

# Cancer registries in India – data collection, challenges and steps to strengthen registries and improve cervical cancer data collection

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## Uses of cancer registries towards cervical cancer control

1. Assessing incidence profiles
2. Assessing time trends
3. Benchmarking survival
4. Differentiating estimated and observed incidence
5. Monitoring the long-term impact of scaleup of activities- how far are countries from the elimination target?
6. Estimating the number of cervical cancer cases that could be averted through HPV vaccination
7. Monitoring the short-term impact of scaleup of interventions: precancerous conditions of the cervix
8. Monitoring treatment of screened populations and those with invasive cancers

# National Cancer Registry Program (NCRP), India

Collects information on all confirmed invasive cancers for all anatomical sites

NCRP  
started in 1981

190

Hospital Based Cancer Registries



38

Population Based Cancer Registries

Collate information on **diagnosis staging treatment modalities and outcomes** of patients in registry hospitals

**Patterns of care and survival of cancer cervix**

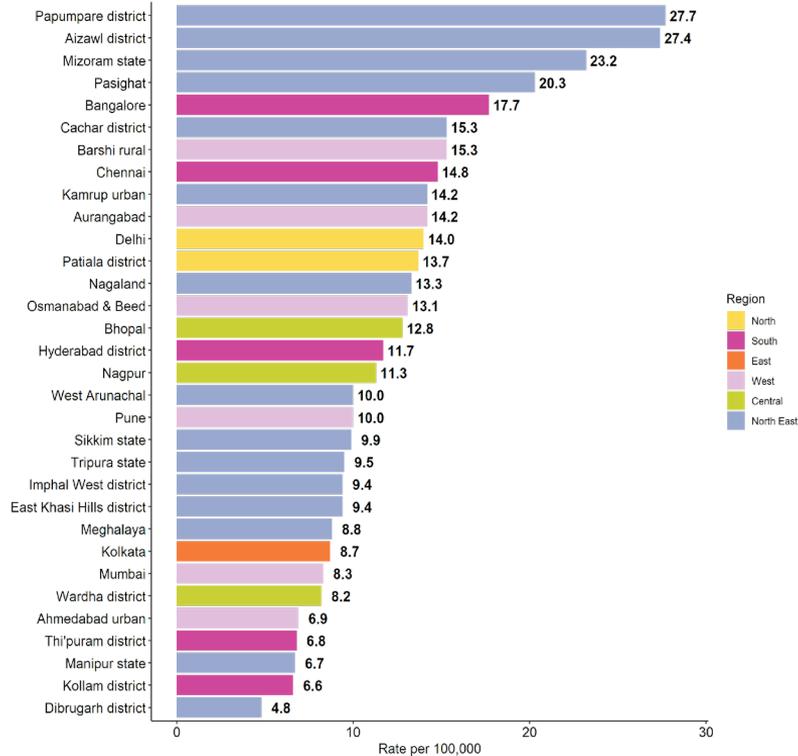
**Cancer incidence, mortality, trends and survival** in well-defined geographical area population

**Population Based Cancer Cervix Survival**

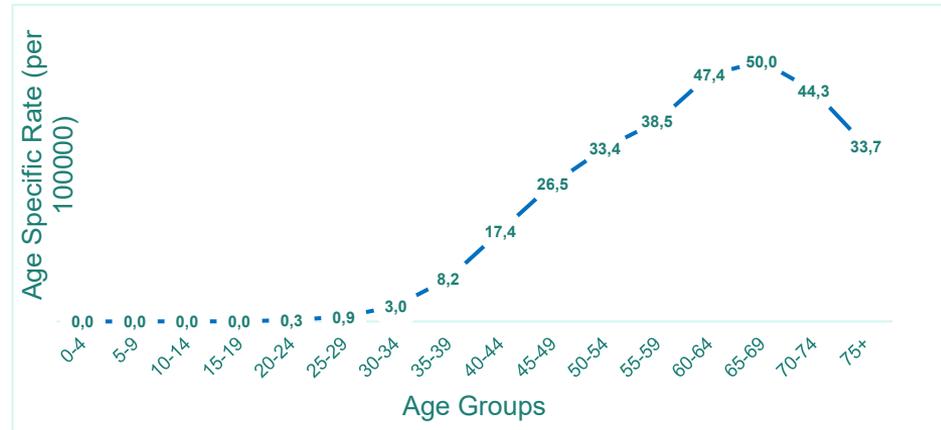
Together, both inform cancer prevention and control efforts in the country

