

POLICY FORUM: INVITED COMMENTARIES & SIDEBARS

Information as Equity: Building a Health Data Utility to Protect Coverage for Eligible Latine and Immigrant Communities in North Carolina

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North Carolina's Latine and immigrant residents face deepening health coverage gaps amid restrictive federal policy shifts. This commentary proposes Health Data Utility capabilities to integrate health and social data, enhance trust, and enable targeted enrollment and care coordination. Equitable governance and community partnership can transform fragmented systems into instruments of inclusion and care.

Introduction

North Carolina stands at a critical juncture. Medicaid expansion enrolled nearly 67,000 Latine residents, yet Latine communities remain both the state's and the nation's largest share of uninsured but eligible individuals.¹ ² Persistent barriers—limited language access, misinformation, fear of data sharing, and fragmented information systems—continue to erode trust among Latine and immigrant populations.^{3,4} Out of approximately 1 million foreign-born North Carolina residents, or 9.3% of the state's overall population, only 47.3% of those foreign-born residents are from Latin American countries (e.g., Mexico, Central America, Caribbean).⁵ Therefore, although this commentary focuses on the state's Latine population, the implications are likely applicable to other foreign-born populations.

Recent federal policy shifts have reversed progress in health equity and widened coverage gaps among the state's most vulnerable residents. Eligible individuals remain unenrolled in public benefits due to data fragmentation across systems, driving preventable costs as people forgo primary care, mental health services, and social supports in favor of costly emergency department visits. Without proactive intervention, the state will ultimately bear the consequences.

By maturing NC HealthConnex, the statewide health information exchange, with additional Health Data Utility (HDU) capabilities, North Carolina could address both dimensions of the problem: identifying eligible individuals for targeted outreach and enrollment while improving care coordination and whole-person health. HDU capabilities go beyond clinical data for clinical care to incorporate health-adjacent data, such as health-

related social needs, social service engagement, and service history across providers. By enabling secure, appropriate sharing of these data types, an HDU provides a more complete view of the individuals being served, strengthening care coordination and referral management across both clinical and community-based settings. By strategically leveraging data already collected across systems, North Carolina can increase enrollment, reduce preventable utilization, improve outcomes, and contain costs—ultimately advancing health equity for Latine and other immigrant communities historically excluded from health and social systems despite their legal eligibility.

A Perfect Storm: Recent Policy Changes and Their Cascading Effects

The 2025 health policy environment poses unprecedented challenges for Latine and immigrant communities. The Centers for Medicare & Medicaid Services (CMS) began reviewing state funding to reduce spending on “unlawfully present” immigrants, targeting state-supported programs.⁶ The 119th Congress’ House Resolution 1, the “One Big Beautiful Bill Act,” revoked public benefit eligibility for asylees, refugees, domestic violence survivors, trafficking victims, and Temporary Protected Status holders—including Medicare, Medicaid, CHIP, SNAP, WIC, and ACA subsidies.⁷ Meanwhile, the Department of Health and Human Services narrowed “qualified immigrant” definitions to include only lawful permanent residents, certain humanitarian parolees, and individuals granted asylum, while excluding many groups previously eligible such as TPS holders, DACA recipients, and worker or student visa holders, and additionally broadened “federal public benefits” to encompass Head Start, behavioral health, workforce, and homelessness programs.⁸

These shifts compound fiscal and administrative strain. Shrinking Medicare reimbursements threaten hospital solvency, states face reduced Medicaid allocations, and federal Emergency Medicaid costs have shifted to state budgets.⁹⁻¹¹ CMS and U.S. Immigration and Customs Enforcement (ICE) established a temporary agreement to share patient data, validating long-held fears of surveillance within immigrant communities.¹² ICE increased its presence across North Carolina in November 2025 as part of Operation Charlotte’s Web, conducting arrests and enforcement actions in counties with large Latine populations such as Mecklenburg, Wake, and Durham, heightening fear and mistrust among residents. A recent Supreme Court decision allowing ICE to profile individuals based on perceived immigration status exacerbates those concerns.¹³

Together, these actions create a chilling effect far beyond their explicit targets. Mixed-status families—even those with eligible members—will forgo enrollment due to fear, misinformation, and language barriers.^{14,15} The

complex redefinitions of eligibility will drive many away from health, education, and other essential services.¹⁶ Counties with high immigrant density and limited bilingual infrastructure—such as Duplin, Sampson, and Johnston—may experience disproportionate impacts, compounding existing health disparities.¹⁷ North Carolina’s experience during the unwinding of the COVID-19 Public Health Emergency offers a sobering preview of what may come: 86% of disenrollments were procedural, resulting from incomplete paperwork or outdated addresses rather than actual ineligibility.³ Yet limited data were collected on who was most impacted, impeding targeted solutions.³

History is poised to repeat itself. As redetermination frequency increases, budgets contract, and enforcement fear spreads, administrative burdens rise. The CMS–ICE agreement, increased ICE presence, and the Supreme Court ruling amplify these challenges, fueling widespread fear among all Latine and immigrant individuals—citizens, permanent residents, visa holders, and undocumented individuals alike.

