

MINI-REVIEW

Roles of Cancer Registries in Enhancing Oncology Drug Access in the Asia-Pacific Region

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Abstract

Cancer registries help to establish and maintain cancer incidence reporting system, serve as a resource for investigation of cancer and its causes, and provide information for planning and evaluation of preventive and control programs. However, their wider role in directly enhancing oncology drug access has not been fully explored. We examined the value of cancer registries in oncology drug access in the Asia-Pacific region on three levels: (1) specific registry variable types; (2) macroscopic strategies on the national level; and (3) a regional cancer registry network. Using literature search and proceedings from an expert forum, this paper covers recent cancer registry developments in eight economies in the Asia-Pacific region - Australia, China, Hong Kong, Malaysia, Singapore, South Korea, Taiwan, and Thailand - and the ways they can contribute to oncology drug access. Specific registry variables relating to demographics, tumor characteristics, initial treatment plans, prognostic markers, risk factors, and mortality help to anticipate drug needs, identify high-priority research area and design access programs. On a national level, linking registry data with clinical, drug safety, financial, or drug utilization databases allows analyses of associations between utilization and outcomes. Concurrent efforts should also be channeled into developing and implementing data integrity and stewardship policies, and providing clear avenues to make data available. Less mature registry systems can employ modeling techniques and ad-hoc surveys while increasing coverage. Beyond local settings, a cancer registry network for the Asia-Pacific region would offer cross-learning and research opportunities that can exert leverage through the experiences and capabilities of a highly diverse region.

Keywords: Asia-Pacific region - Asia - cancer - drug access - registry - oncology

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Introduction

Worldwide, nearly 12.7 million new cancer cases and 7.6 million cancer deaths occurred in 2008 and these figures are expected to nearly double by 2030 (American Cancer Society, 2011). Making up more than 60% of the world population and nearly half of cancer cases in 2010 (UN ESCAP, 2011), the impact of cancer burden in the Asia-Pacific region is huge. With access to oncology drugs varying across jurisdictions, the highly diverse Asia-Pacific region presents an excellent opportunity to examine ways to improve access.

Existing Knowledge

The United Nations Development Group defined access as “having essential medicines continuously available and affordable at public or private health facilities or medicine outlets that are within one hour’s walk from the homes of the population” (United Nations, 2012). Availability and affordability, closely guided by the ability to prioritize, are central to this definition. Conventionally, cancer registries establish and maintain cancer incidence reporting system, serve as a resource for investigation of cancer and its causes, and provide

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information for planning and evaluation of preventive and control programs (National Cancer Institute, 2012). In the face of a growing cancer epidemic and burgeoning health care costs, a concerted effort to tackle the challenges from all fronts is necessary. Whilst cancer registries are a ready resource in many countries, many have concentrated on characterizing burdens and risks, and concurrent applications that proactively and directly enhance oncology drug access have been limited.

New Knowledge

In this article, we describe the data captured by individual national cancer registries in eight economies in the Asia-Pacific region – Australia, China, Hong Kong, Malaysia, Singapore, South Korea, Taiwan, and Thailand. This is followed by suggestions of national-level strategies that use these registries to enhance oncology drug access, and a proposal for a regional cancer registry network in the Asia-Pacific region.

Methods

An expert panel comprising of clinicians, academicians, health care administrators and industry experts from China, Hong Kong, Malaysia, Singapore, South Korea, Taiwan and Thailand convened at the “Asian Expert Forum for Oncology Drug Access” in Singapore on 25 May 2012. Co-organized by the International Society for Pharmacoeconomics and Outcomes Research Singapore Chapter and the Singapore Society of Oncology, in partnership with Novartis Asia Pacific Pharmaceuticals Pte Ltd, this event aimed to further understanding on oncology drug access in the eight participating economies and their respective reimbursement systems.

This paper is a summary of the discussions at the event, complemented by searches using PubMed and relevant internet sites such as those of the respective administering bodies. Combinations of search terms “oncology”, “cancer”, “drug”, “access”, and “registry” as well as the names of the economies under study were used. Hand searches of cited references were also conducted.

Ethics review was not required as this paper draws on information at the “Asian Expert Forum for Oncology Drug Access” as well as database and internet searches.

