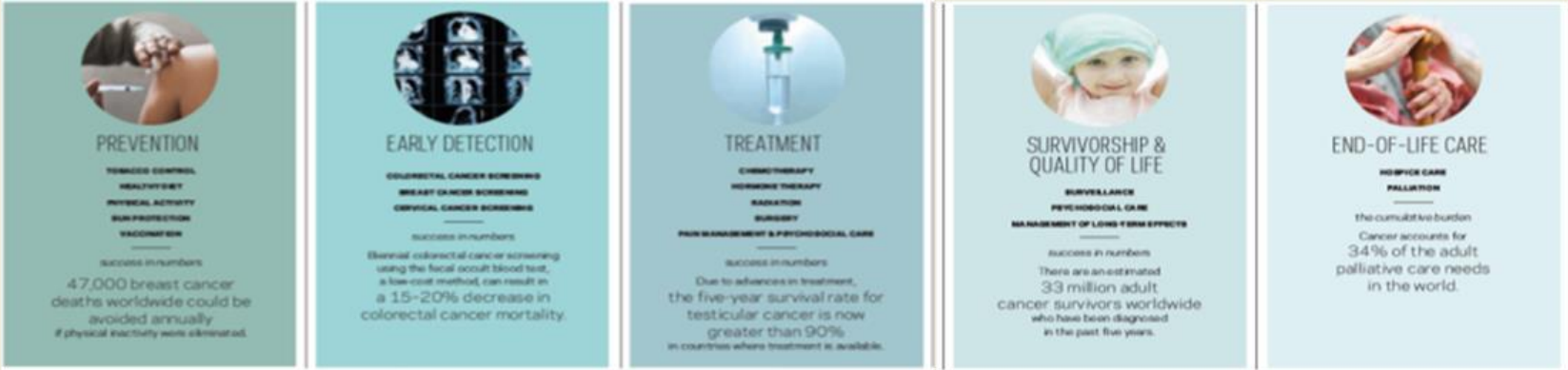
Surveillance Strategy

Extended Surveillance measures



Measures and strategies: cancer surveillance as input for national cancer control plans

