



NORTH CAROLINA HEALTH INFORMATION EXCHANGE AUTHORITY

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Advisory Board Update on the Stroke Registry
December 8, 2022



Justice-Warren Heart Disease & Stroke Prevention Task Force

Start With Your Heart
Justice-Warren Heart Disease & Stroke Prevention Task Force



Coverdell National Acute Stroke Program

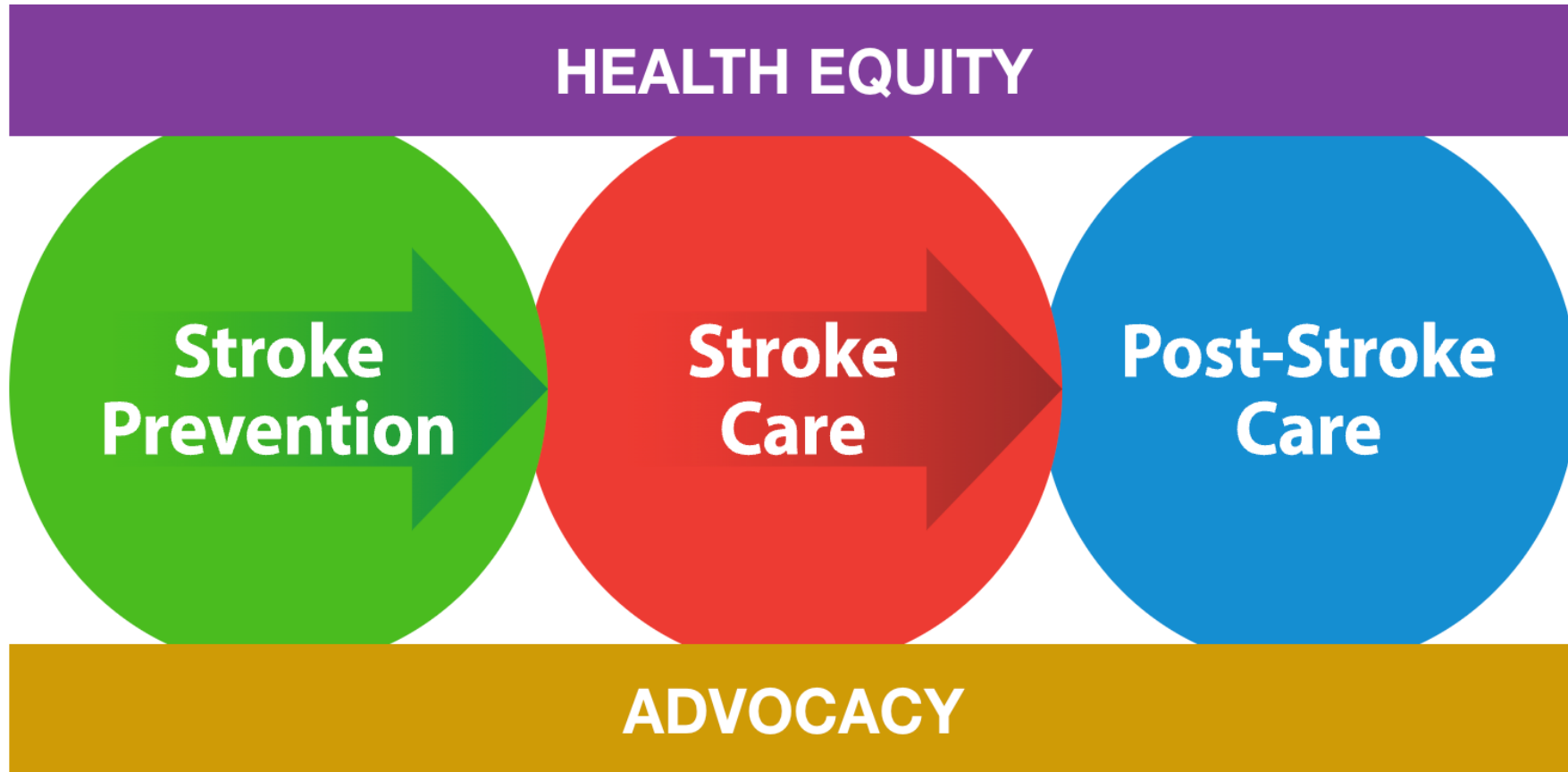
Stroke Advisory Council



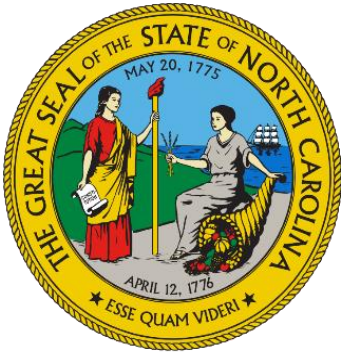
startwithyourheart.com



Role of Stroke Advisory Council



Partnerships



NC DEPARTMENT OF
HEALTH AND HUMAN SERVICES

Division of Public Health

Community & Clinical
CONNECTIONS
for Prevention & Health
Branch NORTH CAROLINA
DIVISION OF PUBLIC HEALTH



