North Carolina Diabetes Registry

Data Management, Analytics, and Visualization

North Carolina

Initiated: October 2017

Completed: June 2018

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EXECUTIVE SUMMARY

North Carolina has the 12th highest rate of diabetes in the United States. More than 11 percent of our adult population is diabetic, and a third of the population is considered pre-diabetic. This is a significant burden for the state, from both a public health and a cost perspective. People with diabetes have medical expenses approximately 2.3 times higher than those who do not have diabetes.[1]

The American Diabetes Association estimates the annual direct cost of diabetes diagnoses in North Carolina to be $7.7 billion, with another $2.9 billion in indirect medical costs.

Our health practitioners and policymakers are working hard to combat this epidemic, but they need data to make informed decisions about diabetes management, both at the patient and population level. With the introduction of NC HealthConnex, our state-managed health information exchange, we saw an opportunity to harness the data collected to inform health policy decisions.

Approximately 98 percent of medical providers in the state are required to connect to NC HealthConnex to securely share patient encounter information, resulting in a robust statewide data set.

The North Carolina Health Information Exchange Authority (NC HIEA), which manages NC HealthConnex, partnered with the Department of Health and Human Services Division of Public Health (DPH) to build a tool within NC HealthConnex to help policymakers understand more about the prevalence of diabetes in the state.

The Diabetes Registry was built as an extension of NC HealthConnex, using patient encounter data that providers are already required to submit. This structure provided maximum benefit with no extra effort from the medical community or diabetes patients.

This tool has allowed DPH and health practitioners to make informed policy decisions regarding diabetes, related conditions, and risk factors. Through the registry, DPH has been able to:

- Identify where there may be geographical areas and/or other populations that would benefit from public health programs;
- Augment other DPH data sources with de-identified clinical information about patients with diabetes;
- Identify diabetes clusters and high-risk populations including health disparities;
- Assess trends in prevalence and control;
- Plan interventions by identifying priority populations and existing gaps in services, both clinical and community-wide, and target those areas; and
- Evaluate the effectiveness of the interventions by assessing the health outcomes.
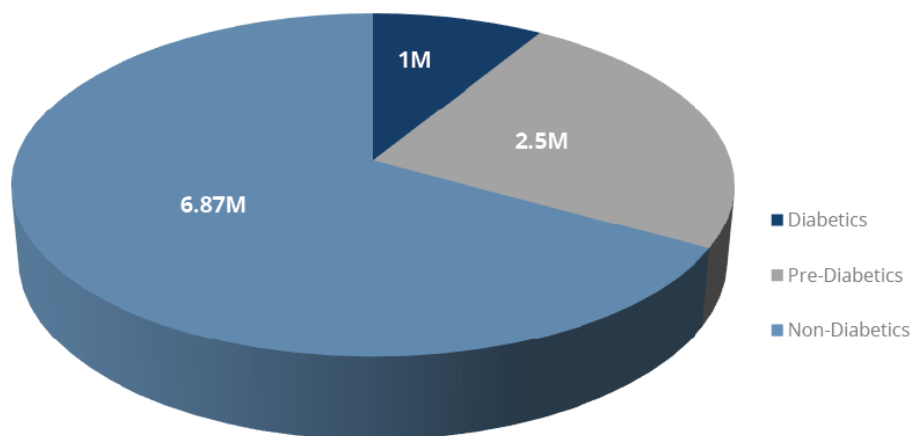
As more providers connect to NC HealthConnex, the registry will provide an even more complete picture of diabetes in North Carolina, leading to better decisions and targeted interventions to protect and promote the health, safety, and well-being of North Carolinians.

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[1] http://main.diabetes.org/dorg/PDFs/Advocacy/burden-of-diabetes/north-carolina.pdf

CONCEPT

Diabetes is a growing epidemic in the United States, affecting all sociodemographic groups. In the last 30 years, prevalence nationwide has increased 26 percent. In 2017, North Carolina had the 12th highest prevalence of adult diabetes, with over 11 percent of the total adult population diagnosed. Additionally, approximately 30 percent of the adult population is prediabetic. The American Diabetes Association estimated the total cost of direct medical expenses for diagnosed diabetes in North Carolina to be $7.7 billion annually. The same study estimated another $2.9 billion in indirect costs of lost productivity resulting from diabetes[2].