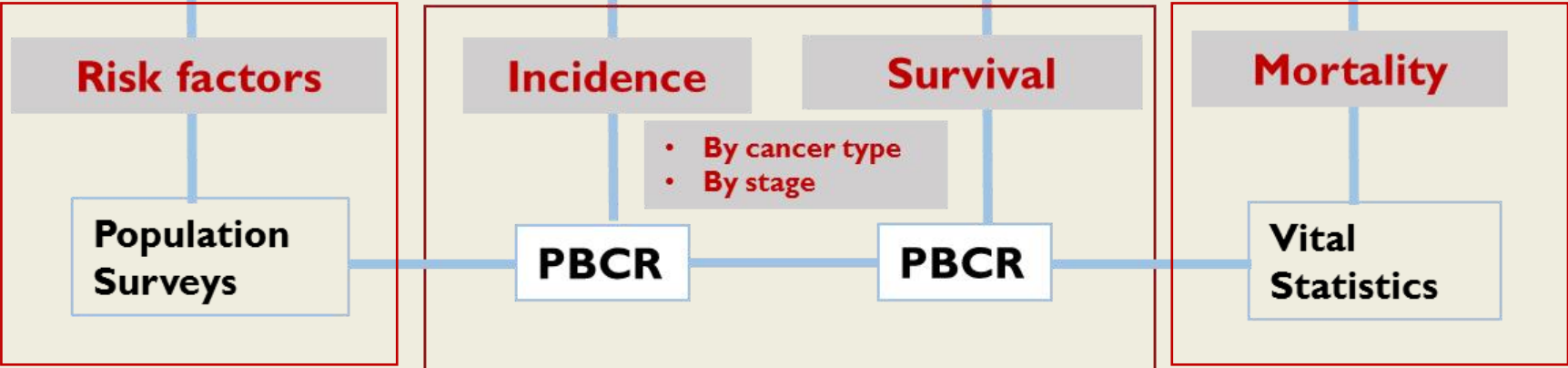
Cancer Control Measures



Population



Basic Surveillance measures



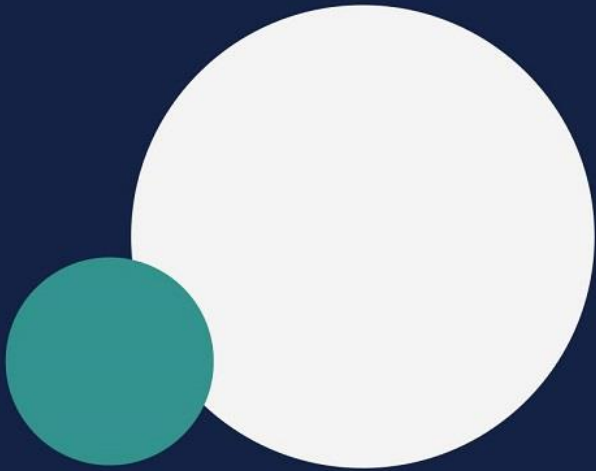
Surveillance Strategy

Extended Surveillance measures



Example:

1 in 5 cancer cases in Europe are attributable to tobacco. Tobacco smoking is the primary cause for lung cancer.



Almost 9 out of 10 cases of lung cancer can be prevented.

International Agency for Research on Cancer



World Health
Organization
REGIONAL OFFICE FOR Europe

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Rwanda Cancer Registry

Data collection Process (previous with paper forms)



Cancer registrars
+/- Selected District/Tertiary
hospital- Nurse



Cancer registrars
+/- Selected District/Tertiary
hospital- Nurse



RBC - Cancer Registrars



RBC - Cancer Registrars

Identify the
Cancer Patients

Transcribe
to NCR Form

Check the
Duplicated Record

Enter into CanReg5

- Collection from **Dept. registry book/patient files** and look for patients diagnosed with cancer
- Leverage the **pathologist lab results**

- **Summarize** the Hospital Level patient information
- **Transcribe into RBC-NCR format**
- Submit by handing to RBC cancer registrars

- Search in Canreg5 based on Name, sex, DOB, Type of Tumor and for Duplications
- Clarify with hospitals for any further information (Optional)
- Facilitate the Referral hospitals data collection

- Enter into CanReg5 .



- Manual process, Time consuming, Data accuracy issue due to multiple data source
- It is not always clearly categorized as cancer

- Data is not in the same structure as NCR Form
- Many duplicated data requiring regular check by central registrars
- Some writing errors, leading to errors or incompleteness of info

- Without Ongoing Follow - Up

Rwanda Cancer Registry

Challenges (previous with paper forms)

Cancer Registry Process

- Human resources (cancer registrars travelling to different sources for data collection)
- Financial resources (budget for transport of registrars , periderm etc)
- Geographical coverage limitation (only Kigali)
- Reliance on existing data sources including Registration Book/EMR/Patient File to identify Cancer Patients
- Manual Paper-Based Collection process
- Central Management and entered into RBC CanReg5



Inconsistency

- No national unique ID
- Recording of data is not standardized



Inefficiency

- Delay of data recording and reporting
- No real time information collected



Inaccuracy

- Cancer Registry is not cross-checked
- Less Data Validation or lack tracking in exiting EMR system

Electronic medical health data linkages

District Health Information System v2, DHIS2

- DHIS cancer module to link data w CanReg5+
- Piloted in Rwanda and the Caribbean (in total 11 countries)

