

## MEETING EDITORIAL

# What Roles should Population-based Cancer Registries be Playing in the 21st Century? Reflections on the Asian Cancer Registry Forum, Bangkok, February 2014

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### Abstract

Cancer registries have fundamental roles in cancer surveillance, research, and health services planning, monitoring and evaluation. Many are now assuming a broader role by contributing data for health-service management, alongside data inputs from other registries and administrative data sets. These data are being integrated into de-identified databases using privacy-protecting data linkage practices. Structured pathology reporting is increasing registry access to staging and other prognostic descriptors. Registry directions need to vary, depending on local need, barriers and opportunities. Flexibility and adaptability will be essential to optimize registry contributions to cancer control.

**Keywords:** Cancer registries - administrative data - data linkage - cancer control

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### Introduction

The Asian Cancer Registry Forum was a great occasion thoroughly enjoyed by all who attended. It provided a wide range of interesting presentations, posters and opportunities for international collaborations. The subject matter was diverse, including: the use of population-based cancer registries in descriptive epidemiology; environmental health, clinical treatment, health-services and population health research; health service performance monitoring and evaluation; the contribution of evidence from registries to guide cancer control policies and health service delivery; and provision of information to the public on cancer in the population, cancer service delivery and outcomes. Emphasis was given to metrics for ensuring achievement of high quality data, as relating to comparability, completeness, reliability, validity and timeliness. Operational issues were also discussed.

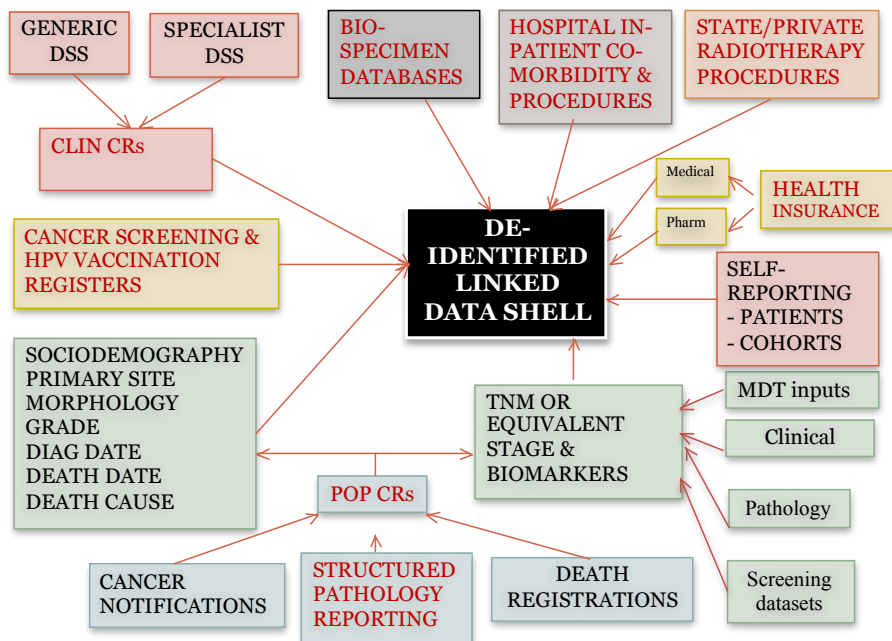
It is clear that the political, operational and funding environments of registries vary markedly in different settings and that this greatly affects roles and capacities. All registries perform traditional core population-based cancer surveillance but many have very limited resources so maintaining operations can be precarious and require extraordinary levels of staff commitment, goodwill from cancer notifiers and a continued willingness of health-record custodians to allow access of registry staff to source records for data extraction and validation. Traditional operational models are still working but some are threatened by increasing barriers from privacy legislation and related concerns.

### Change in Emphasis

Some registries report major changes in direction from a traditional focus on surveillance and research functions to a broader role that also involves data provision for health-service management. In these latter instances, registry activity is often linked to broader health information management systems (Australian Government, 2008). This may pose a threat to core surveillance and research functions in circumstances where funders do not fund these broader additional roles adequately. Conversely, where appropriate additional funding is provided, a more secure funding model may be possible for sustaining traditional registry functions as well as extended roles. Funding requests to health authorities may be compelling when premised on the argument that services need evidence for informed management and that cancer registries have evidence to contribute and need funding from health-service budgets to provide this evidence support.

With increasing costs of cancer services, population-based data are increasingly sought by many health authorities on cancer trends and cancer prevention, screening and treatment service activity and performance (UKACR, 2006; Australian Government, 2008; Cancer Care Ontario, 2013). Cancer registries are increasingly contributing data in response to these needs. In Australia for example, there is close to complete registration of all invasive cancers for surveillance of incidence, mortality and survivals, but more complete clinical and treatment data are being sought by funders to better interpret cancer

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**Figure 1. Data Linkage Pathways Reflecting Australian Cancer Registry Data Strategies**

risk, patterns of care, and survival outcomes for health-system management (Australian Government, 2014).. While cancer registries in Australia do not routinely collect data on cancer stage, other prognostic markers and co-morbidity, R&D projects have had government funding for recording stage and other prognostic indicators on cancer registries, especially for leading cancers like breast, colorectal and lung cancer, to evaluate screening and treatment services (Cancer Australia, 2014).

With increasing structured pathology reporting in some countries, R&D projects in imaging are now under way (RCPA, 2013). There is also greater use of multidisciplinary teams in patient assessment and treatment planning, and broader use of clinical cancer registries.

## Data Linkage

Data linkage units are being used in some countries to link cancer registry data with administrative data on HPV vaccinations, cancer screening, co-morbidity and treatment, which is significantly increasing the linked data available for routine cancer surveillance (Cancer Australia, 2008). Clinical registries, where they exist, provide fundamental “drill down” data that can be used to validate administrative data for population-based surveillance. They also can add value through linkage to bio-specimen data for translational research and are a practical tool for cancer research and quality improvement of clinical care (Cancer Australia, 2008). Data linkage pathways reflecting Australian data strategies are shown in Figure 1.

Cancer registries do not collect data on cancer risk factors, such as tobacco smoking, obesity, lack of exercise, poor diet, high-risk alcohol consumption, excesses in sun exposure and cancer-related infections. However, through data linkage to large population cohort data and other registries, such data can be obtained to monitor risk-factor trends and their associations with cancer rates

in contemporary environments. Cancer registries do not collect patient reported quality of life outcomes, but many registries are well-placed to undertake follow-up to do so.

## Perspectives

In summary, presentations at the Forum demonstrated that through access to structured pathology reporting, and linkage with administrative data on cancer risk factors and management, cancer registries are increasing their data reach. In particular they are contributing increasingly to population-based surveillance and investigations of: (1) stage-specific survivals and patterns of care by socio-demographic characteristics (e.g., age, sex, country of birth, indigenous status, socio-economic status, and geographic remoteness of residence); (2) stage and other relevant prognostic indicators by socio-demographic characteristics; and (3) effects of screening.

It is clear from the Forum that challenges and opportunities vary a lot across registries. All need to find their own pathways and flexibility and adaptability appear essential for all to optimize their contributions to cancer control. Questions arise as to how IARC, IACR, UICC, APOCP, WCRF and other cancer agencies may best assist registries to be adaptable to local needs.

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