Prevalence of Diabetes and Pre-Diabetes in NC
(Pop. of ~10.27M)

1M
2.5M
6.87M

- Diabetics
- Pre-Diabetics
- Non-Diabetics

https://highpointctc.com/2018/06/15/an-inside-look-at-glucose-clamp-studies-in-diabetes-patients/

One of the roles of state government is to advance the health, safety, and well-being of the people we serve. The NC Department of Health and Human Services Division of Public Health (DPH) plays a vital role in this effort, collaborating with local health departments, hospitals, community health centers, practitioners, community agencies and organizations throughout the state and nation. Diabetes is one of the major issues that DPH addresses.

Policymakers and health practitioners need data to make informed decisions about diabetes management both at the population and patient level. North Carolina has one of the largest health information exchanges (HIE) in the country, with over 6.9 million unique patients and over 41,500 providers contributing records. The HIE, called NC HealthConnex, links more than 4,500 health care facilities, including hospitals, physician practices, long term care facilities, local health

NC HealthConnex Statistics
- 6.9 million+ unique patients
- 41,500+ providers with contributed records
- 4,500+ contributing health care facilities
- 52 million+ continuity of care documents (CCDs)
- 187 unique EHRs engaged
- 6 border and intra-state HIEs connected

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[2] Supplementary Table A-16. State level prevalence and cost burden of diabetes, 2017
http://care.diabetesjournals.org/content/diacare/suppl/2018/03/20/dci18-0007.DC1/DCi180007SupplementaryData.pdf

departments, behavioral health providers, Federally Qualified Health Centers (FQHCs), Rural Health Clinics (RHCs), radiology centers and others. More than 4,000 additional facilities are currently in the onboarding process, including laboratories and Emergency Medical Services.

DPH worked with the North Carolina Health Information Exchange Authority (NC HIEA), which manages NC HealthConnex, to leverage the data collected in NC HealthConnex to develop the Diabetes Registry. The registry tracks the clinical care and outcomes of the patient population in North Carolina diagnosed with or presenting signs or symptoms of diabetes.

The registry offers users a dashboard built on SAS Visual Analytics and is integrated with the HIE platform via the SAS Analytics Environment. To produce the metrics shown on the dashboard, code-based definitions are used across several clinical data classes including diagnosis, lab results, procedures, and vitals. No additional effort is required on the part of providers connected to NC HealthConnex – the registry pulls from the encounter data that they already submit. The dashboard is published for use by the NC Department of Public Health (DPH) and is anonymized to support their research-based use case.

SIGNIFICANCE AND IMPACT

Our public health officials work to increase linkages between clinical providers, community organizations, and public health agencies, but have historically lacked accurate and timely data to estimate the prevalence of diabetes and diabetes complications, especially for small areas. Prior to the introduction of the Diabetes Registry, DPH relied heavily on the Behavioral Risk Factor Surveillance System (BRFSS) to estimate statewide prevalence rates. BRFSS data are self-reported and are subject to recall bias, and it does not include individuals residing in nursing homes and households without telephones. As a result, it does not provide a complete picture of diabetes in North Carolina.

The Diabetes Registry, with its extensive, clinically reported data, provides a more complete picture of diabetes in North Carolina and is a valuable tool for population health management and program planning.

Users of the registry can graphically display:

Diabetes prevalence by county: The registry provides a view of the diabetic population in each county. Users can filter the diabetic population using demographic filters. Patients are displayed on a map based on their most recent home address. Data is also displayed in a table which is sorted by county name. Information in the table includes county name, total number of patients who have data in NC HealthConnex, and the percentage of all patients with data in NC HealthConnex with diabetes, hypertension, and high cholesterol. Additionally, a bar chart displays diabetes prevalence for the 10 counties with the highest rates of diabetes.

