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#### **Databases in the Asia-Pacific Region:**

#### The Potential for a Distributed Network Approach

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Databases in Asia-Pacific

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#### Abstract

**Background**: This study describes the availability and characteristics of databases in Asian-Pacific countries and assesses the feasibility of a distributed network approach in the region.

**Methods**: A Web-based survey was conducted among investigators using health care databases in the Asia-Pacific. Potential survey participants were identified through the Asian Pharmacoepidemiology Network.

**Results**: A total of 11 databases participated in the survey. Database sources included 4 nationwide claims databases from Japan, South Korea, and Taiwan; 2 nationwide electronic health records from Hong Kong and Singapore; a regional electronic health record from western China; 2 electronic health records from Thailand; and cancer and stroke registries from Taiwan.

**Conclusions**: We identified 11 databases with capabilities for distributed network approaches. Many country-specific coding systems and terminologies have been already converted to international coding systems. The harmonization of health expenditure data is a major obstacle for future investigations attempting to evaluate issues related to medical costs.

**Keywords**: AsPEN (Asian Pharmacoepidemiology Network); Distributed Network Approach; Claims Database; Electronic Health Records; Patient Registry

## Introduction

With the rapid development of electronic health records and computer technologies in North America and Europe, collaborative multi-database projects within or across nations have increased in the past decade.<sup>1-3</sup> Multinational database studies can offer many advantages, including large sample sizes, cross-country comparisons, and generalizable results. Most importantly, collaboration among countries may also create partnerships that benefit public health.<sup>1,4</sup>

Among European and North American multi-database networks, the distributed network approach has been widely used in the form of common data models.<sup>1-7</sup> This approach allows individual data partners to maintain operational and physical control over their data.<sup>8-10</sup> However, the feasibility of a common data model for heterogeneous databases in the Asia-Pacific region has not been assessed.

The Asian Pharmacoepidemiology Network (AsPEN) was initiated in 2008 and now includes Australia, China, Hong Kong, India, Japan, Singapore, South Korea, Taiwan, and Thailand.<sup>11</sup> The availability of claims databases or electronic health records from the AsPEN founding countries has been briefly introduced elsewhere,<sup>3</sup> but without data component details and information on the new AsPEN countries. We sought to describe the availability and detailed characteristics of databases in Asian-Pacific countries. We also aimed to evaluate the capacity and feasibility of establishing a common data model for Asia-Pacific databases.

# Methods

We used a Web-based survey tool to conduct an online survey for investigators possessing or using health databases in the Asia-Pacific region.

The survey included 142 questions about (1) the characteristics of the database; (2) access policies and restrictions; (3) population demographic characteristics; (4) data components coding systems used, including diagnoses, procedures, prescriptions, and laboratory data; (5) medical expenditures; and (6) traditional Chinese medicine or complementary medicine.

Targeted databases were identified through the AsPEN website and recommendations provided by AsPEN members.<sup>11</sup> A detailed description of our methods is included in the **Appendix**.

#### Results

We invited 17 researchers from 13 databases to participate in the survey, and 15 (88.2%) researchers from 11 (84.6%) databases responded. A list of participating databases and their characteristics is presented in **Table 1**. Detailed descriptions of participating databases are presented in the **Appendix**.

Unique patient identifiers and demographic characteristics, including sex and birth information, were available in the databases. Information on race and ethnicity was available in most electronic health record databases and registries but not in the claims databases. The clinical values for laboratory tests was available in all electronic health records and registries but not in the claims databases. Health expenditure information was available in all the claims databases but not in many electronic health records or registries. Date of death or patient status (ie, alive or dead) was not available in 3 claims databases, but could be estimated using eligibility for compulsory national insurance in 1 claims database. Other data components, including information on health care facilities and providers, are shown in **Table 2**.

 Table 3 details information found in databases about diagnoses, prescriptions, procedures,

 health expenses, and coding systems.

Four databases contained longitudinal dispensing data for traditional Chinese medicine using a domestic coding system. Other information about traditional Chinese medicine, such as drugs records, is compiled in a manner consistent with Western medications (**Table 4**).

#### Discussion

The survey included 11 databases, including health care utilization databases, electronic health records, and registries covering approximately 220 million individual records that are currently available for pharmacoepidemiologic and other clinical researchers. This provides an opportunity to establish a large-scale drug surveillance system for populations in the Asia-Pacific region.

