Landscape of Cancer Registration in South Africa

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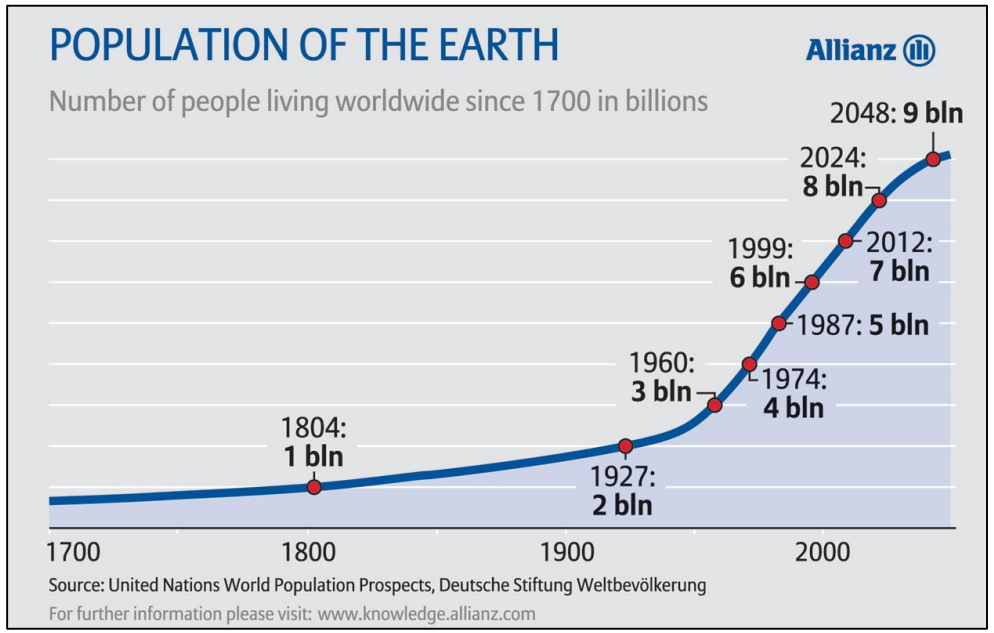
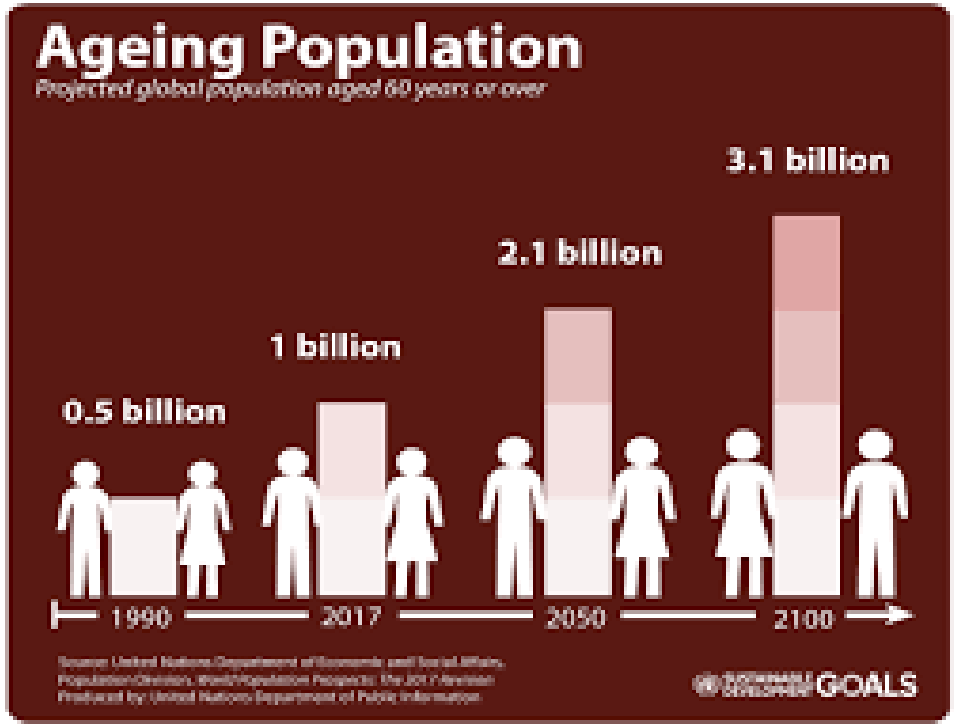
National Cancer Registry
5 September 2018
NCR Cancer Town Hall Meeting