Health indicators: Users can drill down to view details based on their selections on the diabetes prevalence by county tab. Users can select additional filters to view the number and prevalence of diabetes and the number of diabetic patients by zip code within the county(ies) selected. Patients are displayed in a map, table, and bar chart similar to that presented on the prevalence by county tab. Additionally, this tab displays the percentage of patients that have any of the three comorbidities shown

(hypertension, kidney disease, high cholesterol) and the results of their most recent smoking status screening, BMI measurement, blood pressure measurement, LDL test, and HbA1c test. If a patient does not have results for one of the screenings, measurements, or tests, they will display as "No Recent Test."

Health indicators trends: This shows quarterly trends in the number of patients with value set codes to
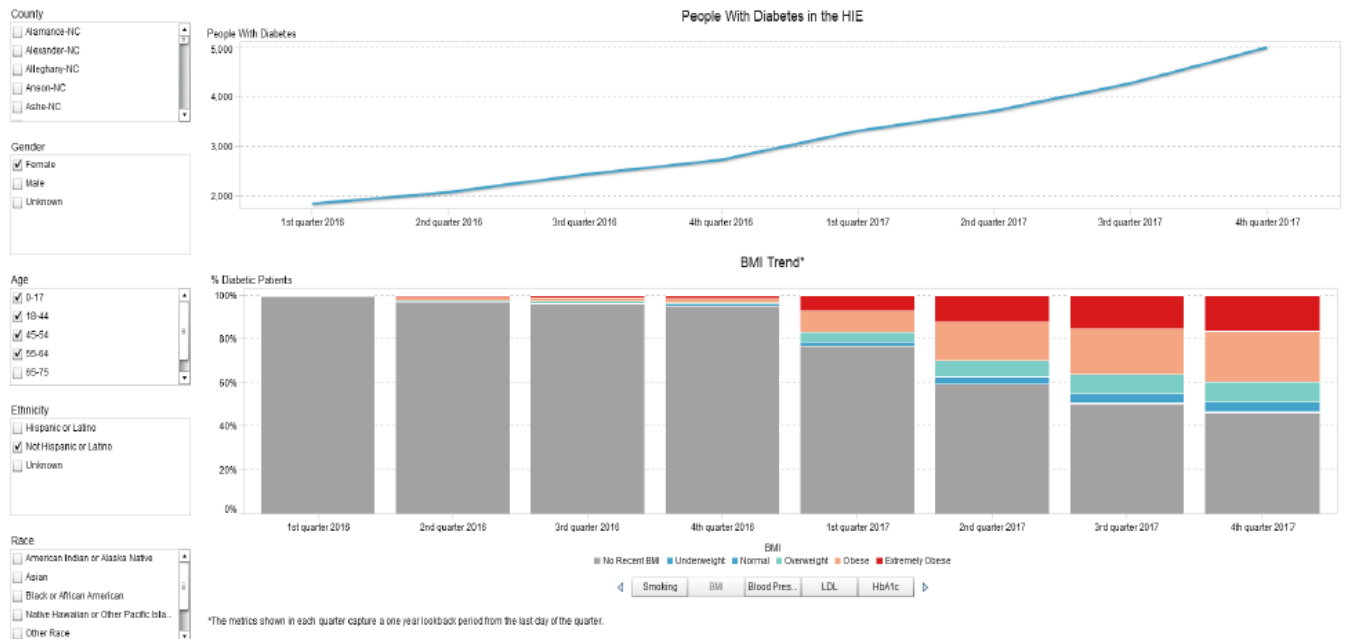

indicate they have diabetes.

Definitions: Codes and code systems that were used to define diagnoses, lab results, procedures, and vitals for this report.