Japan, South Korea, and Taiwan, with universal insurance coverage, reimburse most health care services from their national budgets,<sup>12</sup> which has led to the establishment of nationwide claims databases for administrative and reimbursement purposes, creating pharmacoepidemiologic data sources representative of the national population. Unlike claims databases, hospital-based electronic health records are usually compiled for clinical purposes,<sup>13</sup> and therefore could provide information to improve the validity of pharmacoepidemiologic studies by improving the specificity of outcome definitions and/or better measurement of confounding factors for adjustment.

The representativeness of hospital-based electronic health records may depend on the proportion of hospitals included in the area. Nationwide systems, such as those in Hong Kong and Singapore, are representative of the entire population, but systems in China and Thailand may be less representative, as they represent data for specific regions only. The NHIRD, Hong Kong's Clinical Data Analysis and Reporting System, Japan's National Database (NDB), and South Korea's Health Insurance Review and Assessment Service are population-based databases, enabling the calculation of the rate of incidence for specific events.

Data privacy and related ethical issues are a major concern when using databases, resulting in a number of policies and restrictions to be established by data custodians. In particular, the privacy of nationwide health databases is paramount because of national security

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issues.<sup>14,15</sup> Currently, the data custodians of all Asia-Pacific databases included in this study request researchers obtain approval from an ethics review committee before accessing databases and require encryptions or truncations of specific data. Furthermore, we found that the custodians or regulators may partly restrict the availability of data. For example, researchers using NHIRD data receive data for 10% or less of the population.<sup>16</sup> The NDB is usually not available for purchase and may only be shared in some cooperative research. Alternatively, the Japan Medical Data Center Database, a commercial claims database, is less restrictive.<sup>17</sup> Although there are 2 registry databases available in Taiwan that provide significant information, linking them to the NHIRD is prohibited due to ethical considerations.<sup>16,18</sup>

Due to existing data privacy policies, no individual-level data from the participating databases could be shared with researchers from other countries, raising questions about how to conduct cross-database studies. A common protocol approach is to have each data partner translate their raw data using an identical study protocol into analytic programs.<sup>19</sup> Our findings indicate we will be able to apply this approach to conduct pharmacoepidemiologic studies, including descriptive studies of disease prevalence and incidence, patterns of drugs and health recourse utilization, and associated studies, in the current Asian-Pacific database environments. Given that date and cause of death are available through direct records or indirect proxy measures, studies considering mortality would also be possible.

A distributed network approach using a common data model can help avoid inconsistency in analytical processes that arises from different investigators implementing the study protocol differently. This approach executes a systematic program established by a coordinating center on a common data format, which enables quality control of the analyses. This also enables analysts who are knowledgeable about participating health systems to ensure their data are analyzed and interpreted properly.<sup>9,20</sup> However, researchers could get entangled in another challenge: the

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conversion of the database to a common data model structure.<sup>9</sup> The common data model could be study-specific or could be a global model applied for most routine pharmacoepidemiologic studies (eg, the common data model developed by the Observational Medical Outcomes Partnership<sup>21</sup> or Mini-Sentinel<sup>22</sup>). Given the diversity of language systems among Asia-Pacific countries, the communication of a common format and translations of descriptive information stored in databases could be more arduous than in networks where the same language is used. According to our survey, information on drugs and diagnoses are recorded by common coding systems in the majority of participating databases, which would ease the conversion to a common data model. Although NHIRD uses ICD-9 codes for diagnoses, a crosswalk from ICD-9 to ICD-10 is almost established.<sup>23</sup> Nevertheless, many databases use domestic coding system for drugs, drug ingredients, strength, and route of administration, which provides a foundation to map these codes to an international coding system (eg, ATC codes). We found that the harmonization of health expenditure data would be complicated. In addition to challenges in the conversion of currency and adjustment of the consumer price index, many categories of health expenditures were specific to countries and their health systems. For example, there is no concept of a copayment and deductible in Japan, and in Taiwan the dispensing fee is based on the prescription and not at the ingredient level,<sup>16</sup> both of which differ from some of the other countries.