Changing

Cancer

Burden



Cancer Epidemiology and Surveillance

- Cancer surveillance - identify changes in cancer rates
- Interventions can be implemented and resources can be allocated
- Being a chronic disease, cancer rates change gradually over time
- Cancer interventions and cancer surveillance are a long-term investments - 10-20 year trends in incidence

Uses of Cancer Registry Data

- Estimating current cancer incidence
- Examining long cancer trends
- Predicting future evolution of cancer trends
- Evaluating healthcare interventions over the medium/long term
  - Primary prevention – evaluate success of anti-tobacco interventions
  - Early detection and screening
  - Evaluating cancer care – through cancer survival

Table 2.1. Characteristics, purposes, and uses of different types of cancer registries

Registry type	Characteristics	Purpose
Hospital-based cancer registry	Collects information on all cases of cancer treated in one or more hospitals	Useful for administrative purposes and for reviewing clinical performance
Pathology-based cancer registry	Collects information from one or more laboratories on histologically diagnosed cancers	Supports the need for laboratory-based services and serves as a quick "snapshot" of the cancer profile
Population-based cancer registry	Systematically collects information on all reportable neoplasms occurring in a geographically defined population from multiple sources	The comparison and interpretation of population-based cancer incidence data support population-based actions aimed at reducing the cancer burden in the community.