PAUL
Coverdell
NATIONAL ACUTE STROKE PROGRAM



NC **HealthConnex**
Powering Health Care Outcomes

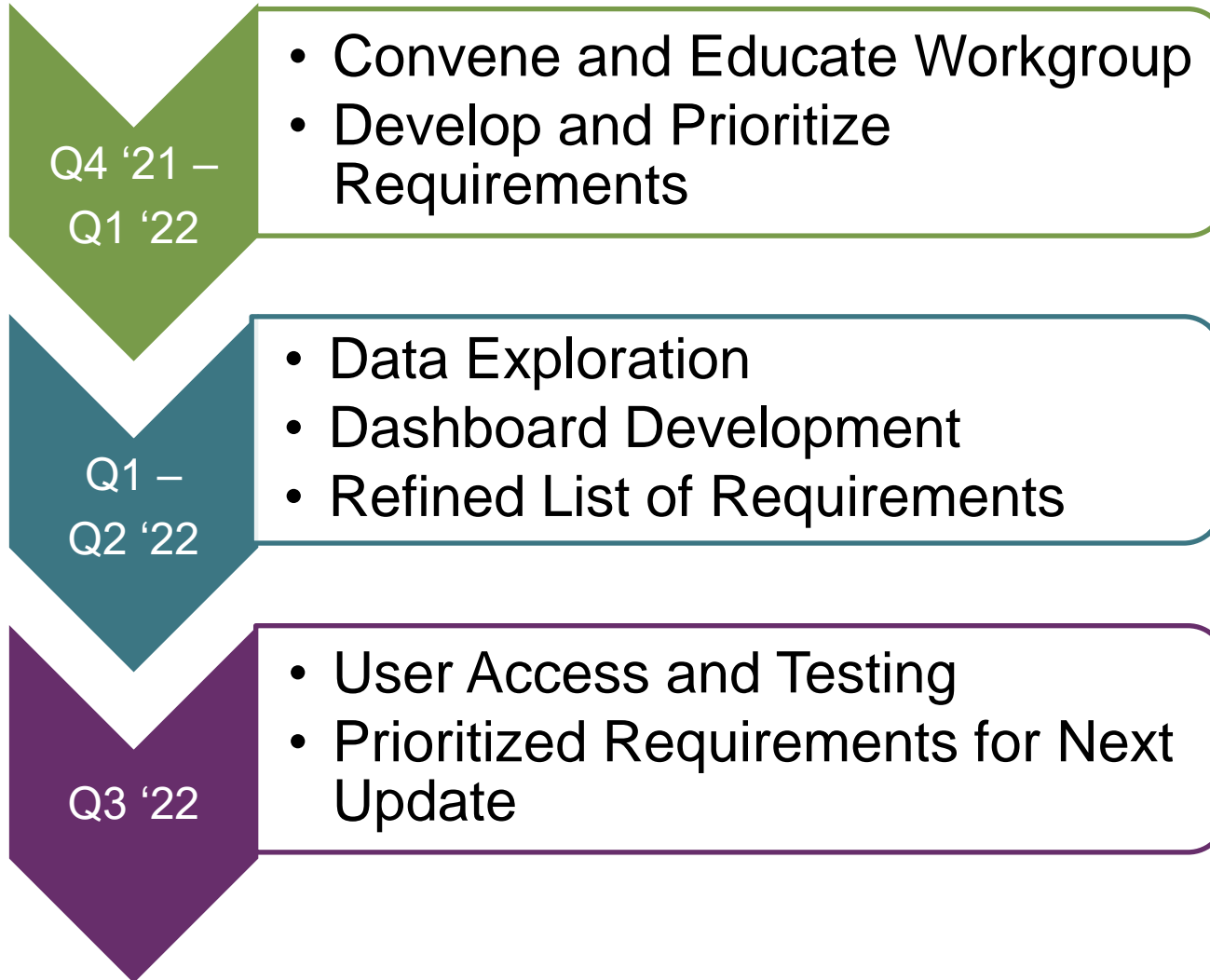
Goals of NC Coverdell Stroke Program

- Build a Stroke Registry within NC HealthConnex
- Leverage EHR and HIT to Monitor and Address Disparities
- Strengthen the Stroke System of Care
- Provide Workforce Development Training
- Build and Strengthen Partnerships
- Fund QI Projects