Traditional Chinese medicine, including prescribing herbal medications and acupuncture, is widely used in all of the countries. We found that utilization data were only available in databases in China, Japan, and Taiwan. To our knowledge, no international coding system for traditional Chinese medicine currently exists. Consequently, more effort is needed to standard relevant terminologies related to traditional Chinese medicine before establishment of a coding system, including acupuncture, traumatology, manipulative therapies, and Chinese herbal products.

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In conclusion, we identified multiple databases with the capability to conduct collaborative studies using a distributed network approach in the Asia-Pacific region, which would enable large-scale surveillance to facilitate prompt identification of emerging safety issues. Participating health databases are generally comprehensive in population coverage. Some data contents, and many country-specific coding systems and terminologies, have already been converted to international coding systems. However, the harmonization of health expenditure data presents a major obstacle for future investigations in evaluating issues related to medical cost.

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				Estimated No.	Age group
Country	Database name (abbreviation)	Source type	Starting date	of individuals	
China	Hospital Information System of West China Hospital (HISWCH)	1 hospital EHR	August 1, 2008	> 5 million	All ages
Hong Kong	Clinical Data Analysis and Reporting System (CDARS)	National EHR	January 1, 1995	>7 million	All ages
Japan	Japan Medical Data Center Database (JMDC)	Claims database	January 1, 2005	> 2.3 million	Mostly $< 65$ y
Japan <sup>f</sup>	National Database (NDB)	Claims database	April 1, 2009	>128 million	All ages
Korea	Korea Health Insurance Review and Assessment Service (HIRA)	Claims database	December 31,	> 50 million	All ages
			2008		
Singapore	National Electronic Health Record (NEHR)	National EHR	January 1, 2011	> 5 million	All ages
Taiwan	National Health Insurance Research Database (NHIRD)	Claims database	January 1, 1996 <sup>a</sup>	>23 million	All ages
Taiwan	Taiwan Stroke Registry (TSR)	Registry	August 1, 2006	> 100,000	>18 years
Taiwan	Taiwan Cancer Registry (TCR)	Registry	June 2003 <sup>b</sup>	> 720,000 <sup>d</sup>	All ages
Thailand	Buddhachinaraj Hospital Database (BH)	1-hospital EHR	January 1, 2008	> 350,000	All ages
Thailand	Hospital Information (HI)	21-hospital EHR	January 2003 <sup>c</sup>	> 1 million	All ages

#### Table 1. Database characteristics.

Abbreviation: EHR, electronic health record.

<sup>a</sup> Medication data is from January 1997.

<sup>b</sup> The Taiwan Cancer Registry (TCR) started in 1996 and became nationwide in June 2003. TCR has included patients with cervical cancer patients since 2002, extending to patients with breast cancer, oral cavity cancer, lung cancer, hepatocellular carcinoma, and colon/rectal cancer in 2007. In 2008, TCR expanded to include patients with prostate cancer, gastric cancer, esophageal cancer, and bladder cancer. TCR has also included patients with nasopharynx cancer, salivary gland tumors, uterine sarcoma, ovarian cancer and hematopoietic and lymphoid neoplasms since 2009.

<sup>c</sup> Databases from the 21 community hospitals have different starting dates, but every database covers over 10 years (as of December 31, 2013).

<sup>d</sup> Approximately 90 000 incident cases per year.

<sup>e</sup> All databases are updated continuously.

<sup>f</sup> The NDB is not usually available for purchase. Use of the NDB is restricted to individuals with government or academic affiliations, who must apply for access. Applications for access typically have a low acceptance rate (about 14% and 30% of all applications in 2011 and 2012, respectively). Information such as hospital/clinic/pharmacy identifying information, the number of beds in a hospital, and personal identifiers are typically not shared with users, but these data are available in the JMDC.