The Cost of Fragmentation and the Promise of Integration

North Carolina must balance shrinking budgets and growing administrative obstacles with the need to improve health outcomes and rebuild trust. The state has made important progress by linking SNAP, WIC, and Medicaid through digital tools such as ePass, which enables multi-program applications.¹⁸ The Nutrition Insecurity Cross-Enrollment (NICE) pilot adds eligibility indicators for SNAP and WIC within Medicaid care-management data and creates referral pathways connecting patients to food benefits via the More In My Basket program.¹⁸ Yet, the effort covers only 5 out of North Carolina’s 100 counties—Alamance, Durham, Granville, Orange, and Vance—underscoring the need for statewide expansion. Although Medicaid, CHIP, WIC, and SNAP share the Common Name Data System (CNDS) identifier, public health, mental health, education, and other state agencies remain disconnected. This fragmentation obscures those who are eligible but unenrolled.

Other states demonstrate what North Carolina could achieve. Maryland’s Chesapeake Regional Information System for Our Patients (CRISP) network offers a real-time clinical and non-clinical data exchange that has been shown to reduce redundant tests and admissions.^{19,20} Massachusetts’ Common Application attempts to align enrollment between health and human-service benefits, though it struggles with sustainability and evaluation gaps.²¹⁻²³ California’s Data Exchange Framework is working toward linking health and social services statewide.²⁴ New York’s regional exchanges share social determinants of health data for improved screening, referral, and goal planning.^{25,26}

North Carolina's 99% *ex parte* renewal rate (i.e., automated renewal if ongoing eligibility can be ascertained from available data) in August 2024 highlights the efficiency of cross-system data use.²⁷ Developing additional HDU capabilities would institutionalize these gains through ethical, transparent governance and standardized data-sharing protocols, rather than relying on *ad hoc* administrative fixes.

The Health Data Utility Opportunity: 6 Core Functions

A Health Information Exchange (HIE) is an organization or technology platform that enables the secure electronic sharing of clinical and administrative health data among health care providers and sometimes payers and/or public health agencies, typically within a region or community.²⁸ HIEs facilitate real-time access to patient information to improve care coordination, quality, and efficiency, but their scope is often limited to clinical care and varies in technical standards, participation, and interoperability.²⁸

A Health Data Utility (HDU) is an evolution of the HIE concept, in which HDUs are envisioned as public-good infrastructure that not only supports clinical data exchange, but also serves broader purposes such as public health surveillance, research, and population health management.^{28, 29} HDUs reflect a continuum of maturity, in which entities like North Carolina's HIE already demonstrate many HDU characteristics. Expanding capabilities such as supporting exchange of non-clinical data and enabling access for non-covered entities represent continued advancement along this trajectory, connecting clinical interventions and cross-sector networks for broad societal benefit.²⁸ Six core benefits distinguish this approach:

Quantify the unseen. Link Medicaid, SNAP, housing, and education data to estimate program reach and identify gaps, enabling public dashboards that visualize disparities by race, preferred language, and county. This transparency makes invisible populations visible to those who can help.

Prevent coverage churn. Real-time monitoring to indicate individuals at risk of losing coverage when incomes change or addresses are updated, facilitating timely intervention before disenrollment occurs.^{19,20}

Integrate social care. Link clinical data with social needs screening to identify Medicaid enrollees facing food insecurity or housing instability and connect them to local assistance programs. In addition to referrals, health systems could directly partner with community-based organizations (CBOs) that distribute food to reduce the burden on patients to navigate multiple systems. Such integration yields measurable reductions in preventable utilization and costs.²¹

Support community engagement. The importance of community health workers (CHWs) and CBOs in improving outreach, education, enrollment, and utilization is well established. By sharing de-identified aggregate data, the HDU can further equip these partners to target outreach while maintaining ethical boundaries. Strengthening these capabilities would also enhance coordination across clinicians, clinic-based care managers, and community-based supports such as CHWs and CBOs.

Strengthen medical-legal partnership capabilities within the current HDU infrastructure. Medical-legal partnerships help patients navigate legal barriers that impede benefit access. Building HDU capabilities to enable secure referral pathways between health care providers and legal aid teams would advance holistic care.

