International Journal of Population Data Science

Evaluation of the Western Australian population based data linkage Intellectual Disability Exploring Answers (IDEA) surveillance system

Strobel, N[1,2], Bourke, J[3], Leonard, H[3], Richardson, A[2], Edmond, K[1], and McAullay, D[1]

[1] The University of Western Australia
[2] Australian National University
[3] Telethon Kids Institute

Introduction

The IDEA system is a population-based data linkage system for intellectual disability (ID), which combines data from two government departments. Due to recent policy changes the future of the IDEA system is unknown. Understanding the IDEA system's strengths and limitations will provide data custodians with the opportunity to re-design the system.

Objectives and Approach

An evaluation of the IDEA surveillance system was undertaken to assess the quality, efficiency and usefulness of the system. The primary objectives were to evaluate systematically and objectively the attributes of the system and provide recommendations to data custodians and stakeholders to strengthen the surveillance system.

The evaluation was based on the methods from the 2001 U.S. Centers for Disease Control and Prevention guidelines on evaluation of public health surveillance systems. We assessed the following system attributes: usefulness, simplicity, flexibility, data quality, acceptability, representativeness, timeliness, and stability. This was completed by process observation, semi-structured interviews and data analysis.

Results

Our results found the IDEA system was flexible, acceptable, representative, timely and stable. Given data linkage process and maintaining confidentiality the data linkage process was considered relatively simple. We compared individuals in the IDEA surveillance system to a sub-group of individuals, cerebral palsy with ID, to the mandatory reporting surveillance system WARDA-CP. There were 582 individuals identified in the WARDA-CP surveillance system as having cerebral palsy and ID. Of those identified 501 (86.1%) were also in the IDEA database and 81 (13.9%) were not. There were little differences in WARDA-CP cases that were not identified in the IDEA system between Indigenous status, sex and place of residence.

Conclusion/Implications

The IDEA system has successfully been used to understand prevalence rates and inform resource allocation. Advocacy organisations could play an important role in the sustainability of the system. Additional variables or enhanced surveillance for functional capacity could strengthen the system and provide important information to inform policy and practice.