	Claims database Electronic health record						rd	Registry			
Data component/database									н		
	NDB	HIRA	NHIRD	JMDC	CDARS	NEHR	BHD	IH	HIS-WCH	TSR	TCR
Patient identifiers		×				×	×	×	×	×	
Scrambled identifiers	×	×	×		×	×			×		×
Eligibility of database			×	×			×	×	×	×	×
Demographics											
Sex	$\times$	×	×	×	×	×	×	×	×	×	×
Year of birth	×	×	×	×	×	×	×	×	×	×	×
Month of birth		×	×		×	×	×	×	×	×	×
Date of birth		×	×		×	×	×	×	×	×	×
Race					×	×		×	×	×	
Ethnicity					×	×		×	×	×	
Location of patient		×	$\times^{a}$		×	×	×	×	×	×	×
Other health information											
Body weight						×		×	×	×	
Body height						×		×	×	×	
Smoking status								×		×	
Year of death	×		$\times^{\mathrm{b}}$	×	×	×	×	×	×	$\times^{c}$	×
Month of death	×		×b	×	×	×	×	×	×	$\times^{c}$	×
Date of death			$\times^{\mathrm{b}}$		×	×	×	×	×	$\times^{c}$	×
Cause of death					×	×	×	×	×		×
Health records											
Inpatient	×	×	×	×	×	×	×	×	×	×	×
Outpatient	×	×	×	×	×	×	×	×	×	$\times^{d}$	×
Emergency room	×	×	×	×	×	×	×	×	×	$\times^{e}$	×
Diagnosis	×	×	×	×	×	×	×	×	×	×	×
Drug	×	×	×	×	×	×	×	×	×	×	×
Procedure	×	×	×	×	×	×	×	×	×	×	×
Type of laboratory test	×		×	×	×	×	×	×	×	×	
Laboratory data value					×	×	×	×	×	×	
Health expenditure	×	×		×		×	×	×	×		
Hospital information											
Identifiers		×			×	×		×	×	×	
Scrambled identifiers	Ì	×	×	×	l	×			×		×
Level of hospital	$\times^{\mathrm{f}}$	×	×	$\times^{\mathrm{f}}$	İ	×		×	×	×	×
Location of hospital	Ì	×	×		İ	×		×	×	×	×
Physician information	Ì		İ		İ						
Identifiers	1		İ		İ	×		×	×		
Scrambled identifiers	Ì		×		İ	×					
Specialty	$\times^{\mathrm{g}}$	×	×	$\times^{g}$	1	×		×	×	×	
Starting date of specialty	Ì		×		İ	×			×		
Year of birth	Ì		×		İ			×			
Month of birth	Ì		×		İ			×			
Date of birth	1	1	×		l	1	1		1	1	
Sex	1	1	×		l	×	1	×	1	1	
Place of service	1	1	×	1	1	×	1	×	1	1	

Table 2. Health information i	n partici	pating	databases.
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Abbreviations: BHD, Buddhachinaraj Hospital Database (Thailand); CDARS, Clinical Data Analysis and Reporting System (Hong Kong); HI, Hospital Information (Ubon Ratchathani, Thailand); HIRA, Health Insurance Review and Assessment (South Korea); HIS-WCH, Hospital Information System of West China Hospital; JMDC, Japan Medical Data Center; NDB, National Database (Japan); NEHR, National Electronic Health Record (Singapore); NHIRD, National Health Insurance Research Database (Taiwan); TCR, Taiwan Cancer Registry; TSR, Taiwan Stroke Registry.

- <sup>a</sup> Determined using the zip code in the National Health Insurance Research Database.
- <sup>b</sup> Determined using the date of disenrollment date from Taiwanese national insurance.
- <sup>c</sup> Only for death within 6 months after stroke events.
- <sup>d</sup> Summary of stroke-related medication use before the index stroke event, and outpatient visits at 1, 3, and 6 months after the index stroke event.
- <sup>e</sup> Summary of emergency department visits for the index stroke event.
- <sup>f</sup> Determined using the number of beds in the hospital.
- <sup>g</sup> Determined using the department name or specialty of the physician's clinic.