# Epidemiology of Cervical cancer in India

## Age Adjusted Incidence Rates (AARs) of PBCRs Cervical cancer (ICD – 10: C53)

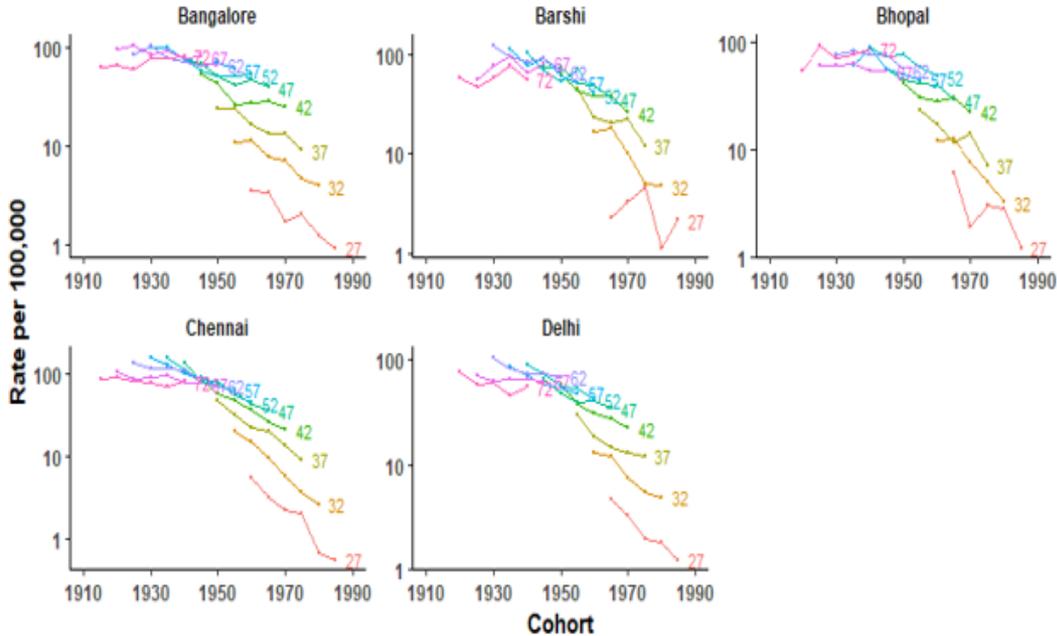


## Age-specific incidence rates of cervical cancer in India (estimates for 2020)

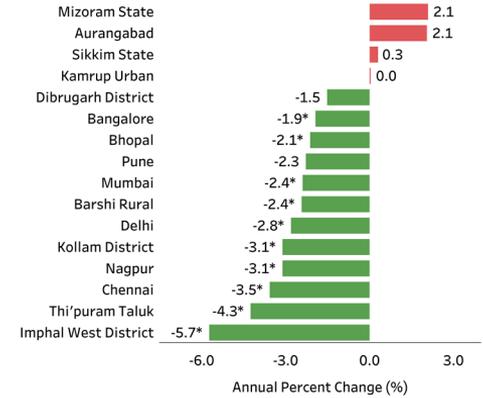


# Trends in Cervical cancer incidence

## Age specific incidence rates of cervical cancers vs birth cohort



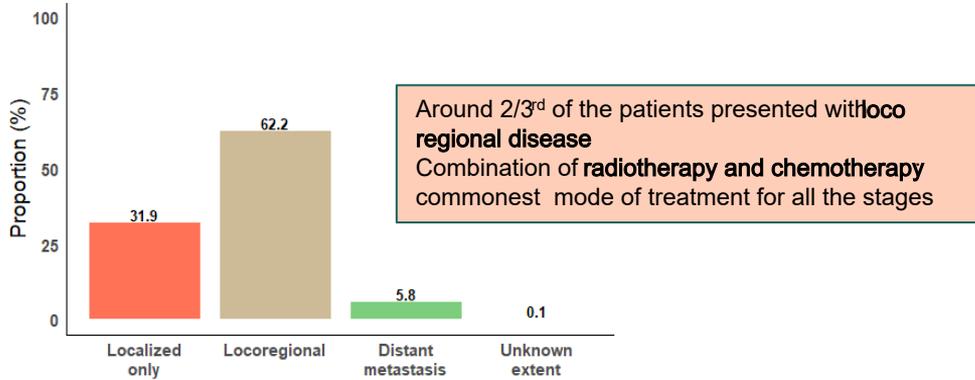
