



## Insight: An ontology-based integrated database and analysis platform for epilepsy self-management research



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### ABSTRACT

We present *Insight* as an integrated database and analysis platform for epilepsy self-management research as part of the national Managing Epilepsy Well Network. *Insight* is the only available informatics platform for accessing and analyzing integrated data from multiple epilepsy self-management research studies with several new data management features and user-friendly functionalities. The features of *Insight* include, (1) use of Common Data Elements defined by members of the research community and an epilepsy domain ontology for data integration and querying, (2) visualization tools to support real time exploration of data distribution across research studies, and (3) an interactive visual query interface for provenance-enabled research cohort identification. The *Insight* platform contains data from five completed epilepsy self-management research studies covering various categories of data, including depression, quality of life, seizure frequency, and socioeconomic information. The data represents over 400 participants with 7552 data points. The *Insight* data exploration and cohort identification query interface has been developed using Ruby on Rails Web technology and open source Web Ontology Language Application Programming Interface to support ontology-based reasoning. We have developed an efficient ontology management module that automatically updates the ontology mappings each time a new version of the Epilepsy and Seizure Ontology is released. The *Insight* platform features a Role-based Access Control module to authenticate and effectively manage user access to different research studies. User access to *Insight* is managed by the Managing Epilepsy Well Network database steering committee consisting of representatives of all current collaborating centers of the Managing Epilepsy Well Network. New research studies are being continuously added to the *Insight* database and the size as well as the unique coverage of the dataset allows investigators to conduct aggregate data analysis that will inform the next generation of epilepsy self-management studies.

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*Insight* can be accessed at: <http://mew.meds.cwru.edu/>

### 1. Introduction

Persons with chronic health conditions can significantly benefit from self-management techniques, which consist of understanding their health conditions and adopting a set of behaviors to manage their conditions [1–5]. Epilepsy is one of the most common serious

neurological disorders, affecting an estimated 50 million persons worldwide [6], with 200,000 new cases reported each year [7]. Development and adoption of self-management techniques have been strongly recommended for persons with epilepsy to positively influence their prognosis and ability to manage the symptoms of epilepsy [8,9]. Patients with epilepsy experience repeated seizures that manifest as physical or behavioral changes that disrupt normal activities [10]. Repeated epilepsy seizures have a negative impact on quality of life, education, and employment, and also increase the risk of early mortality [11]. In addition, epilepsy as a chronic condition imposes a high economic burden on patients, their families, and society; in the US the total cost per year for medical expenditure and informal care for patients with epilepsy is estimated to be

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\$9.6 billion [12]. Some studies have described the burden associated with non-adherence to anti-seizure drugs, which can result in negative outcome for persons with epilepsy [13]. Therefore, there is clear need to develop and use approaches that improve the ability of people with epilepsy to control their seizures and improve their health.

Epilepsy self-management includes a set of behavioral practices that are likely to help patients better control their seizures and that may positively impact their symptoms as well as prognosis [8,14]. These self-management techniques are often categorized into three areas of: (1) treatment management (e.g., medication adherence), (2) seizure management (e.g., keeping track of seizures), and (3) lifestyle management (e.g., getting regular sleep, engaging in safe physical activity) [7]. Self-management techniques can reduce healthcare utilization by lowering the number of inpatient hospitalizations, inpatient days and visits to the Emergency Department [13]. Since 2007, the U.S. Centers for Disease Control and Prevention's (CDC) Prevention Research Centers (PRC) has funded the Managing Epilepsy Well (MEW) Network, a thematic research network whose mission is to advance the science of epilepsy self-management. CDC MEW Network programs are designed to enhance the quality of life of people with epilepsy [7]. A key feature of MEW Network self-management approaches has been to incorporate consideration of comorbidity, such as depression, and to address the pervasive problem of cognitive impairment among individuals with epilepsy. The MEW Network currently comprises eight PRCs (connected with accredited schools of public health or schools of medicine with a preventive medicine residency program) that collaborate on epilepsy self-management research.