Description

Overview

Population-based national cancer registries exist in all eight economies (see Table 1). Of the eight economies, Australia, Singapore, South Korea and Taiwan have specific legislations to mandate compulsory notification or registration of each cancer case. National registries in Australia, China, Malaysia, South Korea and Thailand work through registries established at the state, county or regional centers; whereas those covering relatively smaller geographical areas like Hong Kong, Singapore and Taiwan tend to work directly with the hospitals.

In terms of data collection, although data variables vary across the eight economies, broadly, all of them

collect data relating to demographics, diagnosis and tumor characteristics to different extents. Australia, China, Singapore and Thailand have also distinguished mandatory variables from non-core ones.

Specific registry variables

Demographics data collected in national cancer registries in all economies allow analyses by sub-groups such as age group, sex, ethnic group, and in those covering larger geographical areas, rural-urban and geographic differences. Coupled with information on cancer type, tumor size and clinical staging, as well as mortality data, cancer drugs needed to treat these conditions may be mapped out. Besides analyzing drug utilization trends, population patterns of cancer drug needs can be mapped to inform the design and negotiation of oncology drug access programs, as well as early detection initiatives.

Economies such as Singapore, South Korea and Taiwan collect initial treatment plans either as mandatory or optional data fields. By complementing them with tumor staging and mortality data, associations between treatment patterns, drug utilization and survival outcomes can be drawn. These post-marketing data are especially valuable to clinicians and decision-makers.

Hong Kong collects certain prognostic markers in its cancer registry. Prognostic markers (e.g. Human Epidermal Growth Factor Receptor 2 (HER2) status) help to inform possible therapy options. As newer oncology drugs become increasingly more targeted, collecting data on validated prognostic markers in a centralized repository allows examination into how these markers may inform or anticipate drug needs and usage patterns, and identify high-priority research areas.

Singapore and Taiwan capture smoking status in their registries, with the latter also capturing information on other risks such as obesity and betel nut chewing. This allows studies on how risk factors differentially affect select groups of people and quantification of their contributions to the cancer development and prognosis. This may also inform whether certain groups of the population require innovative ways of allowing them to access cancer drugs to minimize disparity in cancer outcomes.

National-level strategies

Linking data: Linking data as stand alone entities, population-based registries are often limited to public health surveillance. Combined with clinical, safety and financial data, the collective value of the data can help to address some of the challenges in oncology drug access.

National cancer registries often collect data at two points – first diagnosis and death. Between diagnosis and death, patient may worsen, change treatment, be cured, or experience a relapse. In addition, although some national cancer registries capture basic information on types of initial treatment plans, they do not capture oncology drugs prescribed. Linking national registries with clinical data as well as dispensed cancer drugs offer several advantages.

Integrated use of outcomes, safety and registry data helps to deduce associations in cancer drug utilization, side effects, treatment outcomes and survival. Drug

Table 1. National Cancer Registries and their Respective Information Collected (by Economy)