Registries in South Africa

South African Paediatric Tumour Registry

National Cancer Registry

Eastern Cape Population Based Registry

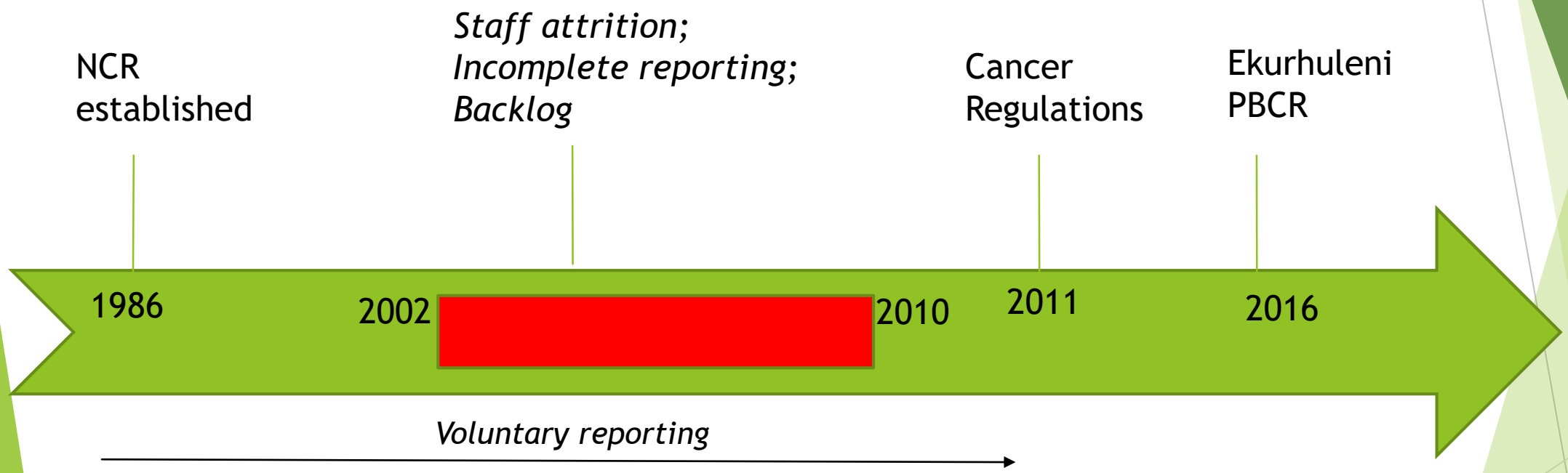
Eastern Cape Province Cancer Registry

- SAMRC Registry in former Transkei region in EC
- Initially developed to investigate the high prevalence of Oesophageal Cancer in the region
- Now fully fledged population-based cancer registry reporting its results to IARC
- 1 million people covered in 8 magisterial districts – provides data from rural populations
- Regularly reports its incidence through surveillance reports and peer-reviewed publications
- Population structure characteristic of migrant population – excess of older women and children. Shortage of working age adults and men
- Disproportionally high rate of oesophageal cancer
- Scarcity of screening and diagnostic services in this area affects the rates of cancer reported
- Not networked to the NCR

South African Paediatric Tumour Registry

- Collects and reports on malignancies in individuals younger than 15 years
- Central repository for paediatric oncology units across the country and other private practitioners who see paediatric cancer cases
- Currently hosted at the University of Pretoria
- Clinically and pathologically diagnosed cases
- South African Childhood Cancer Study Group
- Under-reporting for various reasons
  - Children dying before they seek care
  - Failure to refer to oncology centres from where reporting occurs
  - Cancer not included in differential diagnosis
  - Treatment by adult oncologists in under-served areas
- Formal reporting of paediatric cancers important for will help clarify childhood cancer epidemiology for SA