### 1.1. Motivation for integrated analysis of MEW network data

The MEW Network was founded on principles of community-based participatory research. Each collaborating site develops its own capacity to conduct independent research with community partners to respond to variations in the needs and interests specific to these communities. Since 2007, each site has collected, securely stored, analyzed, and published their study findings. However, pooled data from both completed and ongoing MEW self-management studies represent valuable, untapped information relevant to the epilepsy self-management research community. Integrative analysis of these datasets will enable epilepsy researchers to gain new insights into various aspects of epilepsy self-management that may ultimately help people with epilepsy and their families. A MEW database can harness the power of aggregated data to better understand the different factors that impact people with epilepsy, for example identifying the association between seizure frequency and quality of life or depression. Indeed, effective secondary use of healthcare data for advancing research, a critical aspect of biomedical informatics, maximizes the value of existing data [15,16]. A database containing aggregated data collected by the MEW Network sites will potentially allow researchers to propose new studies on self-management techniques across subpopulations, geographical locations, and healthcare settings with sufficient statistical power.

There are many MEW study-specific data repositories that store data using various approaches, including relational databases, MS Excel spreadsheet, and paper forms [17]. These data repositories are conceptually similar to "data silos" with limited or no support for data sharing, integration, and secondary analysis. In addition, there is limited terminological standardization across epilepsy research studies, which impedes integrated analysis of data across different studies. Similar to initiatives such as the International Epilepsy Electrophysiology Portal (IEEG-Portal), which aims to create a database for epilepsy electrophysiological data [18], there is a clear need to develop an integrated and scalable database for

epilepsy self-management research data. To meet this need, a MEW Network database workgroup was established in 2014 to explore the feasibility of a common epilepsy self-management database. The goals of the workgroup included establishment of an analytical platform that would eventually enable members of the MEW Network to interactively create cohorts of patients for secondary data analysis.

The consortium of researchers involved in this initiative included representatives from all the MEW Network collaborating centers. Since September 2014, a Steering Committee representing research data stakeholders, has developed a standardized process for sharing de-identified study data across the MEW Network through a Data User Agreements (DUA) and provides continued oversight and guidance for the expansion, management and use of the MEW self-management study data for research purposes. The MEW Network is currently coordinated by Dartmouth College. While the MEW Network currently includes 8 collaborating centers, a total of 11 centers have been active during the extant tenure of the MEW Network, including previously and currently funded centers. These centers are: Emory University; the University of Texas Health Center at Houston; the University of Michigan; the Dartmouth Institute at the Geisel School of Medicine; New York University; the University of Arizona; the Morehouse College School of Medicine; the University of Illinois at Chicago; the University of Minnesota; the University of Washington at Seattle; and Case Western Reserve University (CWRU).

The development of the *Insight* MEW Network data analytics platform (hereafter called *Insight*) is led by CWRU. Data contribution from participating sites is purely voluntary and not required under the respective CDC PRC cooperative agreements. As of November 2015, data from five research studies have been integrated into *Insight*. The five research studies have a total of over 400 de-identified participants with more than 7552 data points represented using 16 MEW Common Data Elements (CDEs) recommended for inclusion in study designs by the MEW Network to standardize the terminology in the database. Although *Insight* contains only de-identified data from the research studies, the data is stored using standard best practices in terms of data security, data accessibility, and maintenance of user access log data.

### 1.2. Aims of the Insight database

*Insight* is being developed as a national resource for the epilepsy self-management research community. To the best of our knowledge there is no existing epilepsy self-management data analysis platform similar to *Insight*, which together with the integrated dataset features a rich set of data exploration and query functions for easier data analysis by epilepsy researchers. The four primary goals of *Insight* are: (1) integrate data using MEW CDEs as standard terminology, (2) enable users to interactively explore the data using visualization functions, (3) provide an intuitive and flexible provenance-enabled query environment for users to perform cohort identification; and (4) serve as the basis of a proposed epilepsy self-management registry. *Insight* uses an epilepsy domain ontology called Epilepsy and Seizure Ontology (EpSO) [19] to support advanced data exploration, query composition, and execution strategies through use of ontology reasoning for "query unfolding" and for reconciling semantic heterogeneity. These techniques are described in detail in the next section.

## 2. Material and methods

Data from a MEW Network research study are added into *Insight* in accordance with a standardized protocol. After a DUA is completed between the *Insight* team and a specific MEW Net-

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