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

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OBJECTIVE

B.R.I.D.G.E. TO DATASM (www.bridgetodata.org) was developed as a web-based directory with detailed profiles of population research databases. This resource allows pharmacoepidemiology, pharmaceconomics 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 DATASM (Benefit-Risk Information for Drug Evaluations) was launched in 2009. B.R.I.D.G.E. TO DATASM is an advanced version of the original RAD-AR (Risk Assessment of Drug-Use & Response) book 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 DATASM team.

Rebranding the website 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.

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:

- The earlier template was updated to include 75 common fields covering the categories listed in Table 1.
- 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.
- As part of the goal to actively maintain B.R.I.D.G.E. TO DATASM, a quality assurance process involved systematic review and regular updates of each profile.

RESULTS

Comparison Feature: Demographic and Economic Data Elements

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.

B.R.I.D.G.E. TO DATASM was launched in November 2009 with 50 database profiles from USA, Canada, Europe & Asia.

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

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