Development of the Nova Scotia Diabetes Repository

Background: The Diabetes Care Program of Nova Scotia (DCPNS) maintains a comprehensive registry of clinically confirmed diabetes (DM) cases; however, only Diabetes Centre attendees are represented (≈70% of DM population). The Nova Scotia Atlee Perinatal Database (NSAPD) and Nova Scotia Seniors' Pharmacare Database (NSSPD) also contain gold standard DM cases, but for a limited population. The National Diabetes Surveillance System (NDSS) derives nationally comparable DM statistics using administrative data; however, these cases are estimated not clinically confirmed. Combining data from various Programme Databases with routinely collected administrative data could greatly enhance DM case ascertainment. In Nova Scotia, all of these data sources are readily linkable, making the province an ideal sentinel surveillance site for DM in Canada.

Aims: To determine technical and organizational requirements for combining data from disparate sources into an ongoing Nova Scotia Diabetes Repository (NSDR)

Methods: An advisory group with ≥1 representatives from each partner as well as expert consultants and several working groups identified organization and technical requirements for constructing a sustainable NSDR. These issues were addressed and a provisional NSDR was constructed using data from the DCPNS Registry, NSAPD, NSSPD, and NDSS. The repository was tested using 7 preapproved requests.

Results: Each partner has a specific mandate to collect personal information about the population it serves. Sharing this data across programmes required a Privacy Impact Assessment. Some ethical and jurisdictional issues were also clarified. To streamline access, a single Application for Access to Provisional NSDR Data was developed to replace several Programme-specific applications.

Programme-specific case definitions were used to extract 107,643 unique DM cases from 1996/97 to 2005/06 for the provisional NSDR. Of the 81,447 cases for 2005/06, 33% were found in 1 source, 48% in 2 sources, and 19% in 3 sources. No single case appeared in all 4 sources.

Discussion: Many fully engaged partners collaborated successfully to develop the provisional NSDR. This work will in turn attract more partners, further enhancing the NSDR. A third of DM cases were contributed by a single partner, highlighting the importance of collaboration to DM surveillance. Merging disparate data sources identified several data quality issues, resulting in improved data quality for both the NSDR and the contributing partners.