Source type		Claims o		/ 1	,		onic health				gistry
Data component/			•		70						
database	NDB	HIRA	NHIRD	JMDC	CDARS	NEHR	BHD	IH	HIS- WCH	TSR	TCR
Drug information											
Domestic coding system	×	×	×	×	×	×	×	×	×		
International coding system	ATC <sup>a</sup>	ATC <sup>a</sup>	ATC <sup>a</sup>	ATC <sup>a</sup>	BNF			ATC			
Prescription place of service		×	×		×	×	×	×	×	×	
Prescription date	×	×	×	×	×	×	×	×	×	×b	×°
Dispensing pharmacist		×	×			×		×	×		
Dispensing date	×	×	×	×	×	×	×	×	×	×b	
Drug supply day	×	×	×	×	×	×	×	×	×	×b	
Quantity	×	×	×	×	×	×	×	×	×	×b	
Route or drug administration	×	×	×	×	×	×	×	×	×	×b	
Dose strength	×	×	×	×	×	×	×	×	×	×b	
Usage frequency	×	×	×	×	×	×	×	×	×	×b	
Specific indication						×	×	×	×	×b	
Reason for discontinuation						×		×		×b	
Diagnosis information											
Domestic coding system					×				×		
International coding system	ICD 10	ICD 10	ICD 9	ICD 10	ICD 9/ ICD 10	ICD 10	ICD 10	ICD 10	ICD 10	ICD 9	ICD 9
Diagnosis start date	×	×	×	×	×		×	×	×	×	×
Diagnosis end date	×			×			×	×		×	
Diagnosis stop reason	×			×				×		×	
Procedure information											
Domestic coding system	×	×	×	×	×		×		×		×
International coding system			ICD 9		ICD 9	ICD 9		ICD 9			
Procedure place of service		×	×		×		×	×	×	×	×
Procedure date	×	×	×	×	×		×	×	×		×
Specific indication			×					×	×		
Health expenditure information											
Total paid per visit	× <sup>d</sup>	×	×	× <sup>d</sup>		×	×	×	×		
Total drug payments		×	× <sup>e</sup>			×					
Total procedure payments						×					
Copayment	N/A <sup>f</sup>	×	×	N/A <sup>f</sup>		×		×	×		
Coinsurance	$\times^{g}$	×		$\times^{g}$		×		×			

**Table 3**. Detailed information on medications, diagnoses, procedures, and health expenditures in participating databases.

Paid by payer	$\times^{h}$	×	N/A <sup>f</sup>	$\times^{\mathrm{h}}$	×			
Paid by coordination benefits	N/A <sup>f</sup>	×	N/A <sup>f</sup>	N/A <sup>f</sup>	×			

Abbreviations: Anatomical Therapeutic Chemical Classification System; BHD, Buddhachinaraj Hospital Database (Thailand); BNF, British National Formulary; CDARS, Clinical Data Analysis and Reporting System (Hong Kong); HI, Hospital Information (Ubon Ratchathani, Thailand); HIRA, Health Insurance Review and Assessment (South Korea); HIS-WCH, Hospital Information System of West China Hospital; ICD, International Classification of Diseases; JMDC, Japan Medical Data Center; NDB, National Database (Japan); NEHR, National Electronic Health Record (Singapore); NHIRD, National Health Insurance Research Database (Taiwan); TCR, Taiwan Cancer Registry; TSR, Taiwan Stroke Registry.

<sup>a</sup> Converted by the database partner.

<sup>b</sup> Only for the prescription date and route, and reasons for discontinuing thrombolytic therapy with alteplase.

<sup>c</sup> Only for the first regimen of chemotherapy.

<sup>d</sup> Total payments for health care services per month.

<sup>e</sup> The dispensing fee is based on prescription but not at the ingredient level.

<sup>f</sup> No relevant concept in the country.

<sup>g</sup> The information for patient type with fixed percentage coinsurance.

<sup>h</sup> The information for patient type with fixed percentage paid by payer.

Data component/database	NDB	JMDC	NHIRD	HIS-WCH
Diagnosis			×	×
Procedure	$\times^{a}$	× <sup>a</sup>	×	×
Chinese herbal products				
Domestic coding system	×	×	×	×
International coding system				
Prescription place of service			×	×
Prescription date	×	×	×	×
Dispensing pharmacist	×	×	×	×
Dispensing date	×	×	×	×
Drug supply day	×	×	×	×
Quantity	×	×	×	×
Route or drug administration	×	×	×	×
Dose strength	×	×	×	×
Usage frequency	×	×	×	×
Specific indication				×
Reason for discontinuation				×

 Table 4. Information on Chinese herbal products.

Abbreviations: HIS-WCH, Hospital Information System of West China Hospital; JMDC, Japan Medical Data Center; NDB, National Database (Japan); NHIRD, National Health Insurance Research Database (Taiwan).

<sup>a</sup> Acupuncture is covered by health insurance only for specific diseases in special cases. Only a small proportion of acupuncture records are available in the databases.