## Annual Percent Change (APC) in Age Adjusted Incidence Rates



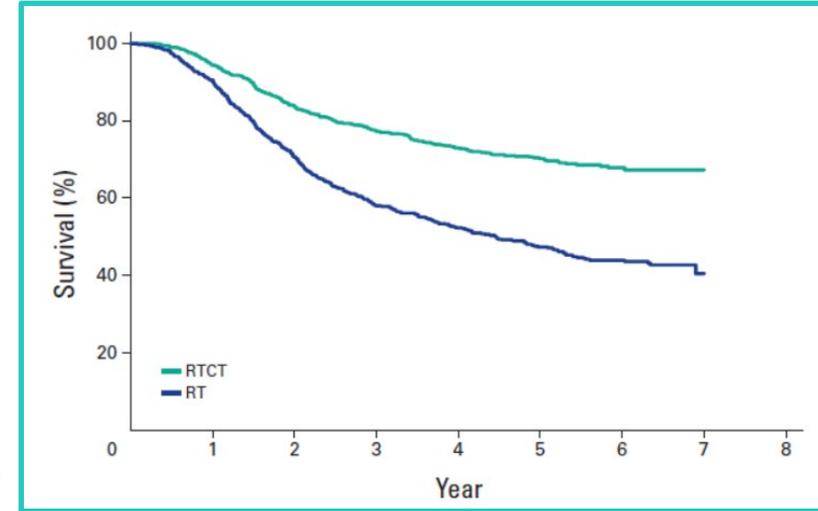
Increase in APC, Decrease in APC; \*Significant increase or decrease in APC at 95% confidence level

# Clinical Extent of Disease, Treatment and Hospital Based Survival

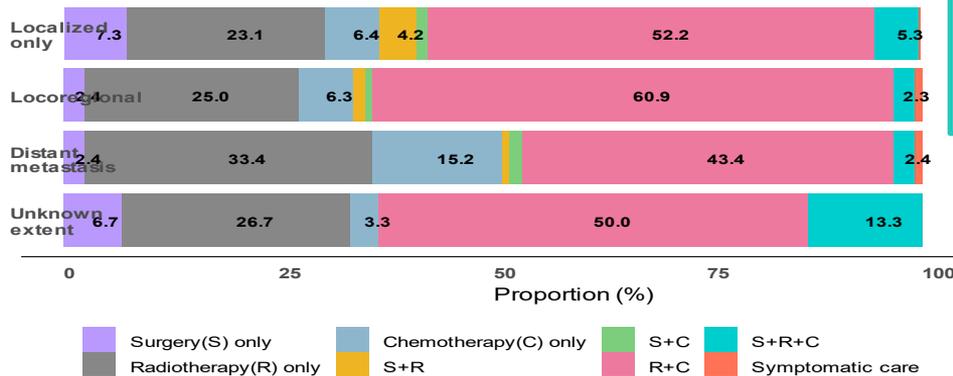
Relative proportion (%) by clinical extent of disease



Survival of patients received radiotherapy (RT) alone and radiotherapy & chemotherapy (RTCT)



Types of treatment according to clinical extent of disease (%)