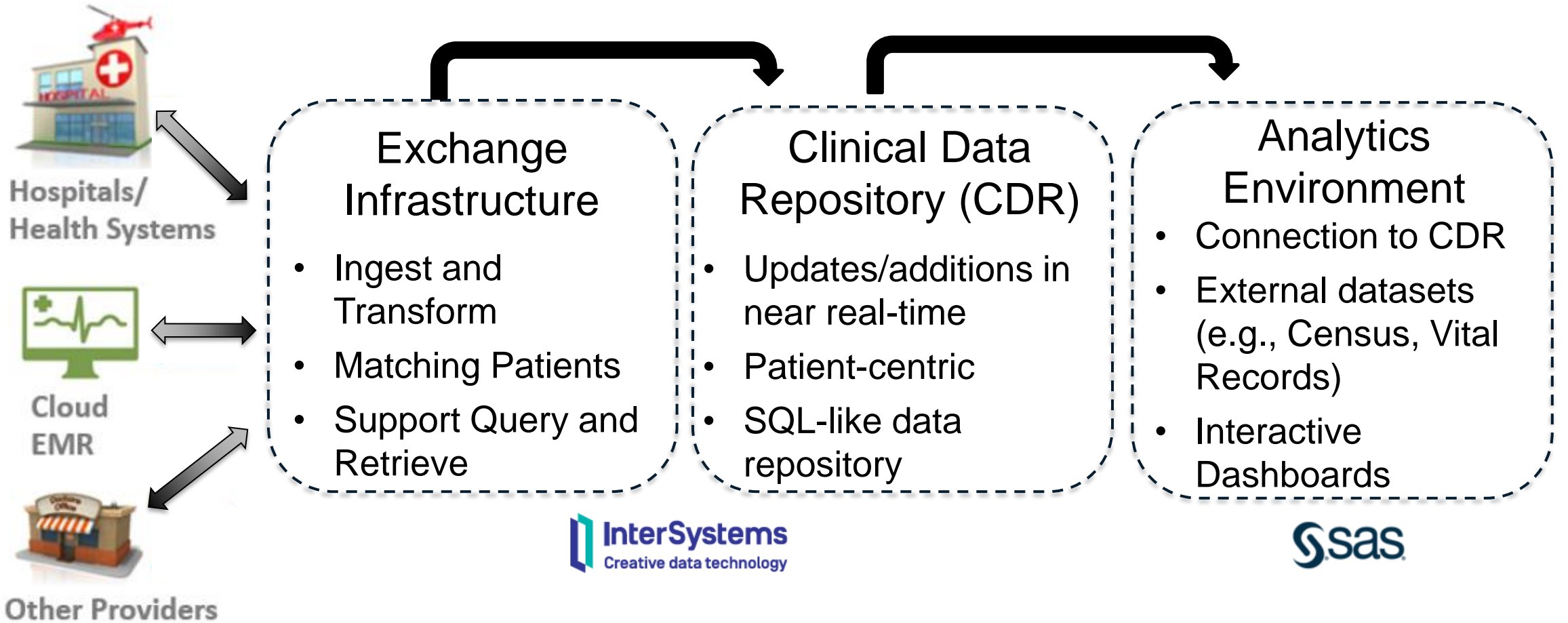
Stroke Registry – Workgroup Approach

- Convene workgroup of clinical and data experts
- Understand data available in NC HealthConnex & other similar NC HealthConnex Services
- Develop broad requirements across all functions of the Stroke Registry:
 - Define code lists (e.g., ICD-10, SNOMED) to classify stroke patients and identify clinical indicators
 - Identify key data fields for grouping and organizing the data (e.g., age group and gender of the patient)
 - Determine how to best visualize the information

Stroke Registry – Development Timeline & Milestones



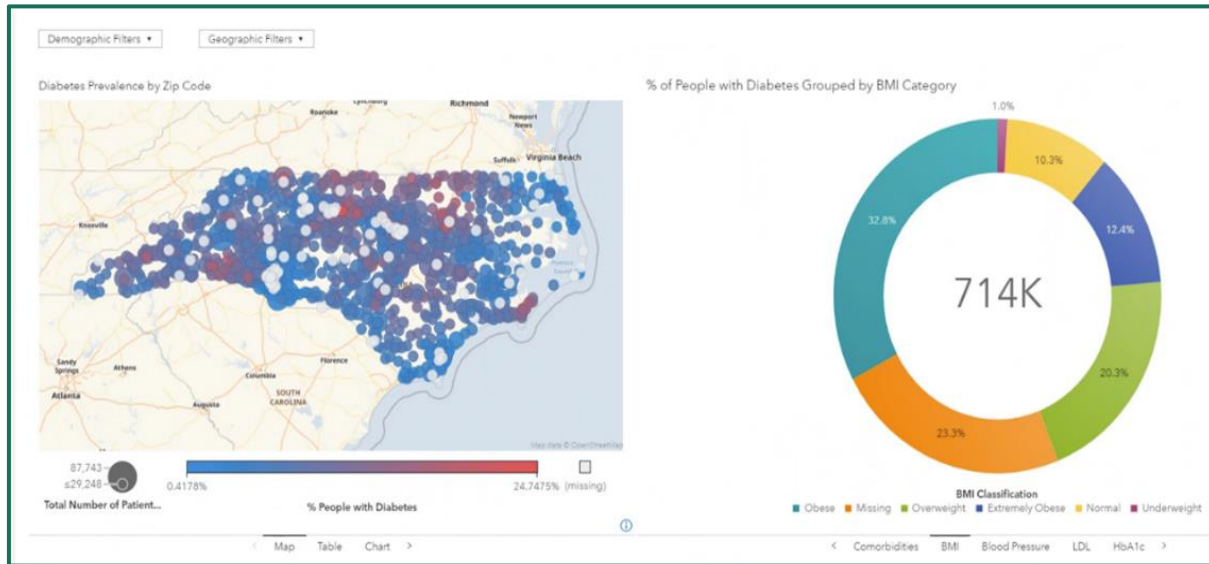
Stroke Registry – High Level Data Flow



NC HealthConnex as a Population Health Tool

- Chronic Disease Registries
- Tracking Cohorts of Patients, e.g., COVID
- Data Extracts for Permitted Use Cases

Diabetes Registry



Medicaid COVID Dashboard



Stroke Registry – End-User Info and Data Definitions

Two examples of documentation included within the Stroke Registry Dashboard:

- Information about what data is included in each section
- Data definitions at the detail code level

Welcome : Stroke Prevalence by Patient Address Encounters by Organization Trends He > ☰

Stroke Registry

North Carolina Health Information Exchange

Stroke Registry Purpose:
Serves as an analytical tool to provide essential information on stroke epidemiology, management, and outcomes.

Stroke Prevalence by Patient Address:
Provides a view of stroke population by stroke type (ischemic stroke, hemorrhage, transient ischemic attack, cerebral infarction, stroke complicating pregnancy), region, county and county subdivision. Stroke population using demographic, geographic, and other filters. Patients are displayed on a map by their most recent address. A table shows the number of patients by county and stroke type. Finally, users can view a distribution of patients by age.

Welcome Stroke Prevalence by Patient Address Encounters by Organization Trends Health Indicators Code Definitions :

Code Definitions

< Diagnosis Code Table Region Table >

CodeSystem	Code Groups	Code	Description
LOINC	Blood Pressure	8462-4	Diastolic blood pressure
LOINC	Blood Pressure	8480-6	Systolic blood pressure
SNOMEDCT	Blood Pressure	271649006	Systolic blood pressure (observable entity)
SNOMEDCT	Blood Pressure	271650006	Diastolic blood pressure (observable entity)
SNOMEDCT	Blood Pressure	399007006	Left ventricular peak diastolic tissue velocity during atrial systole (observable entity)
SNOMEDCT	Blood Pressure	399304008	Systolic blood pressure on admission (observable entity)
SNOMEDCT	Blood Pressure	400974009	Standing systolic blood pressure (observable entity)
SNOMEDCT	Blood Pressure	400975005	Standing diastolic blood pressure (observable entity)
SNOMEDCT	Blood Pressure	407555005	Sitting diastolic blood pressure (observable entity)
ICD-10-CM	Carotid Artery Disease	I25.1	Atherosclerotic heart disease of native coronary artery
ICD-10-CM	Carotid Artery Disease	I25.10	Atherosclerotic heart disease of native coronary artery without angina pectoris