S/N	Economy	National Cancer Registry	Legislation on Cancer Notification	Administrative Units	Person-level attributes	Diagnosis- & Tumor-related	Others	Output
1	Australia (Australian Institute of Health and Welfare 2012)	Australian Cancer Database	State and territory-based legislation	<ul style="list-style-type: none"> Data from: Australasian Association of Cancer Registries Maintained at: National Cancer Statistics Clearing House Monitoring, investigation and reporting by: Cancer and Screening Unit, Australian Institute of Health and Welfare 	<ul style="list-style-type: none"> Person identification number Surname First, second, third names Sex Date of birth Date of birth accuracy flag Indigenous status Country of birth Date of death Age of death Cause of death 	<ul style="list-style-type: none"> Date of diagnosis Date of diagnosis accuracy flag Age at diagnosis ICD-10 disease code Most valid basis of diagnosis Statistical local area at diagnosis Postcode at diagnosis Tumor identification number ICD-O-3 morphology code ICD-O-3 topography code Melanoma thickness 	-	<ul style="list-style-type: none"> Australian Cancer Incidence and Mortality (ACIM) books AIHW cancer and screening publications
2	China (Chinese Academy of Medical Sciences 2009, Chen, Zeng et al. 2012, Wei, Liang et al. 2012)	National Central Cancer Registry	Nil	National Office for Cancer Prevention and Control	<ul style="list-style-type: none"> Name Sex Age Date of birth Residential address Personal identification number Ethnic group Marital status Occupation Date of death Primary cause of death 	<ul style="list-style-type: none"> Diagnosis date Diagnosis unit Basis of diagnosis First diagnosis date Name of tumor Tumor site TNM staging system 	<ul style="list-style-type: none"> Reporting unit 	<ul style="list-style-type: none"> China Cancer Registration Handbook
3	Hong Kong, SAR (Hong Kong Cancer Registry 2011, Kwong, Mang et al. 2011)	Hong Kong Cancer Registry	Nil	Hospital Authority	<ul style="list-style-type: none"> Basic demographic Cause of death 	<ul style="list-style-type: none"> Date of diagnosis Information on anatomical site (topography) <ul style="list-style-type: none"> Tumor side Last date seen Status of disease last seen Staging and prognostic marker, histopathology (morphology) information <ul style="list-style-type: none"> Tumor size Tumor type Tumor grade Lymph node status Stage at diagnosis Receptor status 	<ul style="list-style-type: none"> Survival information Relapse-related information <ul style="list-style-type: none"> Date of relapse Clinical management 	<ul style="list-style-type: none"> Yearly statistics report on cancer in Hong Kong Cancer Statistics Query System provides web access to local cancer incidence and mortality statistics stored in online databases
4	Malaysia (Ministry of Health Malaysia 2007)	National Cancer Registry	Nil	Ministry of Health	<ul style="list-style-type: none"> Identification card number Age Sex Ethnic group Geographical state 	<ul style="list-style-type: none"> Stage of cancer at time of diagnosis Primary sites and morphology 	-	<ul style="list-style-type: none"> National Cancer Registry Reports

Table 1 (continued). National Cancer Registries and their Respective Information Collected (by Economy)

S/N	Economy	National Cancer Registry	Legislation on Cancer Notification	Administrative Units	Person-level attributes	Diagnosis- & Tumor-related	Others	Output
5	Singapore (Ministry of Health Singapore 30 Jan 2012)	Singapore Cancer Registry	National Registry of Disease Act	National Registry of Diseases Office (NRDO)	<ul style="list-style-type: none"> Name Identification number Date of birth Gender Ethnic group Residential status Country of birth Date, time, place of death 	<ul style="list-style-type: none"> Date of diagnosis Primary site of cancer Basis of diagnosis Primary site Histological diagnosis Histological grade/ differentiation TNM stage grouping and classification Tumor size 	<ul style="list-style-type: none"> Name of notifying hospital/clinic/department Department/clinic where patient was diagnosed or receiving treatment Name of doctor-in-charge Hospital/clinic responsible for subsequent treatment/follow-up Screen detected Alive or dead First treatment care plan Smoking status 	<ul style="list-style-type: none"> Interim reports Health Factsheets Cancer survival report
6	South Korea (Park 2010)	Korea Central Cancer Registry	The Cancer Act	Division of Cancer registration and Surveillance, National Cancer Center	<ul style="list-style-type: none"> Name Personal identification number Sex Age Address Occupation Death date Cause of death 	<ul style="list-style-type: none"> Diagnosis date Primary site Morphology Behavior Method of diagnosis Summary staging (SEER) TNM stage 	<ul style="list-style-type: none"> Treatment method 	<ul style="list-style-type: none"> Cancer statistics relating to incidence, survival and prevalence
7	Taiwan (Taiwan Cancer Registry, Chiang, et al. 2010)	Taiwan Cancer Registry	Cancer Control Act	Bureau of Health Promotion, Department of Health	<ul style="list-style-type: none"> Short form**: Demographics Long form**: Demographics 	<ul style="list-style-type: none"> Short form**: Clinical diagnosis information Long form**: Confirmation of cancer information Initial staging of cancer information Site-specific factors 	<ul style="list-style-type: none"> Short form**: Reporting hospital Initial treatment information Risk factors Long form**: Reporting hospital Initial treatment information Outcomes information Risk factors 	<ul style="list-style-type: none"> Annual registry report by Department of Health
8	Thailand (Patel, et al.)	Thailand	Nil	National Cancer Institute Thailand	<ul style="list-style-type: none"> Registry number Name Residential address Date of birth Age Sex 	<ul style="list-style-type: none"> Date of diagnosis Site of cancer Cancer histology Method of diagnosis Extension of cancer Number of primary tumors 	<ul style="list-style-type: none"> Date of last contact (alive or death) 	<ul style="list-style-type: none"> Annual cancer registry reports

