



# Rationale and Development of an Online Directory of Database Profiles for Pharmacoepidemiology, Outcomes, and Population Research

Kamani SA, Goehring Jr EL, Singh VP, Nguyen-Khoa BA, Kapasi AJ, Jones JK DGI, Inc., Arlington, VA, USA

## OBJECTIVE

B.R.I.D.G.E. TO DATA<sup>SM</sup> ([www.bridgetodata.org](http://www.bridgetodata.org)) was developed as a web-based directory with detailed profiles of population research databases. This resource allows pharmacoepidemiology, pharmacoconomics and other researchers to be more aware of databases and registries available worldwide.

## BACKGROUND

Large epidemiology studies using population databases are in high demand in the current healthcare environment. Simultaneously, the number of healthcare databases available for research has risen considerably worldwide. Increasingly complex research questions require researchers to:

- Locate the appropriate data source;
- Understand the specific characteristics of each database;
- Know how to access the data.

To address this growing need, B.R.I.D.G.E. TO DATA<sup>SM</sup> (Benefit-Risk Information for Drug Evaluations) was launched in 2009. B.R.I.D.G.E. TO DATA<sup>SM</sup> is an advanced version of the original RAD-AR (Risk Assessment of Drugs-Analysis & Response) books and the web-based version, BRIDGE On-Line. The RAD-AR books, published in the 1990s with 200+ database profiles consisted of 5 regional volumes; these books were converted in 1999 to BRIDGE On-Line, the first web-based international collection of 100 database and registry profiles.

## METHODS

Over a twenty-month period, an advisory board was convened, the website was re-branded, and an initial set of databases and registries were profiled.

The DGI Advisory Board, consisting of 8 international members from academia, government, and industry, provided feedback at multiple stages, assisted in selection of databases to profile, and actively worked with the B.R.I.D.G.E. TO DATA<sup>SM</sup> team.

Rebranding the web site involved designing a new logo, getting it service marked (SM), as well as working with a web development firm to build the infrastructure of [bridgetodata.org](http://bridgetodata.org).

Databases were identified by assessing existing database profiles in the RAD-AR books and the earlier web-based version, BRIDGE On-Line. Additionally, extensive literature reviews were conducted to identify other population healthcare databases and registries.

Profiles were developed as follows:

(a) The earlier template was updated to include 75 common fields covering the categories listed in **Table 1**.

(b) Each of the databases was researched and profiled by our expert staff at DGI, Inc. After a final review by the Chief Editor, Dr. Judith K Jones, the profiles were sent out to respective database managers to check for accuracy, completion, and to get authorization for listing and content approval.

(c) As part of the goal to actively maintain B.R.I.D.G.E. TO DATA<sup>SM</sup>, a quality assurance process involved systematic review and regular updates of each profile.

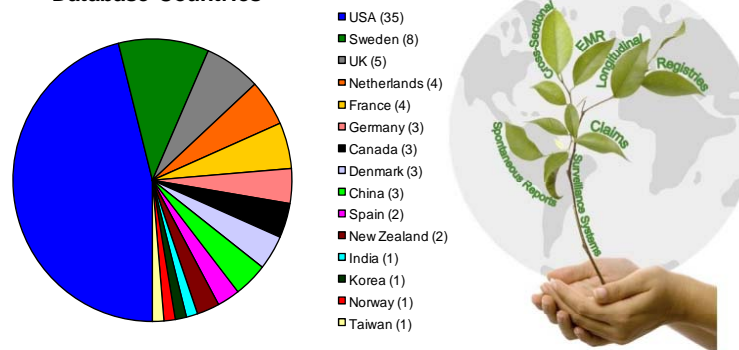
Table 1. Brief Description of Data Elements

Summary	Database history, uses, strengths / limitations
Population Dynamics	Population size (active/final), annual change in size, sample weights
Demographic Data	Age, gender, ethnicity/race, geographic location, date of birth, death data
Physician & Practitioner Info	Physician ID & specialty; Pharmacy ID
Diagnoses/Signs & Symptoms	Date parameters, coding system(s), as well as data on physical exam, birth defects, cancer, infectious disease, environmental exposures, and behavior
Procedures	Date parameters, coding system(s), lab data
Drug Information	Date parameters, regimen & route, manufacturer, dosage, coding system(s), generic name
Economic Data	Cost data including type, surrogate cost data
Validation & Linkage	Database linkage capabilities to and validation against other sources; access to medical records
Administrative Data	Contact and accessibility information for each database, recent references, and date the database was last updated

## RESULTS

B.R.I.D.G.E. TO DATA<sup>SM</sup> was launched in November 2009 with 50 database profiles from USA, Canada, Europe & Asia.

Database Countries



### Site Features:

- Compendium of worldwide population database profiles;
- Comparison of different database profiles on one site;
- Searchable web interface;
- Relevancy-ranking of search results;
- Saving of search results that can be updated later;
- Creation of individual search collections;
- Database profiles updated annually;
- Profiles verified by respective database managers;
- Glossary explaining profile fields and coding systems;
- Audio-visual tutorial to learn about the site and its features.