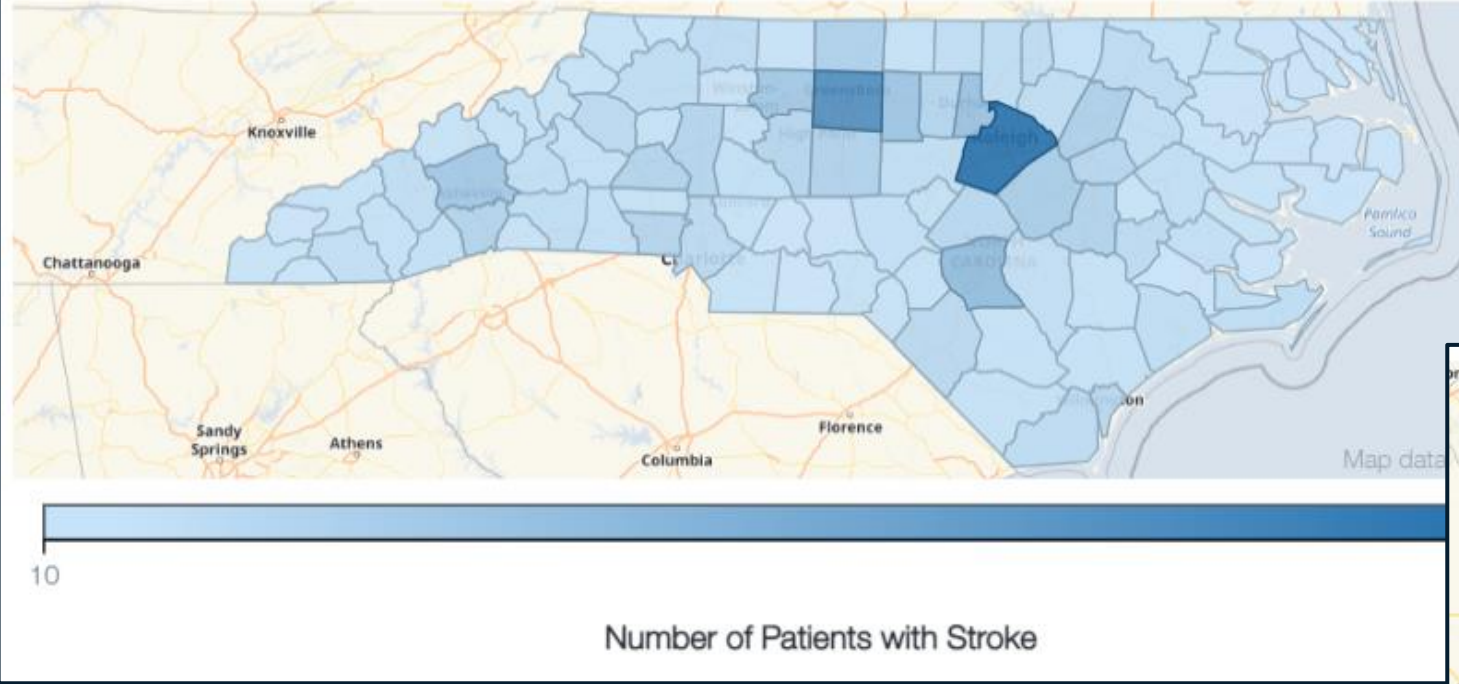
Select Code Group

- Blood Pressure
- Carotid Artery Disease
- Carotid Artery Stenosis

Search County in Region Table

Stroke Registry – Prevalence

Number of Patients with Stroke by County



Number of Patients with a Stroke Diagnosis, by county and zip code of patient residence

Zip Code:	27610
Number of Patients with Stroke:	1,174
County:	Wake

Stroke Registry – Filter by Many Characteristics

Sections of the dashboard can be filtered by characteristics of the Stroke, Patient or Encounter

Stroke Type

- Ischemic
- Hemorrhagic
- Pregnancy
- TIA

Gender

- Female
- Male
- Unknown/Missing

Age Group

- 0-18
- 19-44
- 45-64
- 65-74
- 75-84
- 85+


Ethnicity


- Hispanic or Latino
- Not Hispanic or Latino

Race

- American Indian or Alaska Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- Other
- Unknown/Missing
- White