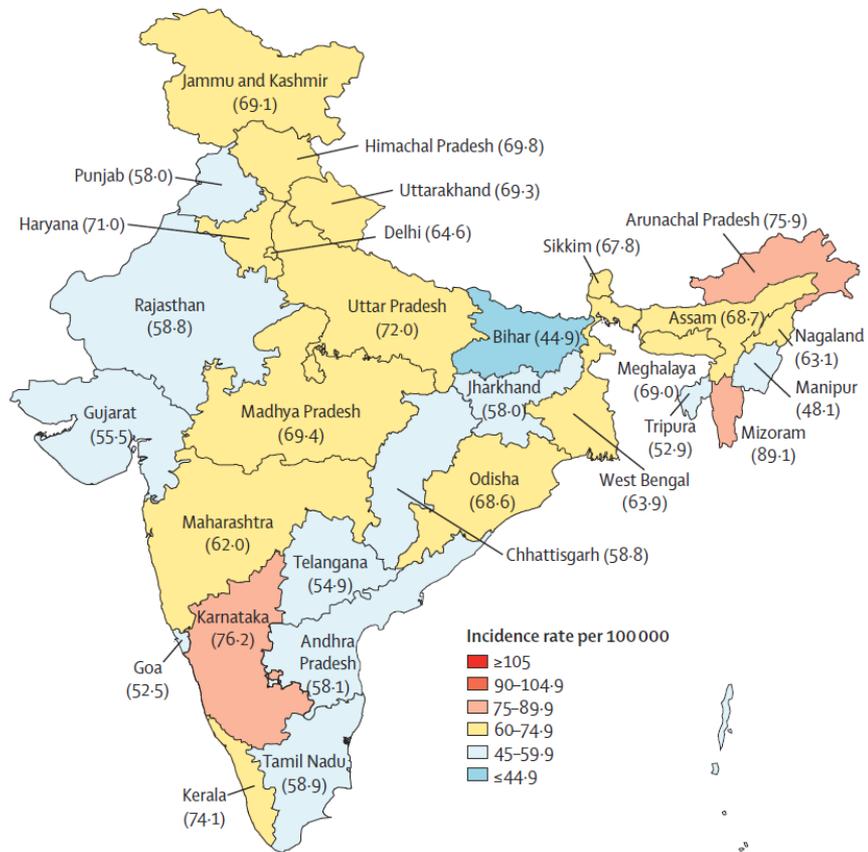


Significantly better survival (5 year) was observed with RTCT than with RT alone

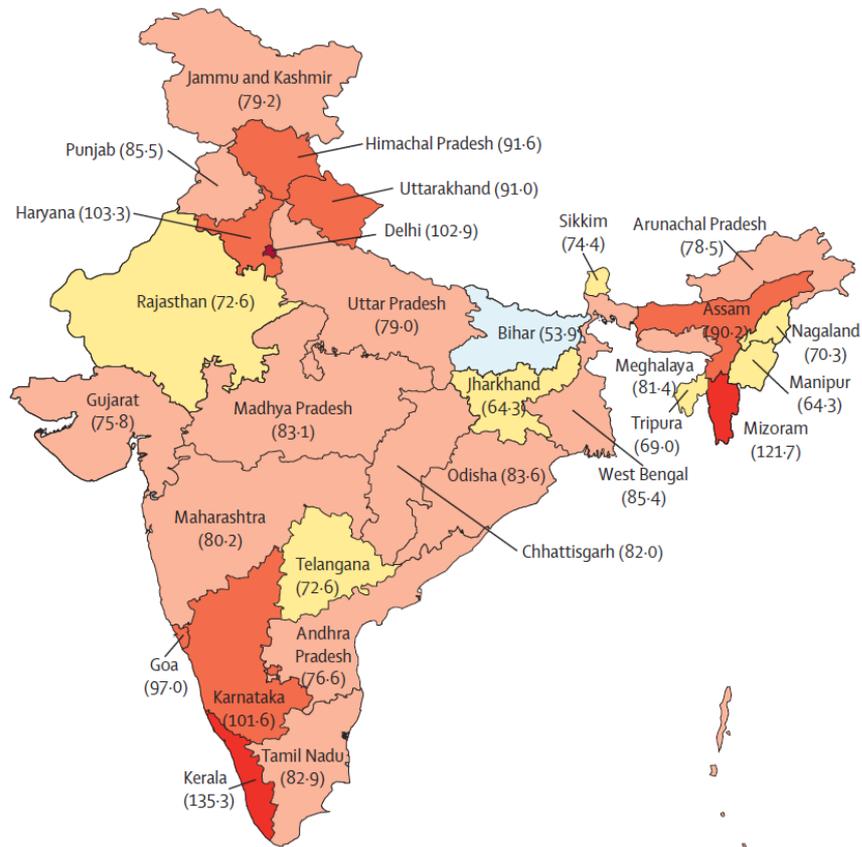
*Clinicopathological Profile of Cancers in India: A Report of the Hospital Based Cancer Registries, 2021*  
Nandakumar A, et al (2015). Concurrent chemoradiation for cancer of the cervix: results of a multiinstitutional study from the setting of a developing country (India). *J Glob Oncol*