*The minimum data variables are shown. Additional or non-core data variables are italicized. **The Short Form of the Taiwan Cancer Registry has 42 fields and the Long Form has 114 fields. The detailed fields can be found in the respective references

reimbursement entities often lack information on overall survival and validated surrogate markers during initial assessments of novel cancer therapies. With pooled data, this could help in the development of algorithms to validate surrogate endpoints for wider application and contribute to discussions on treatment in difficult situations such as that beyond disease progression.

Combining national data allows policy-makers to take a proactive approach in surveillance of drug access patterns by capturing ground practice information on a national level. For example, certain evidence-based but off-label drug usage patterns that are unfunded by the drug reimbursement schemes in the country can be brought to their attention (Mellor et al., 2012). Mismatches in cancer incidence rates and oncology drug utilization patterns may also prompt policy-makers to optimize geographical distribution of access points to care and lead in negotiating for patient access programs for particular drugs or groups of patients.

Globally, governments are trying to get the most value for every health dollar spent. National cancer registries complemented with linkages to national health insurance schemes, medical service and drug utilization costs can help decision-makers better estimate the impact of oncology drugs use in cancer patients. Financial determinants of access to oncology drugs such as income levels, out-of-pocket expenditure on drugs can be derived and analyzed together with demographics and diagnosis- or tumor-related data from the national cancer registries. Such analyses can, for example, evaluate whether certain groups in the population are falling through the cracks of the health care system and the consequent repercussions on outcomes, with a view to design targeted programs to improve access and mitigate disparity.

Clearly, analyses based on standalone institution-based or national cancer registry are limited. Incorporating additional data can be done in two ways – linking up with existing registries or systems, or direct incorporation into an existing registry. In various states and territories in Australia, there has been a strong development in clinical cancer registries to capture clinical profiles and changes of cancer patients, with some states integrating such information with their state cancer registry. Guidance documents have also been developed to promote similarities in data sets for pooling and comparison. Others such as Taiwan incorporated many clinical variables in their national cancer registries. Creating new variables in national cancer registries is a resource-intensive endeavor and requires careful planning as the cost and logistics need to be balanced against the usefulness of the data. Linking national cancer registries with satellite clinical cancer registries, drug safety reporting infrastructure and cost or insurance databases is an attractive alternative if harmonized definitions and data-sharing policies are established.

Making data available: Data are useful only when they can be translated into knowledge and the importance of having defined channels for obtaining data from the custodians and providing feedback to the decision-makers cannot be further emphasized. Fundamentally, all data should be used in a way that respects proper usage and

confidentiality. To encourage research and ethical use of data, avenues for making data requests for the purpose of research should be established.

All eight economies have individually published data from their registries, mostly in the form of aggregate statistics on websites or annual reports. Advanced economies such as Australia (Australian Institute of Health and Welfare) and Hong Kong (Hong Kong Cancer Registry, 2011) have taken a risk-based approach in making registry data available. De-identified and validated cancer incidence and mortality data are made freely available online via excel workbooks or statistics query system, complemented by an option for data request for more detailed information. Singapore, on the other hand, offers an on-request system for cancer registry data (Ministry of Health Singapore, 2012). Such a tiered-approach can confer the right level of protection for data of varying sensitivity while encouraging streamlined administrative processes that build a collaborative research environment.