Encounter Date


Jan2021  Sep2022

Jan2021  Sep2022

Encounter Type

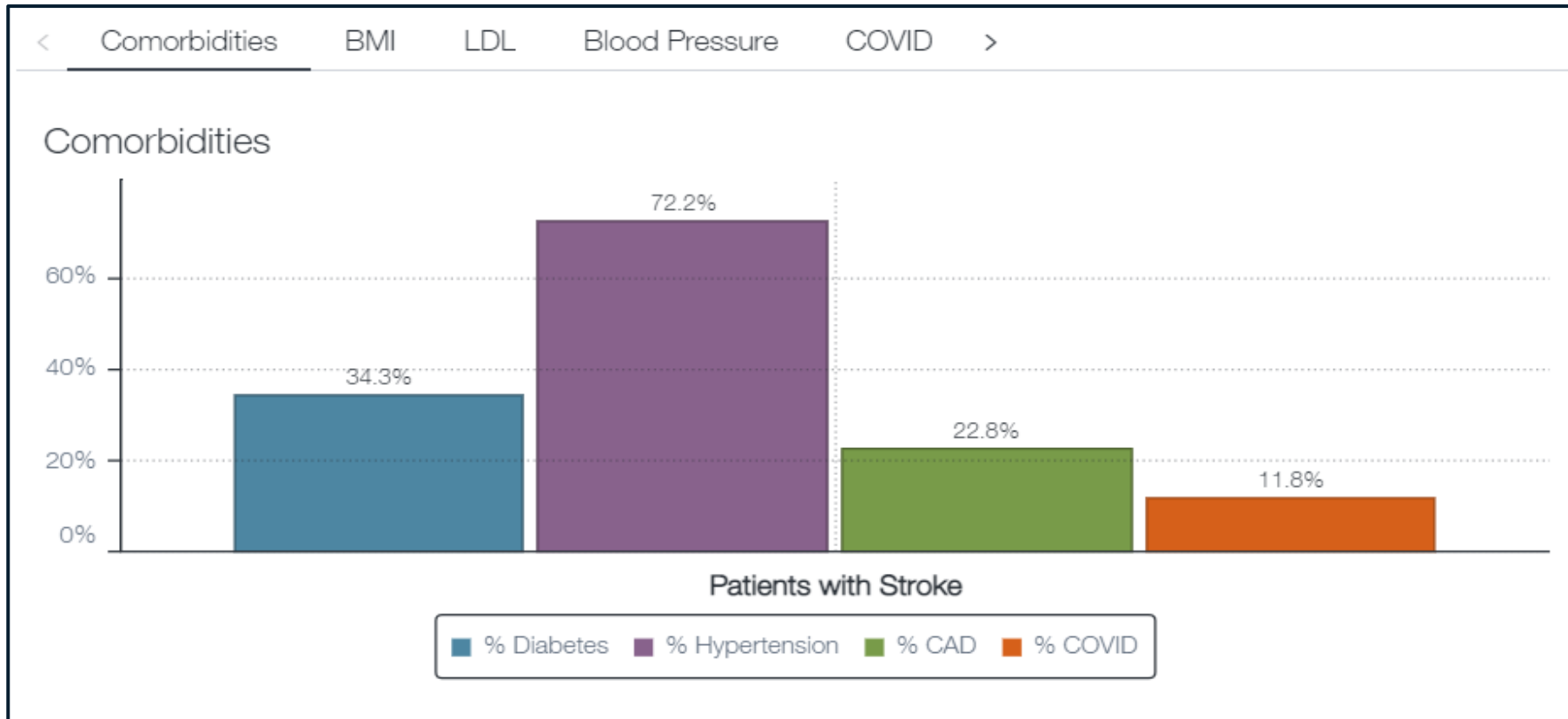
- Emergency
- Inpatient
- Outpatient

Show Top Facilities by # of Encounters

3  50

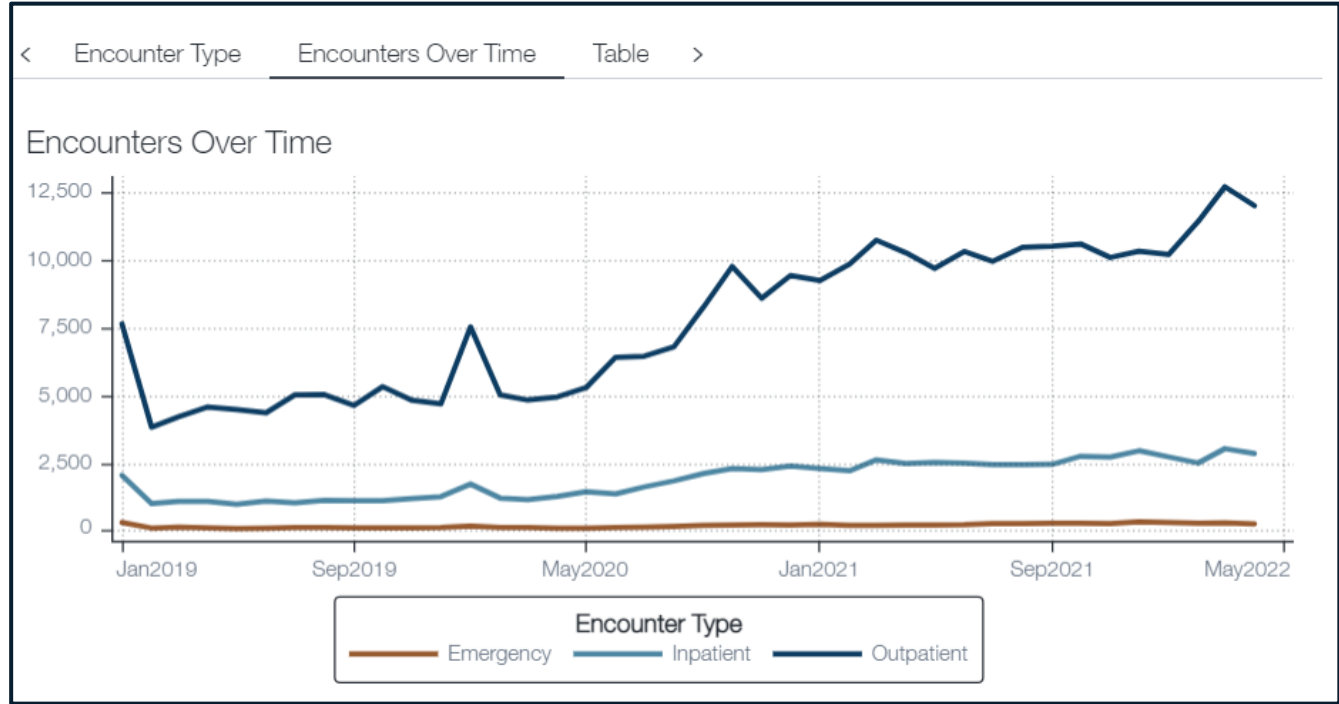
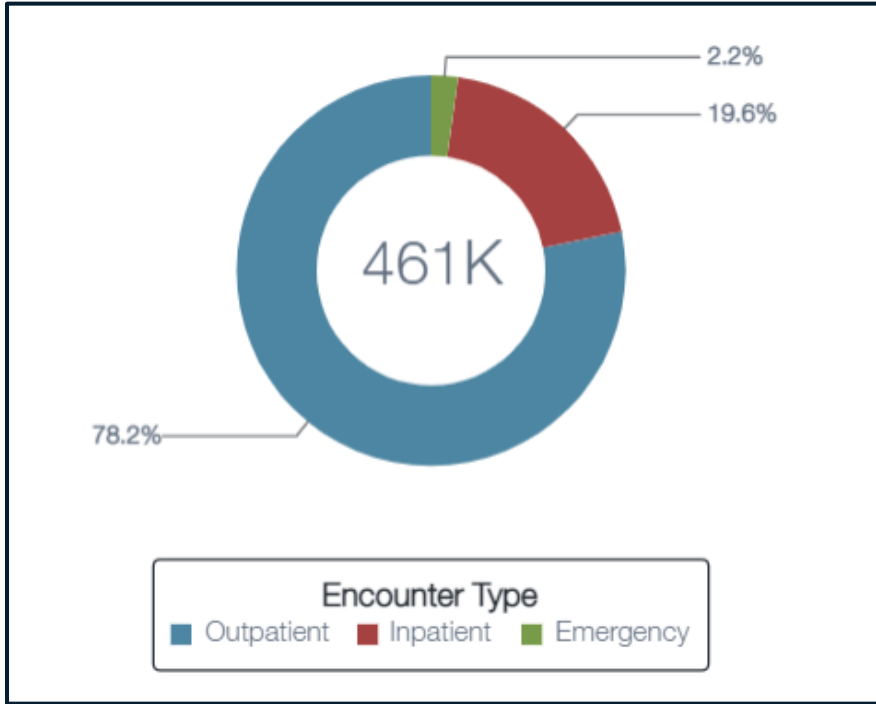
Stroke Registry – Health Indicators