# STATE WISE CHANGE IN CRUDE ANNUAL INCIDENCE RATE OF ALL CANCERS, INDIA, 1990 AND 2016

1990



2016



The burden of cancers and their variations across the states of India: the Global Burden of Disease Study 1990-2016. Lancet Oncol. 2018

# Ranking of death rate of the leading cancers in India

| Cancer types                  | India          | Bihar | Jharkhand | Uttar Pradesh | Rajasthan | Meghalaya | Assam | Chhattisgarh | Madhya Pradesh | Odisha | Arunachal Pradesh | Mizoram | Nagaland | Uttarakhand | Gujarat | Tripura | Sikkim | Manipur | Haryana | Delhi | Telangana | Andhra Pradesh | Jammu & Kashmir | Karnataka | West Bengal | Maharashtra | Other UTS | Himachal Pradesh | Punjab | Tamil Nadu | Goa | Kerala |   |
|-------------------------------|----------------|-------|-----------|---------------|-----------|-----------|-------|--------------|----------------|--------|-------------------|---------|----------|-------------|---------|---------|--------|---------|---------|-------|-----------|----------------|-----------------|-----------|-------------|-------------|-----------|------------------|--------|------------|-----|--------|---|
|                               | <b>Females</b> |       |           |               |           |           |       |              |                |        |                   |         |          |             |         |         |        |         |         |       |           |                |                 |           |             |             |           |                  |        |            |     |        |   |
| Breast                        | 1              | 1     | 1         | 2             | 1         | 2         | 1     | 1            | 1              | 1      | 2                 | 3       | 2        | 2           | 1       | 1       | 4      | 2       | 2       | 1     | 2         | 2              | 3               | 1         | 1           | 1           | 2         | 2                | 1      | 1          | 1   | 1      | 1 |
| Cervical                      | 2              | 2     | 2         | 3             | 3         | 4         | 4     | 2            | 2              | 5      | 3                 | 4       | 3        | 3           | 2       | 2       | 7      | 3       | 5       | 3     | 3         | 3              | 6               | 2         | 2           | 2           | 4         | 3                | 2      | 2          | 5   | 2      |   |
| Stomach                       | 3              | 7     | 3         | 1             | 2         | 3         | 8     | 3            | 4              | 2      | 1                 | 2       | 1        | 1           | 10      | 7       | 1      | 6       | 1       | 12    | 1         | 1              | 1               | 3         | 3           | 8           | 1         | 1                | 10     | 4          | 2   | 8      |   |
| Colon and rectum              | 4              | 4     | 4         | 4             | 5         | 8         | 5     | 5            | 5              | 3      | 9                 | 5       | 5        | 5           | 3       | 4       | 10     | 5       | 4       | 6     | 5         | 4              | 4               | 6         | 4           | 3           | 5         | 6                | 3      | 3          | 7   | 3      |   |
| Lip and oral                  | 5              | 11    | 11        | 6             | 10        | 5         | 10    | 6            | 3              | 4      | 13                | 17      | 15       | 9           | 5       | 9       | 14     | 15      | 6       | 11    | 6         | 6              | 16              | 5         | 8           | 7           | 3         | 11               | 16     | 7          | 3   | 5      |   |
| Lung                          | 6              | 3     | 7         | 8             | 7         | 7         | 7     | 10           | 9              | 8      | 6                 | 1       | 4        | 4           | 6       | 6       | 2      | 1       | 7       | 5     | 9         | 9              | 2               | 9         | 5           | 6           | 6         | 9                | 7      | 6          | 8   | 6      |   |
| Ovarian                       | 7              | 8     | 6         | 9             | 8         | 11        | 6     | 9            | 7              | 9      | 4                 | 9       | 8        | 8           | 7       | 8       | 9      | 7       | 10      | 4     | 8         | 8              | 8               | 8         | 7           | 5           | 10        | 7                | 6      | 5          | 6   | 4      |   |
| Other Pharynx                 | 8              | 16    | 8         | 5             | 4         | 9         | 9     | 4            | 10             | 6      | 16                | 12      | 16       | 6           | 14      | 14      | 11     | 20      | 3       | 17    | 4         | 5              | 5               | 4         | 13          | 16          | 7         | 4                | 20     | 14         | 4   | 18     |   |
| Gallbladder and biliary tract | 9              | 6     | 5         | 7             | 6         | 6         | 3     | 7            | 6              | 7      | 8                 | 8       | 9        | 7           | 13      | 3       | 5      | 4       | 9       | 2     | 7         | 7              | 9               | 10        | 6           | 14          | 9         | 8                | 5      | 16         | 9   | 17     |   |