Enhance language and cultural competence by enabling appropriate use of existing data. Collection of preferred language, country of origin, and other health-related, self-identified categorization (i.e., tribal affiliation) already occurs across systems. HDU capabilities to surface and share these data with authorized, non-covered entities would ensure culturally appropriate outreach and service delivery.

NC HealthConnex, North Carolina's statewide HIE, already aligns with many HDU goals, linking hospitals, urgent care, primary care clinics, specialists, pharmacies, laboratories, local health departments, and state-based payers ([Figure 1](#)). However, a full-fledged HDU would position North Carolina at the frontier of the national push for integrated clinical-social care.²³ In order to fully realize this vision, North Carolina must focus on maturing both technical and governance infrastructure, balancing inclusivity with privacy protection. This would include: 1) creating an appropriate cross-sector organizational infrastructure for governance; 2) convening a subcommittee of the N.C. Health Information Exchange Authority (NC HIEA)'s advisory board and additional stakeholders to govern non-clinical use cases; 3) enhancing technical infrastructure to include additional data types and more sophisticated consent management; and 4) identifying sources for up-front investment and ongoing sustainability.

Trust, Ethics, and Protecting Vulnerable Groups

Scams and misinformation during Medicaid expansion left many individuals wary of any communication about enrollment.³⁰ The ICE-CMS agreement validates long-held fears of predatory data sharing within Latine and immigrant communities. The chilling effect of increased ICE arrests and anti-immigrant policies will further erode willingness to engage with health and social systems.¹⁵ Therefore, any data integration effort must center transparency, consent, and community participation.

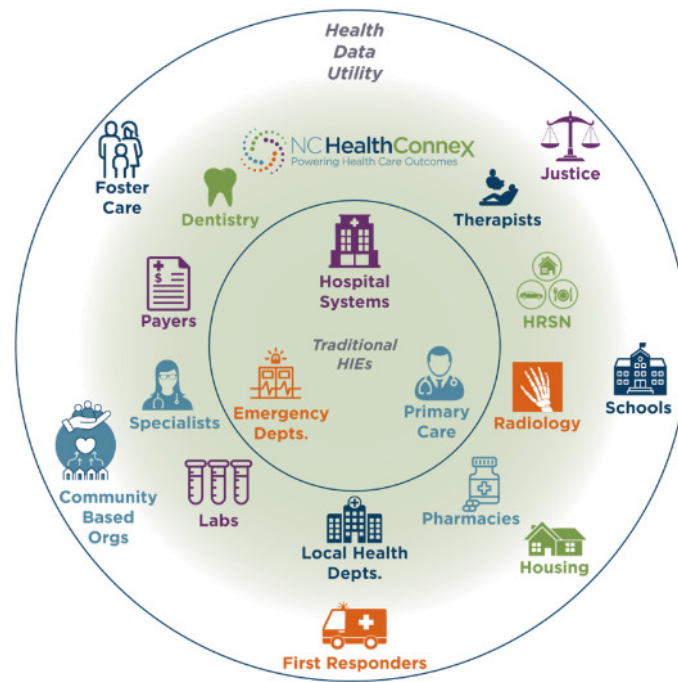


Figure 1. Graphical Overview of the Scope of a Health Information Exchange (HIE) Versus Health Data Utility (HDU), Including NC HealthConnex's Current Advanced Capabilities

Figure note. Overview of the expanding scope as one moves from a traditional HIE (center circle) to NC HealthConnex today (green shading) to a full health data utility or HDU (outer circle). NC HealthConnex already functions in some ways as an HDU. As shown in the green shaded area, it includes sources and data types beyond a basic health information exchange. Reaching the outer circle will require both enhanced technical infrastructure and multi-sector governance.

Source: North Carolina Health Information Exchange Authority (NC HIEA).

Ethical protocols should include data minimization—collecting only what is necessary—along with comprehensive audit trails and multilingual consent procedures. Strengthening cybersecurity and developing privacy-preserving analytics will allow data insight without unnecessary exposure. Advisory boards with immigrant advocates and privacy specialists must ensure accountability. CHWs and CBOs can act as trusted brokers between systems and communities, an approach proven to outperform purely technological outreach and education solutions.^{22,25} Additionally, HDUs require robust infrastructure and workforce training, including data-stewardship education across public health and social service agencies, for sustained value gains.¹⁹

From Vision to Action: Practical Applications and Recommendations

With community-engaged governance, adding the capabilities outlined above to North Carolina's HIE, NC HealthConnex, could facilitate data integration to improve risk stratification and population health management across North Carolina. For example, the state could use HDU data to identify zip-code-level social risks like food insecurity, housing instability, and transportation deficits and deploy tailored interventions via Medicaid Care Management organizations.