Clinical indicators from the patient longitudinal record, e.g., comorbidities and most recent BMI



Stroke Registry – Encounters

Encounters across the care continuum for patients with a Stroke Diagnosis



Stroke Registry – Data Challenges & Opportunities

- NC HealthConnex includes longitudinal care records aggregated from many care settings and encounter types
- NC HealthConnex includes a broad set of patient characteristics that may identify intervention opportunities
 - Age, Race, Ethnicity, Patient County and Zip Code of Residence
- To understand prevalence, need to account for significant growth in data available from NC HealthConnex

Stroke Registry – Future Work

- Identify patients at risk for having a Stroke
- Identify gaps in care to target care coordination activities
- Support required CDC reporting and performance measures for the Paul Coverdell National Acute Stroke Program



Questions and Discussion



NORTH CAROLINA HEALTH INFORMATION EXCHANGE AUTHORITY

Department of Information Technology
Christie Burris
Executive Director

NC HIEA Advisory Board Meeting
December 12, 2:00-5:00 pm



2023 Dates for Advisory Board Meetings

- March 2, 2023
- June 7, 2023 – *planning in person*
- September 11, 2023
- December 7, 2023 – *planning in person*



Year in Review – 2022 Accomplishments

Provider Relations & Outreach:

- Conducted outreach to unconnected providers; 28,395 letters and emails between Feb 14-March 7
- Executed 665 Participation Agreements representing 2,120 facilities
- Completed 97 trainings, as well as 4 Teletown Hall webinars, 12 How to Connect webinars, and 11 conference presentations
- Distributed participant survey
- Completed promotional video

Data Exchange:

- Added 3,195 facilities to the Network since January 2022
- Added 3 states to Patient Centered Data Home network and 2 via the eHealth Exchange network
- Continued to support direct integrations to the CVMS, NCIR and ELR via the HIE
- Added 26 participants to NC*Notify service
- Performed data integrity audit for patient matching

Year in Review – 2022 Accomplishments

Use Cases:

- Developed population health Stroke Registry Dashboard with the Division of Public Health
- Delivered with the GDAC team record linkage for DHHS that has now allowed broader insight across their population
- Delivered Priority Data Element data extracts to Medicaid and PHPs required for monthly performance measurement to support value-based care
- Provided annual extract to Medicaid of clinical data elements needed to run hybrid quality measures (Diabetes, Hypertension, BMI measures, and Depression Screening)

What We'll Be Working On Quarter 1 2023:

FOUNDATION:

- Promoting Services and Training to Participants; Continuing educating about the HIE Act requirements
- Planning upgrade of InterSystems HealthShare
- Planning data quality dashboard and patient matching enhancements
- Planning for user access leveraging NCID and MFA for enhanced security
- Leveraging API technology for exchange use cases
- Implementing data retention process

EXCHANGE SERVICES

- Continue building data connections with health care providers
- Complete pharmacy pilot, begin onboarding pharmacies
- Begin onboarding skilled nursing facilities
- Complete unidirectional data connection from State Lab

What We'll Be Working On Quarter 1 2023:

