Patient Registries in India –
National Cancer Registry Program

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Introduction

• A patient registry is defined as “an organized system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition or exposure, and that serves one or more predetermined scientific, clinical, or policy purposes”\(^1\).

• In a vast country like India it is important to have patient registries in order to understand epidemiology and plan healthcare programs effectively in order to reduce morbidity and mortality, and develop a long term strategy to provide appropriate care to patients.

First such registry was started in India by Indian Council of Medical Research (ICMR) in December 1981, which was a network of cancer registries across the country.

This network of cancer registries across the country was termed National Cancer Registry Program (NCRP).
National Cancer Registry Program

• The objectives of the NCRP were to generate reliable data on magnitude and patterns of cancer, undertake epidemiological studies, provide strategies for National Cancer Control Program and Develop human resource in cancer registration and epidemiology.

• The data for NCRP is collected through hospital based cancer registry and population based cancer registry.

• The NCRP has generated invaluable human resources in cancer epidemiology and registration.
Population and Hospital based Registry

• Three Population Based Cancer Registries (PBCRs) at Bangalore, Chennai and Mumbai and three Hospital Based Cancer Registries (HBCRs) at Chandigarh, Dibrugarh and Thiruvananthapuram were commenced from 1 January 1982.

• The PBCRs have gradually expanded over the years and as of now there are 23 PBCRs under the NCRP network.
Population and Hospital based Registry

Collaborating Centers

Poster presentation for ISPOR 6th Asia Pacific Conference; Beijing, China. September 6-9, 2014
Utility of NCRP

• The registry has provided high level data on cancer occurrence, which is used for National Cancer Control Program (NCCP).

• However, the notification of cancer cases by public and private hospitals, for NCRP, is not mandatory.

• This might lead to possibility of many cancer cases go unnoticed.

Chaudhury K, Luthra UK. Cancer Registration in India. Available: http://mohfw.nic.in/WriteReadData/1892s/Cancer%20Registration%20In%20India.pdf

Poster presentation at ISPOR Annual Conference; Philadelphia, USA. May 2015
Major results from NCRP

• Among males, cancers of lung, mouth, oesophagus, and stomach are leading sites among all registries.

• Among females, cancer of breast and cervix are the leading sites of cancer.

Upper aerodigestive tract cancers as a group have emerged as important sites for undertaking risk factor research and implementing early detection programs.
Future Direction

• A mechanism to have nodal agencies to collect and collate data from public and private hospitals as well as private nursing homes, through legislation mandating compulsory reporting of cancer cases might provide much more useful information on epidemiology, morbidity and mortality cases along with future direction for designing intervention strategies.
Conclusion

• The Cancer registry exist in order to collect data on incidence and prevalence of cancer, the lacunae may provided inconsistent or unreliable data.

• It is important that legislations mandating report of all cancer cases in India is passed in order to get a better insight about the incidence and prevalence, thereby deciding an appropriate strategy.
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