### Comparison Feature: Demographic and Economic Data Elements

Demographic Data	FIELD NAMES	GENERAL PRACTICE PATIENT RECORDS (GPRD) [VIEW]	THE HEALTH IMPROVEMENT NETWORK (THIN) [VIEW]	IMS DISEASE ANALYZER - MEDPLUS UK [VIEW]
Age of Patients at Data Collection		Yes (Calculated using year of birth)	Yes (YCB)	Yes
Approximate Percentage of Participants <18 years and those >65 years		<18 yrs = 20% >65 yrs = 19%	N/A (All ages are included so that it is a representative sample)	<18 years = 12% >65 years = 22%
Gender Data		Yes	Yes	Yes
Percentage of Males/Females		Males = 49.5% Females = 50.5%	N/A (Representative of the UK population)	Males = 48% Females = 52%
Ethnicity / Race Data		Yes (Now recorded by GPs and available for all hospitalizations and other linked data (but not yet 100% from GPs))	Yes (However, it is available only where recorded, as it is not widely recorded in UK general practice)	No
Geographic Location		Eastern London, NI, Ireland, Northwest and West Midlands, Northeast, Scotland, South, Wales (5% of the UK population)	England, Wales, Scotland, Northern Ireland	All regions in the United Kingdom, excluding Scotland and Wales
Date of Birth Recorded		Yes	Yes (Year of birth is recorded, the birth month is also available for patients <15 years of age)	Yes (Year)
Death Recorded		Yes (Date/Month/Year)	Yes (Details are available where the physician is aware of the cause and date of death)	Yes (Only if diagnosis-related)
Availability of death certificate / autopsy information		Yes (All data is now available via link with central death data)	No (However, this is available upon request, subject to approval by ethics committee)	N/A
Economic Data				
Cost Data		No	Yes (Drug costs)	Yes (Prescriptions are linked to the IMS National Descriptor file, so the cost of therapy can be calculated)
Cost Denomination		N/A	British Sterling / Pounds	British Sterling / Pounds
Type of Cost Data		N/A	Yes (Retail drug pack price)	Yes (Treatment cost)
Surrogate Cost Data Link		Yes	No	N/A
Description of Surrogate Link		Yes (Costs can be applied based upon UK, national or regional/cost data that is easily available)	N/A	N/A

## CONCLUSION

A web-based directory of population research database profiles was developed to enable the identification of appropriate databases for pharmacoepidemiologic, economic, and health services research. Other applications may include serving as an educational tool and as a model for developing new healthcare databases.

### Limitations

Limitations included a short time line and budgetary constraints. Another limitation is that some profiles could not be included in B.R.I.D.G.E. TO DATA<sup>SM</sup> since some data centers with private or non-commercial databases have not authorized listing to date.

### Future Plans

B.R.I.D.G.E. TO DATA<sup>SM</sup> currently has ~80 database & registry profiles spanning 16 countries. Since B.R.I.D.G.E. TO DATA<sup>SM</sup> has been well received, our goal is to continue efforts and have ~200 profiles by December 2010, featuring databases from many other countries.

HOME MY COLLECTIONS SEARCH TUTORIALS GLOSSARY ABOUT QUESTIONS & FEEDBACK

**What can B.R.I.D.G.E. TO DATA do for you?**

- Find all possible databases with information on exposure and/or outcomes for pharmacoepidemiology studies, pharmaco-economic studies, and descriptive studies
- Find country-specific database details to conduct a population study describing drug utilization and/or costs by demographic and diagnostic groups
- Compare details from multiple databases including spontaneous reporting, longitudinal, claims, national statistics, and other database types
- Choose databases to assess the comparative population risk for two or more drugs
- Identify database resources to develop teaching materials

**GETTING STARTED**

- My Profile your profile information
- Search database details
- Add your database profile
- Save and Group your database collections
- Questions?

**MY DATABASE COLLECTIONS**

- First database collection
- Go to Database Collections >

**SAVED SEARCHES**

- 1st search try
- View My Saved Searches >

**MOST VIEWED DATABASES**

- United States Renal Data System (USRDS)
- National Disease and Therapeutic Index (NDTI)
- The Health Insurance Coverage Network (HICN)
- IMS Disease Analyzer - MedPlus® Germany
- Shanghai Food and Drug Administration Hospital Medical Record Database

**RECENTLY ADDED**

- SweDIS (Swedish Drug Information System)
- National Registry of Drug Induced Ocular Side Effects (NRODISE)
- Vigibase (WHO Global ICSR Database System)
- New Zealand's Mortality Database (MORT)
- Sexually Transmitted Diseases Surveillance System

Home Tutorials Overview Advisory Board FAQs Terms of Use Privacy Press Releases Contact Us

B.R.I.D.G.E. TO DATA™, DGI, Inc., 1616 R. Fort Myer Drive, Suite 1426, Arlington, VA 22206, USA. Tel: +1 703 896 0804 Fax: +1 703 894 8892 [info@bridgetodata.org](mailto:info@bridgetodata.org)

Copyright ©2010 DGI, Inc. All rights reserved.

# **Rationale and Development of an Online Directory of Database Profiles for Pharmacoepidemiology, Outcomes, and Population Research**

Kamani SA, Goehring Jr EL, Singh VP, Nguyen-Khoa BA, Kapasi AJ, Jones JK

DGI, Inc., Arlington, VA, USA

Presented at ISPOR 15<sup>th</sup> Annual International Meeting.  
May 15-19, 2010, Atlanta, GA, USA.



DGI Center for Health Research and Education Inc.

1616 N Fort Myer Drive, Suite 1430 • Arlington, VA 22209 USA

[www.bridgetodata.org](http://www.bridgetodata.org)

T: +1 703 894 0804

[info@bridgetodata.org](mailto:info@bridgetodata.org)