International Journal of Population Data Science

Journal Website: www.ijpds.org

A National Concept Dictionary

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Overall objectives or goal

Most of the organizations that use population administrative data for research purposes have internal repository of validated definitions and algorithms of their own. Many of these concepts and definitions are applicable or at least adaptable to other organizations and jurisdictions. A comprehensive National (and potentially International) Concept Dictionary could help investigators to carry out methodologically sound work using consistent and validated algorithms using a shared pool of knowledge and resources.

The Institute for Clinical Evaluative Sciences (ICES) in Ontario, Canada has recently modernized its internal Concept Dictionary by adopting standard templates based on the Manitoba Centre for Health Policy (MCHP) Concept Dictionary, reviewing and updating existing content and tagging the concept entries with appropriate MeSH terms and data sources, and adding standard computer code (e.g., SAS coding) where appropriate. A SharePoint® web-based application has been developed to provide advanced tagging, searching and browsing features.

We envision a wiki-based Concept Dictionary hosted on a cloud-based environment with very granular access controls to provide enough flexibility for each participating organization to control their own content. This means each organization will be able to decide on how to share their own concepts (or part of them) with the public or internal users.

All content will be tagged with MeSH terms and as well with the organization's name that initially posts each entry. Other organizations which find the same concept applicable to their own use can tag the same entry with their organization name or refer to a secondary adapted entry if adaptation to fit their data and methodologies is required.

The Search feature will allow refining the search criteria by MeSH terms, data sources, and also organization/jurisdiction name.

Multiple layers of access controls will allow each organization to have their own groups of users with different standard privileges such as Local Administrators, Authors and Approvers (or Publishers).

The Approver (Publisher) users within each organization can publish each entry for internal or public view. This way, for example, a definition/algorithm can be viewable only within the organization until the validation process is complete, and then the entry can be made publically available, while some sections, such as computer code, can remain restricted to the organization.

We will discuss challenges in developing and maintaining such a platform including the costs, governance, intellectual property rights, copyrights and liabilities for the participating organizations.

The intended output or outcome

We aim to use this opportunity to form a working group from the interested organizations that are ready to participate and commit in developing this collaborative platform. After the conference, there will be follow up sessions with the members of the working group to plan and develop the online application.

http://dx.doi.org/10.23889/ijpds.v3i4.709