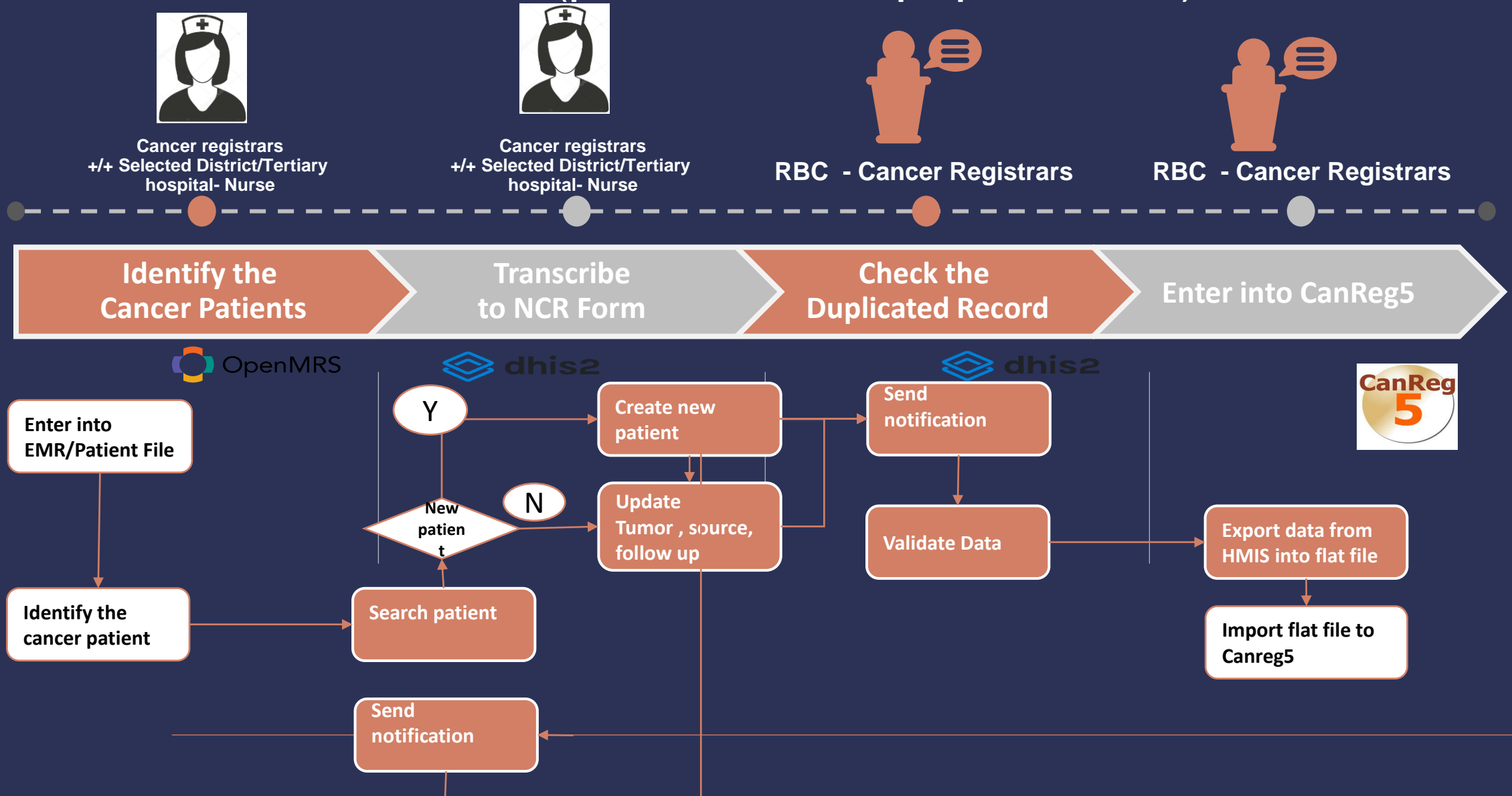
CanReg5+

- Enhanced to take advantage of modern technology using insights gained from users and the CanReg5 GICRNet
- Tool to be developed to streamline and standardize data transfer with DHIS2
- Global implementation w Bloomberg funding: roll-out; user manual; educational support; and installation package



Rwanda Cancer Registry

Data collection Process (previous with paper forms)



Conclusions

- Similarities and differences in health information/data system
- Mapping the above is key, can differ by setting
 - Overlapping goals
 - Resources (data infrastructure, financial, HR)
 - Standards
 - Training
- Opportunities for interaction between system
 - Harnessing technology
- Country (local stakeholder) commitment is key
- Extension collaboration → advocating for better health