| Oesophageal                   | 10             | 5     | 20        | 12            | 9         | 1         | 2     | 8            | 8              | 13     | 7                 | 7       | 6        | 11          | 4       | 5       | 3      | 9       | 8       | 8     | 19        | 18             | 7               | 7         | 11          | 4           | 12        | 5                | 4      | 8          | 12  | 15     |   |
| <b>Males</b>                  |                |       |           |               |           |           |       |              |                |        |                   |         |          |             |         |         |        |         |         |       |           |                |                 |           |             |             |           |                  |        |            |     |        |   |
| Lung                          | 1              | 1     | 3         | 3             | 3         | 3         | 3     | 3            | 3              | 2      | 3                 | 2       | 5        | 1           | 2       | 1       | 4      | 1       | 2       | 1     | 2         | 2              | 2               | 3         | 1           | 1           | 2         | 2                | 1      | 1          | 4   | 1      |   |
| Stomach                       | 2              | 4     | 1         | 1             | 2         | 4         | 5     | 1            | 4              | 1      | 1                 | 1       | 1        | 2           | 9       | 5       | 1      | 2       | 3       | 9     | 1         | 1              | 1               | 2         | 2           | 6           | 3         | 3                | 7      | 2          | 1   | 4      |   |
| Other Pharynx                 | 3              | 11    | 9         | 2             | 1         | 2         | 2     | 2            | 1              | 3      | 5                 | 4       | 4        | 3           | 3       | 2       | 7      | 11      | 1       | 5     | 4         | 3              | 3               | 1         | 4           | 8           | 4         | 1                | 10     | 6          | 2   | 6      |   |
| Lip and oral cavity           | 4              | 8     | 2         | 4             | 4         | 5         | 4     | 4            | 2              | 4      | 6                 | 7       | 8        | 4           | 1       | 4       | 6      | 9       | 4       | 2     | 9         | 9              | 10              | 4         | 3           | 2           | 1         | 4                | 6      | 3          | 5   | 2      |   |
| Colon and rectum              | 5              | 3     | 4         | 5             | 5         | 7         | 6     | 5            | 6              | 5      | 7                 | 6       | 7        | 5           | 5       | 6       | 5      | 3       | 6       | 7     | 6         | 6              | 8               | 5         | 5           | 4           | 7         | 7                | 3      | 4          | 8   | 3      |   |
| Oesophageal                   | 6              | 2     | 16        | 11            | 6         | 1         | 1     | 12           | 7              | 10     | 4                 | 3       | 2        | 10          | 4       | 3       | 2      | 5       | 5       | 6     | 16        | 15             | 5               | 8         | 10          | 3           | 13        | 5                | 2      | 5          | 13  | 9      |   |
| Larynx                        | 7              | 6     | 6         | 6             | 7         | 6         | 7     | 6            | 5              | 6      | 8                 | 9       | 9        | 6           | 7       | 7       | 8      | 13      | 7       | 4     | 5         | 5              | 7               | 7         | 6           | 10          | 10        | 9                | 12     | 10         | 7   | 8      |   |
| Liver                         | 8              | 5     | 5         | 7             | 8         | 8         | 9     | 7            | 9              | 7      | 2                 | 5       | 6        | 7           | 12      | 9       | 3      | 7       | 8       | 12    | 3         | 4              | 4               | 6         | 8           | 7           | 6         | 6                | 8      | 8          | 3   | 5      |   |
| Prostate                      | 9              | 7     | 7         | 8             | 9         | 9         | 8     | 8            | 8              | 8      | 11                | 11      | 10       | 8           | 8       | 8       | 9      | 4       | 9       | 10    | 7         | 7              | 6               | 9         | 7           | 5           | 11        | 8                | 4      | 7          | 6   | 7      |   |
| Leukaemia                     | 10             | 9     | 8         | 9             | 11        | 10        | 11    | 9            | 10             | 9      | 10                | 10      | 11       | 9           | 6       | 10      | 11     | 8       | 10      | 3     | 8         | 8              | 9               | 10        | 9           | 9           | 9         | 10               | 5      | 9          | 9   | 11     |   |