In the aftermath of Hurricane Helene, North Carolina leveraged its existing HIE to create real-time feedback loops among hospitals and state agencies, enabling efficient emergency response coordination and evidence-based policymaking. North Carolina's HIE played a vital role in response efforts by enabling providers to access clinical data despite disrupted systems and by helping to identify and track medically vulnerable and missing individuals through patient data queries and alerts. Its widespread connectivity ensured timely, informed care and coordination across affected counties. However, additional capabilities could identify high-risk populations before disasters strike—individuals with oxygen dependence, mobility limitations, chronic conditions requiring medication, or those in flood-prone areas without transportation. This would enable pre-positioning of resources and targeted evacuation assistance.

CHWs and CBOs equipped with de-identified aggregate data could pre-establish relationships with vulnerable households, ensuring trusted communication channels exist before crisis communications are needed. Building on current capabilities to share address changes, NC HealthConnex could further help share other dynamic information such as income fluctuations and documentation loss, allowing for real-time monitoring to prevent families from losing coverage precisely when it is needed the most. Additionally, shared preferred-language and literacy-level data could ensure that recovery information and assistance reaches non-English speakers and those with digital and literacy barriers through appropriate channels and messengers.

Integrated information systems can be designed not as an intrusion, but as an equity tool. Evidence from HIEs and social-care integration shows that secure data linkage improves outcomes, reduces costs, and supports informed decision-making.³¹ North Carolina has the opportunity to extend these benefits to Medicaid and public programs, improving services for all North Carolinians already enrolled and enhancing the ability to identify and serve those eligible but not enrolled, while providing ironclad protections to warrant the trust of the state's most vulnerable populations.

To realize this vision, we recommend 5 concrete actions:

1. Codify HDU governance in law with explicit privacy protections and guaranteed community representation. Community-engaged governance could be funded and sustained through a combination of state appropriations, state cooperative agreements such as the State HIE Cooperative Agreement Program, braided federal grants (e.g., CMS Innovation or CDC Data Modernization Initiative), and private sector funding that prioritizes equity infrastructure.

2. Invest in technical infrastructure, workforce infrastructure, and the technical workforce training required to add the capabilities outlined in this paper, building on the existing HIE and following successful models like CRISP's approach.
3. Fund CHWs and CBOs as permanent trust brokers, community-based entities with established relationships and credibility that can be leveraged to facilitate connection and information exchange, who can bridge the gap between systems and communities. Potential funding sources include Medicaid administrative match funds, state health equity grants, and partnerships with managed care organizations that recognize CHWs and CBOs as essential components of care coordination.
4. Publish county-level dashboards of eligible but not enrolled populations to drive accountability and target interventions. These dashboards could model the North Carolina Department of Health and Human Services' approach used during the COVID-19 vaccination campaign, providing targeted funding or performance bonuses to counties that reduce enrollment gaps over time.
5. Establish independent oversight auditing specifically focused on preventing malicious data use.

It is also important to consider state-level legislation that would be essential to making these changes. Other states have passed statutes facilitating exchange between covered and non-covered entities, providing potential models for equitable data sharing that allows community organizations, legal aid groups, and social-service providers to identify needs and coordinate care among populations historically excluded from data systems. Current legislative momentum, spurred by efforts following a stabbing incident on Charlotte's light rail line,³² could open policy windows to allow hospital and court staff to access health and criminal justice data for timely decisions to protect individuals in crisis. By removing exemptions for substance-use disorder treatment records, North Carolina can adopt more sophisticated consent protocols that respect privacy while enabling full participation in care. Formally designating NC HealthConnex as an HDU and authorizing it to facilitate patient access under the Trusted Exchange Framework and Common Agreement (TEFCA) would expand equitable access to health information across clinical and social settings. Finally, allowing the North Carolina Department of Public Safety to share data during disasters would empower coordinated responses that prioritize vulnerable residents. With

robust safeguards—data-minimization, encryption, and independent oversight—these legislative steps can advance health equity by using information ethically to make care more inclusive, preventive, and just.

Conclusion: Information as an Instrument of Equity

As federal restrictions tighten and enforcement fears grow, North Carolina must innovate to preserve health equity and control health care costs. An HDU, anchored in ethical governance and community collaboration, can transform fragmented systems into instruments of inclusion and care. In an era when policy threatens to render the vulnerable invisible, integrated and trustworthy data can make them seen, protected, and served. By aligning data integration with community governance and sustainable funding, North Carolina can ensure that information becomes not a tool of surveillance, but a foundation for equitable, effective, and trustworthy public health.

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