The data in the registry is used to make informed health policy decisions on how to best reduce the rates, risks, and comorbidities of diabetes. DPH regularly tracks the clinical care and outcomes of the patient population in North Carolina diagnosed with our presenting signs or symptoms of diabetes. This information is used to:

- Identify where there may be geographical areas and/or other populations that would benefit from public health programs;
- Augment other DPH data sources with de-identified clinical information about patients with diabetes;
- Identify diabetes clusters and high-risk populations including health disparities;
- Assess trends in prevalence and control;
- Plan interventions by identifying priority populations and existing gaps in services, both clinical and community-wide, and target those areas; and
- Evaluate the effectiveness of the interventions by assessing the health outcomes.

For example, if DPH or another health organization wants to target interventions for non-Hispanic female diabetic patients under the age of 65, they can use NC HealthConnex and the Diabetes Registry to visually display the prevalence by location.
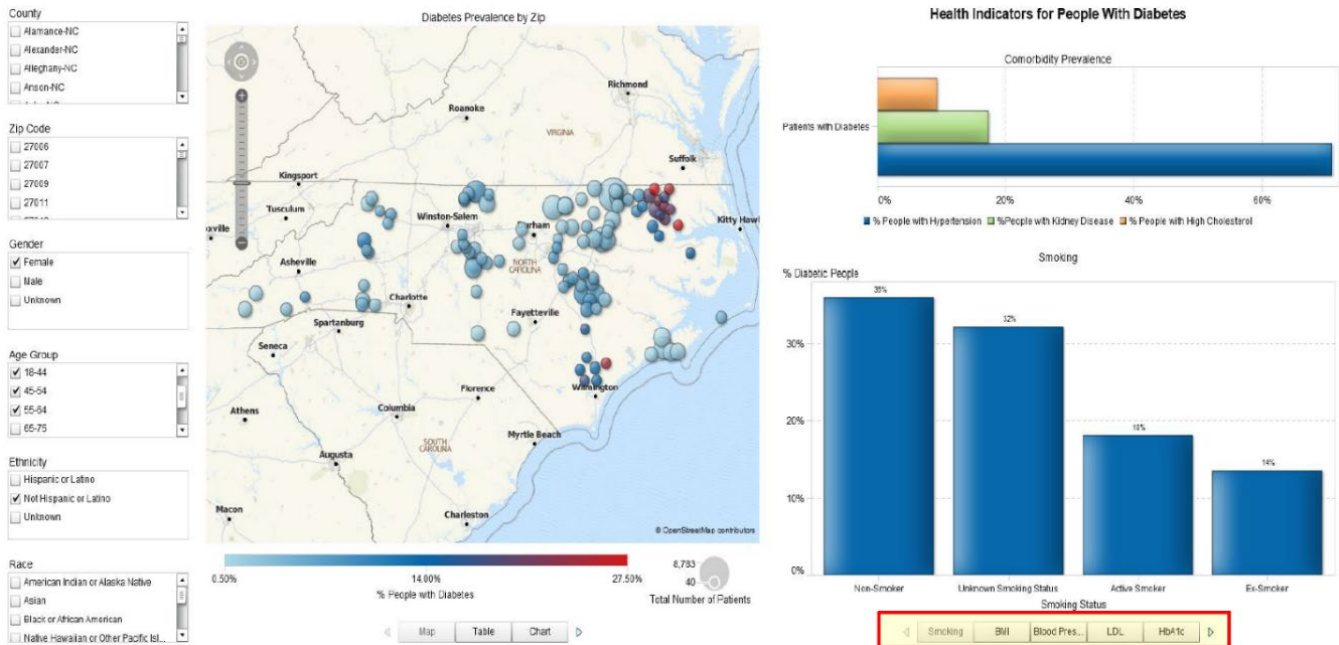
The Diabetes Registry was the first of several registries developed within NC HealthConnex, and was a huge success. Other registries currently in use include the Electronic Laboratory Reporting registry and the North Carolina Immunization Registry.

As more providers connect to NC HealthConnex, the registry will provide an even more complete picture of diabetes in North Carolina. With access to this data, we can make better decisions and provide targeted interventions to advance the health, safety, and well-being of our residents.