1-2   3-5   6-9   10-14   15-20

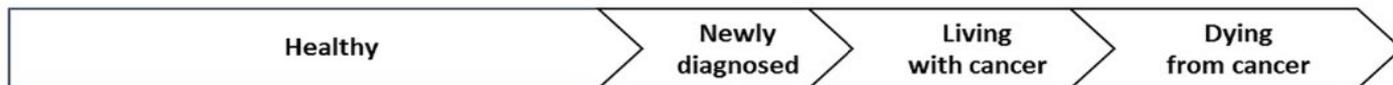
Primary Prevention

Secondary Prevention - Early detection

Treatment

End-of Life care

Populations



|   |  |   |  |
|---|--|---|--|
| <p><b>Population-based Surveillance Indicators</b></p> <p><i>Data sources</i></p> | <p><b>HPV prevalence</b></p> <ul style="list-style-type: none"> <li>By age, type and sex</li> </ul> <p>Surveys</p> | <p><b>Cervical Cancer Incidence</b></p> <ul style="list-style-type: none"> <li>By type, age, stage</li> </ul> <p><b>Precancer Incidence</b></p> <ul style="list-style-type: none"> <li>By type, age</li> </ul> <p><b>Cervical Cancer Survival</b></p> <ul style="list-style-type: none"> <li>By type</li> <li>Age</li> <li>Stage</li> </ul> <p>Population - Based Cancer Registries</p> | <p><b>Cervical Cancer Mortality</b></p> <ul style="list-style-type: none"> <li>By cause, age,</li> </ul> <p>Vital Statistics</p>   |
| <p><b>Interventions/ Programmes</b></p> <p><b>Populations</b></p>                 | <p>HPV Vaccination</p> <p>Eligible population<br/>By sex, age</p>  | <p>Screening</p> <p>Eligible population<br/>By sex, age</p>   | <p>Treatment and Care</p> <p>End of life Care</p> <p>Population with disease<br/>By diagnosis, stage, age,</p>   |
| <p><b>Programme Monitoring Indicators</b></p> <p><i>Data sources</i></p>          | <p>Vaccine Coverage</p> <p>Immunization Registries/<br/>Vaccine monitoring system</p>                              | <p>Screening Coverage</p> <p>Screening Result</p> <ul style="list-style-type: none"> <li>Positivity rate</li> </ul> <p>Screening Registries</p>   | <p>Treatment Protocol<br/>By diagnosis, stage, conditions</p> <p>Adherence to Protocols</p> <p>Patient referral and tracking systems</p> <p>Population or facility-based surveys</p> |
| <p><b>Costs</b></p>   | <p>Cost-effectiveness studies</p> <p>Costing systems – Costing surveys</p> <p>Piñeros M et al. Prev Med. 2021</p>  |   |  |

# The way forward...

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- Making cancer as a Notified disease
- Linkages with databases
  - Screening programs
  - HPV vaccination
  - Genotype surveillance
  - Exposure/risk factor datasets
- South Asia regional consortium of cancer registries

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