

# First Nations Diabetes Registry & Surveillance System (FNDSS): A Critical QI Companion Tool



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## BACKGROUND

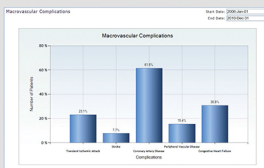
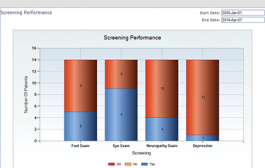
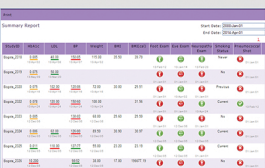
- Indigenous peoples around the globe are disproportionately affected by T2DM and related complications<sup>1</sup> yet high quality national surveillance data is lacking<sup>2</sup>
- QI interventions that have used T2DM surveillance data have shown improvements in glycemic control, monitoring, complication screening rates, reductions in emergency department visits and avoidable hospitalizations, and estimated reduction in healthcare expenses<sup>3-4</sup>
- Canada's national surveillance system lacks patient-level clinical data necessary to inform health interventions
- FNDSS, piloted with 5 First Nations communities in 5 provinces in 2011, demonstrated its potential for creating a national surveillance system for First Nations<sup>5</sup>
- FNDSS features ranked 'highly important' by users during the pilot included the ability to tailor clinical reports, security, and community-level clinical reports and graphs<sup>6</sup>
- Impact of FNDSS identified during the pilot included enhanced ability to track diabetes rates and identify gaps in care<sup>6</sup>

## FORGE AHEAD RESEARCH PROGRAM

- A 5-year national QI research program<sup>7</sup> to enhance chronic disease management in First Nations communities
- Program components: QI Workshops & Action Periods, Readiness Consultations, Diabetes Registry & Surveillance System, and QI Coaching and Support
- Core tenets: Community-Driven, Participatory Research, Culturally Appropriate, and Honoring OCAP® principles
- 9 First Nations communities from 5 provinces completed the full program

## FNDSS FEATURES AND IMPLEMENTATION

- Web-based registry and clinical tracking system
- Community portals allow secure login with levels of access determined by local community leadership
- Built in import/export tools for data migration from Electronic Medical Record (EMR) systems
- Patient and community level reports and graphs
- Implemented in 8 partnering First Nations communities in FORGE AHEAD
- Local Community Data Coordinators (CDCs) were remotely trained and populated the system based on community resources
- The CDCs received regular support and further training if needed throughout the intervention



## RESEARCH METHOD

- Semi-structured interviews with consenting program participants (n = 27)
- Data coded using grounded theory to progressively identify themes by integrating categories of meaning

## MAIN THEMES

### Theme 1: Using FNDSS Information Features

*"I think initially it was almost overwhelming and then to input all that data.... and when it got to the point where they had it all inputted that they can get the graphs and that come out and start testing it with clients that's I guess is when they see the real benefit of using it. Because it was a tool that allowed I guess clients to see where they were doing really good and where they needed to work on. So, yeah they were very pleased with that."*

### Theme 2: Impact of Local and External Contextual Factors

*"And so we-we weren't covered like with it under [Institution (provincial health services)] because we're federal, they're provincial, and so not every reserve has (provincial EMR system). I think quite a few do, but not everybody does. But once [Name (Community Data Coordinator)] had access to that, that just made her life so much easier, she said she was able to go through way more charts in a day because it would take her hours to do ... scan the charts. Some of them were page and page and page. And not only that, we have charts like in the medical clinic, we have charts in diabetes, we have charts in community health, and we have charts in home care, and so not all of the information was located in one chart. And that's because our building is not situated so that there's one-one admission place. So it was, I think, quite a challenge for her initially, but once this was implemented she was able to see the results of testing that had been done off reserve, and I think they were much happier with the results."*

## KEY FINDINGS

- Substantial efforts required by the CDCs to develop the registry and enter clinical data
- Multiple contextual challenges at the local and external levels created significant delays in data entry affecting how FNDSS was used as a QI tool
- Despite delays in data entry, healthcare providers were able to see a nuanced picture of the burden of diabetes in their community and targeted some PDSAs to make clinical improvements
- Graphs and reports from FNDSS proved to be useful for QI initiatives; they were used by some healthcare providers during patient visits

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## ACKNOWLEDGEMENTS

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Diabetes Alliance – www.uwo.ca/DiabetesAlliance