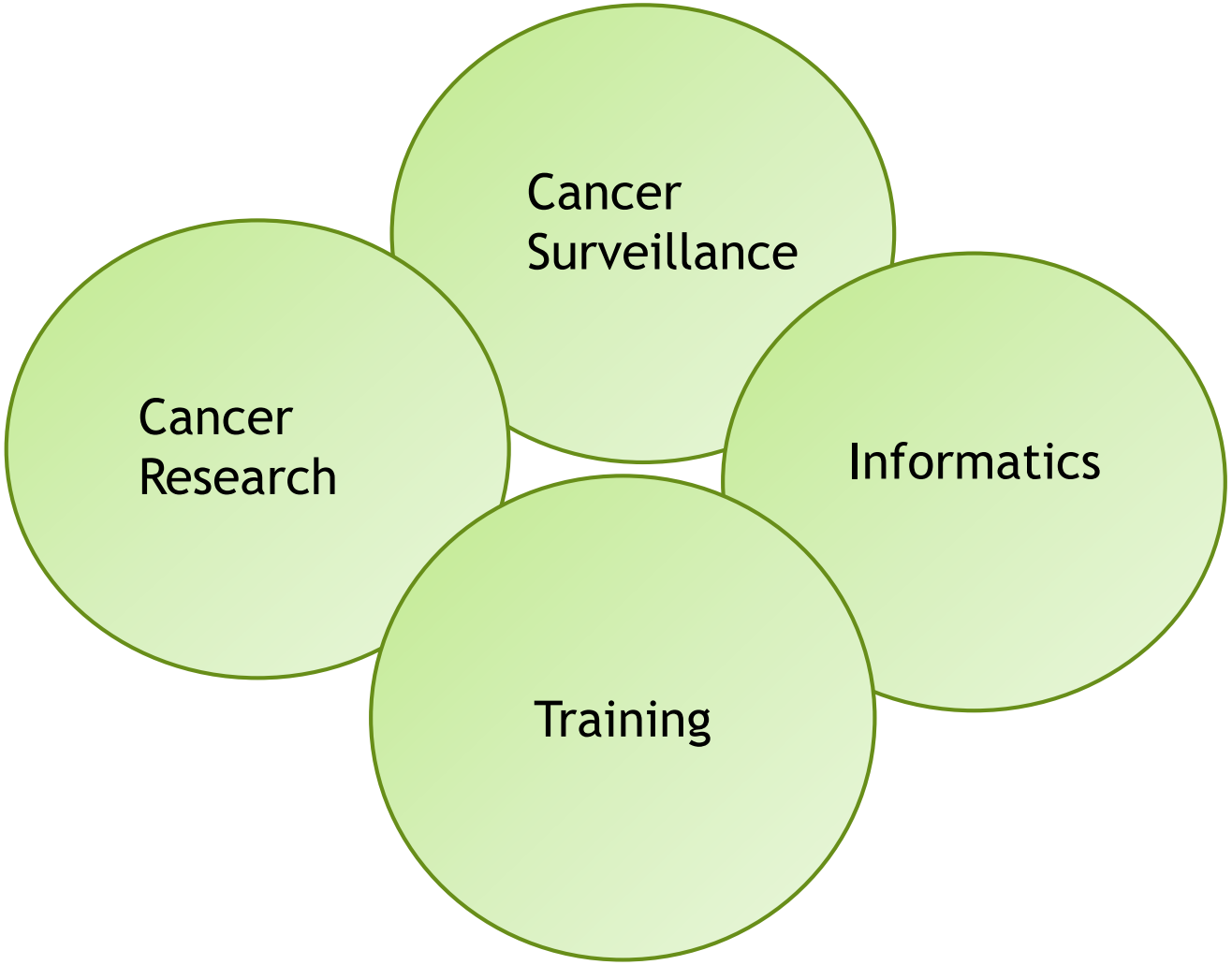
South African National Cancer Registry



Regulations Relating to Cancer Registration

- Regulation 380 of the National Health Act
  - Formally established the NCR as the cancer surveillance arm of the NDOH
  - Collect all cancer information for the country
  - Cancer reporting through the pathology-based registry *compulsory*
  - Mandated NCR to develop PBCR for the country
- A Department under the NHLS reporting to the Director of the NICD
- Directly funded by the NDOH
- Additional funding from donors – grants and industry partners

National Cancer Registry



Goal of NCR Surveillance

- Timely and high quality cancer incidence and mortality data for:
  - Cancer Policy Development
  - Planning Cancer Programs
  - Monitoring and Evaluation of Cancer Interventions

- **Pathology** Based Registration

- **Population** Based Registration

Pathology-Based Registry

Sources of Reporting

Corporate Data Warehouse

NCR

Coding

Capturing

Dataset closed

Data Cleaning

Data Analysis

10 Year Lag

4 Year Lag

Annual Cancer Statistics
www.ncr.ac.za

Outcomes and Uses

- Policies – Breast, Cervical, National Cancer Strategic Framework
- Advocacy groups
- Researchers – international collaborators from US and Europe and local collaborators
- Training of students – Masters and PhD
- African Cancer Research Network - leverage regional and international expertise
- NCR is represented on the MACC
- Reports available at www.ncr.ac.za

Ekurhuleni Population Based Cancer Registry

- National Population Based Registry –resource intensive
- Minimum of 4 PBCR's for the South African population
- Will include cases diagnosed by clinical tests and laboratory tests
- Pilot site in Ekurhuleni funded by the SAMRC
  - 3 million inhabitants
  - Diverse ethnic groups
  - Well demarcated area
  - 6 public hospitals, 3 referral centres, 4+ private facilities providing oncology
- First year's data (2017) has been analysed
- 2080 cancers collected – prostate, breast, colorectal, cervical
- Optimise data collection in this area – missing reporting sources
- Shown that PBCR is feasible in local context

Future Aims

- Pathology Based Registry – reduce lag time to under 3 years
  - Data seamlessly fed into the NCR application from NHLS and private laboratories
  - Eliminate data capturing step
  - Stakeholder feedback on data output
- Ekurhuleni Population Based Registry
  - Optimise data collection in the Ekurhuleni Region
  - Routine quality assurance methodology implemented
  - Reporting to CI5 – SA cancer incidence estimates reported to IARC/WHO
- KZN Population Based Registry

Acknowledgments

- NHLS/NICD
- National Department of Health : Non-Communicable Diseases Directorate
- Campaign for Cancer
- SAMRC
- Industry donors
- CANSA
- Academics who have supported us - Prof Paul Ruff
- All our stakeholders
- Staff of the NCR