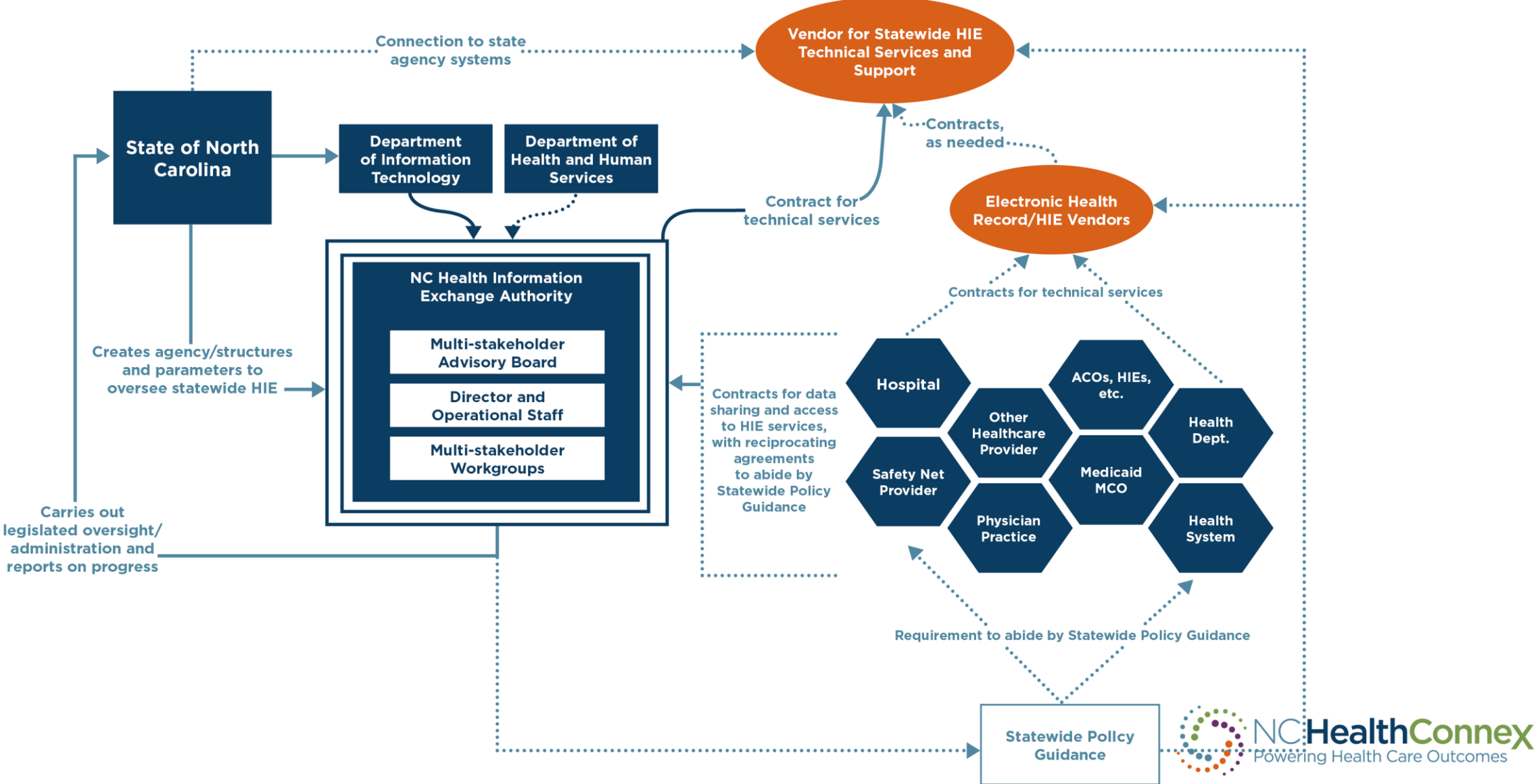
Notifications:

- Continue onboarding participants
- Building maternal health alerts for ACURE4Moms to 20 participating practices

Population Health and Analytics:

- Continue to enhance the Stroke registry to meet grant requirements
- Building maternal health dashboard for ACURE4Moms with data from 40 participating practices

Organizational Governance Review



A Closer Look at Work Groups

Use Case Work Group

Chairs: Dr. Richard Pro (AB), Jenell Stewart, Lisa Lucas

Defined membership and charter

Clinical User Group*

Chairs: Dr. William Way (AB), Michelle Hunt

Will have defined membership and charter

Research Work Group

Chairs: Tim Ferreira (AB, now vacant), Christie Burris

Defined membership and work group objectives

* New – planning to launch Q1 2023

A Closer Look at Work Groups

Behavioral Health*

Supported by NC HIEA Outreach staff

Membership Open to BH providers, stakeholders and vendors

Dental*

Supported by NC HIEA Outreach staff and the NC Dental Society

Membership Open to dental providers, stakeholders and vendors

Now Defunct: HIE Task Force & Specialized Disease Registries

Managed by NCHICA

Membership open to NCHICA members

*These groups have been focused on connectivity for these sectors and do not have defined charters, membership or meeting cadence.

Use Case Work Group

Members:

Dr. Richard Pro – Chair, Cone Health Chief Data and Analytic Officer

Jenell Stewart – Co-chair, NC HIEA Health Analytic Lead

Dr. Lisa Lucas – Co-chair, SAS National Director of Informatics

Dr. Sam Cykert –UNC Cecil G. Sheps Center for Health Services Research

Sam Thompson – Associate Director, Evaluation, Division of Health Benefits

Jonathan Kea –Senior Director, Data and Information Systems, NC Healthcare Association

Shawn Parker – Executive Vice President, NC Academy of Family Physicians

Michael Crist – NC HIEA Assistant Director

Paul Riker – SAS Senior Technical Consultant

Scott Proescholdbell – State Injury Epidemiologist, Division of Public Health

Chris AlMBERG –HIPAA Privacy Officer, State Health Plan

Charter:

Purpose. The North Carolina Health Information Exchange Authority (NC HIEA) Use Case Workgroup (UCW) is a workgroup formed to review qualifying applications for new and innovative uses of HIE data and provides the NC HIEA with recommendations for (i) approval/denial and/or (ii) prioritize requests.

Membership. The UCW membership is a voluntary appointment at the request of the NC HIEA. The workgroup consists of at least seven community health care stakeholders, as well as members of the NC HIEA and SAS. It is chaired by a representative from the NC HIEA Advisory Board with co-chair support of named NC HIEA and SAS team leads. Term limits for serving on the UCW are at the discretion of the NC HIEA.

Structure and Meetings. The workgroup shall meet in person or virtually on a quarterly basis, with additional meetings to occur when deemed necessary by the UCW chairs.