Increasing coverage: Comprehensive coverage of national cancer registries captures data that are reflective of the population to inform policies. However, owing to resource constraints, vital registration is logistically challenging for newly industrialized countries such as China, Malaysia and Thailand although there have been efforts to increase reach by establishing new state-level cancer registries and cancer registry offices. For example in China, current coverage of approximately 190 million people is 13% of the entire population of more than 1.3 billion and universal coverage is logistically and administratively impractical (Wei et al., 2012). In such countries, while pursuing efforts to incrementally extend reach, modeling techniques and ad-hoc surveys can be concurrently employed to derive trends and patterns that can inform policies relating to oncology drug access.

Creating a regional cancer registry network: Besides the International Association of Cancer Registries (IACR) (International Association of Cancer Registries 2012), regional networks like the European Network of Cancer Registries (ENCR) (European Network of Cancer Registries, 2012) and the North American Association of Central Cancer Registries (NAACCR) (North American Association of Central Cancer Registries, 2012) have been established decades ago (Moore et al., 2008). In contrast, to the best of our knowledge, there is currently no regional cancer registry network serving the needs of the Asia-Pacific region despite repeated calls from experts (Moore et al., 2008, Sobue et al., 2010). This may potentially be explained by the diverse health care systems and variable access to cancer care across the region. Other issues faced in relation to cancer registry in Asia include insufficient quality of most registries, weak infrastructure, inadequate coverage, difficulty in sustainability, few opportunities for education and training, low response rates to IACR questionnaire surveys, and wide variation in expertise and resources among Asian countries (Sobue et al., 2010). The poor response rates to IACR may signal a need for alternative ways to engage the interests of Asian countries in order to understand their needs. In spite of the wide

differences, the region offers unique opportunities for cross-sharing and many opportunities for collaborative research by leveraging on existing cancer registries, extending their reach, studying ways to understand the effects of cancer on each country and improving access to care.

In June 2011, a group of clinicians and health economists came together to discuss how access to oncology drugs can be improved in the South-East Asia region leading to a loose alliance of six countries – Indonesia, Malaysia, Singapore, The Philippines, Thailand and Vietnam to form the South East Asia Cancer Care Access Network (SEACCAN). Defining access as the ability of patients eligible for a particular drug to actually receive it for treatment, an inaugural survey on oncology drug access was carried out. The survey had responses from 36 cancer specialists from these six countries and used seven innovative cancer therapies as indexes. Respondents estimated that only 13-55% of eligible cancer patients had access to these index drugs. Zooming in to the individual drugs, estimated access across the six countries ranged from less than 5-90%, showing very high variability in access to oncology drugs in the South-East Asia region.. Efforts like this are the first step to characterizing the oncology drug access differences in the region so that the appropriate initiatives can be developed to minimize disparity and make collective progress.

Discussion

In dealing with cancer, many governments have adopted a multi-pronged approach that includes prevention, early detection and access to care. Although progress has been made in various ways outlined in this paper, the SEACCAN survey offers preliminary evidence that cancer drug access in the Asia-Pacific region is still highly varied and leaves much room for improvement.

National cancer registries established in the Asia-Pacific region offer a wealth of information that can inform policies on oncology drug access. Although there are differences in the types and levels of detail of variables collected, they are the first step to generating informative analyses with high policy impact. Newly industrialized countries can focus on improving reach and completeness of data – a key quality to drawing meaningful conclusions – for the purpose of designing drug access programs; advanced economies can combine or link databases to address technical challenges faced in reimbursement decisions especially pertinent to the highly expensive novel cancer therapies. This can augment the decision-making capabilities of drug reimbursement bodies. In addition, policies guiding data protection need to be carefully balanced against excessive bureaucracy so that meaningful research can be pursued in a constructive manner.

Beyond local settings, there is much value in setting up a regional network. As health care systems in the Asia-Pacific region undergo transformation, a common platform such as a collaborative regional network would offer stakeholders in oncology drug access a regular avenue to share ideas and insights. Regional networks such as the

ENCR in Europe and NAACCR in North America have paved the way and their models can be studied and adapted to meet the capacity, needs and interest of economies in the Asia-Pacific region.

In conclusion, cancer registries are an invaluable resource in enhancing cancer care access. However, their value in directly contributing to oncology drug access in Asia remains largely untapped. Health care decision makers can consider taking more deliberate approaches that harness the full potential of cancer registries through strategies appropriate for local application as well as engagement on a regional level so that collective progress can be made.

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