Research Work Group

Members:

Chair, Now Vacant

Christie Burris, NC HIEA Executive Director, Co-Chair

Anna Szamosi, NCDIT Deputy General Counsel

Dr. Sam Cykert, UNC Cecil G. Sheps Center for Health Services Research

Dr. Armando Bedoya, Duke Health, Associate Chief Medical Informatics Officer

Matthew Rish, State Health Plan

Jessie Tenenbaum, NC DHHS Chief Data Officer

Carol Burroughs, NCDIT Chief Data Officer/GDAC Director

NC Community Health Center Association, Vacant

ECU Health, Vacant

Patient Representative, Vacant

Two primary objectives:

- 1) Create a process/framework for the NC HIEA to review research requests that would not be reliant upon DIT creating an internal IRB
- 2) Review and amend the NC HIEA Privacy and Security Policies

Framework presented to the Advisory Board September 2021

Legislative Reporting as of Nov. 2021

Summary of Organization Connectivity 2021

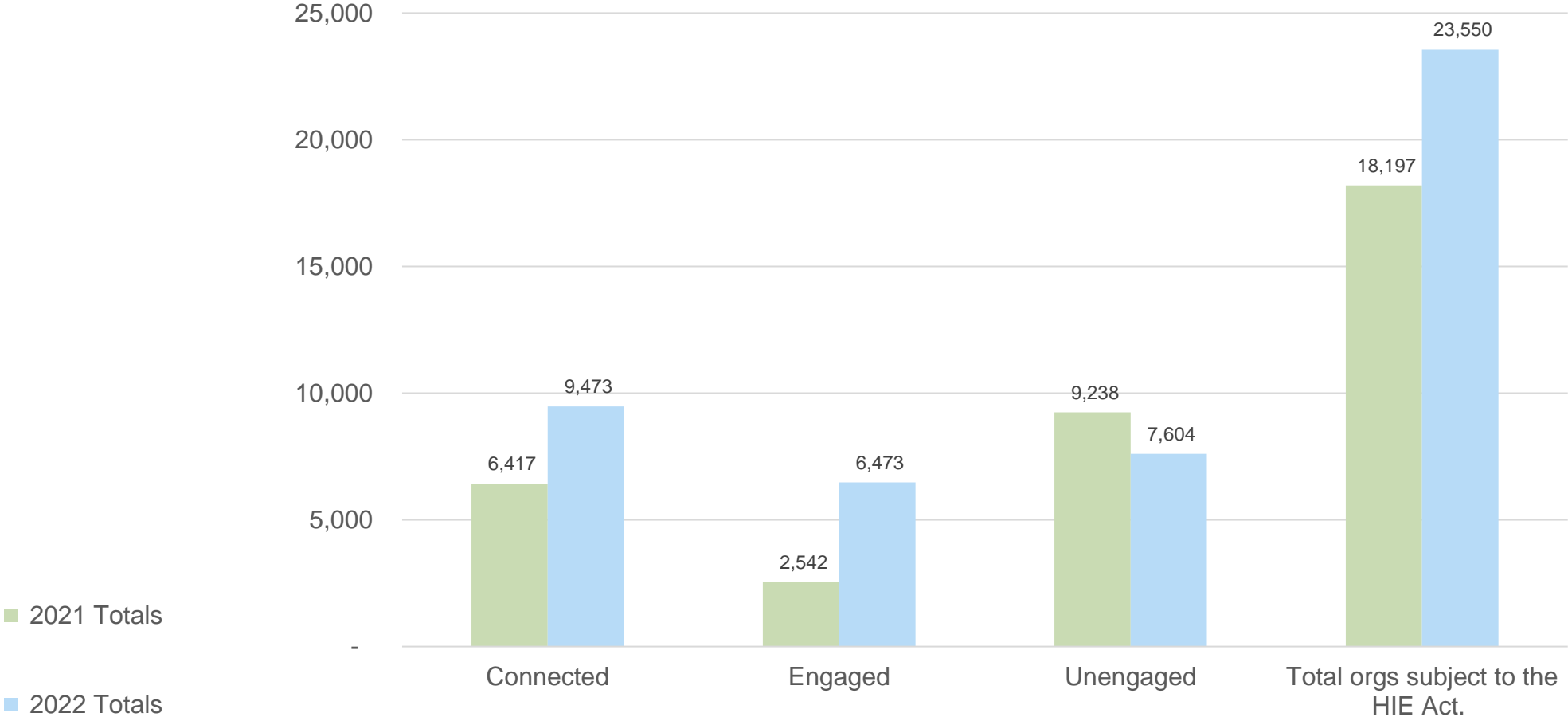
- 18,197 entities found to be subject to the requirement to connect and submit data.
 - 35% (6,417) organizations were connected
 - 14% (2,542) organizations were under contract with the NC HIEA with connections in process.
 - 51% (9,238) organizations remained unengaged with the NC HIEA.

Legislative Reporting as of Nov. 2022

Summary of Organization Connectivity 2022

- 23,550 entities found to be subject to the requirement to connect and submit data.
 - 40% (9,473) organizations were connected
 - 27% (6,473) organizations were under contract with the NC HIEA with connections in process.
 - 32% (7,604) organizations remained unengaged with the NC HIEA.

Legislative Reporting - Comparison



Legislative Reporting as of Nov. 2022

- We have seen positive movement for “Connected,” “Engaged” and “Unengaged” categories.
- 2022 reporting is based just on organizations. Individual entities are not within the scope of this report.
- The number of organizations that are required to connect and submit data increased from 18,197 to 23,550 based on additional “connected” and “engaged” NPI data housed within our participant onboarding system.
- This report is only counting unique organizational NPIs, and not individual entities associated with a single organizational NPI.



Legislative Discussion & Next Steps



Questions and Discussion