From HIE to HDU: Advancing Connectivity for Whole Person Health

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NC HealthConnex Powering Health Care Outcomes

Objective

This presentation details the first phase of North Carolina's transition from a Health Information Exchange (HIE) to a Health Data Utility (HDU).

Approach

Using the Implementation guide created by Civitas and CRISP[1], we conducted a landscape analysis to identify the feasibility and implementation considerations for an HDU in North Carolina. Our approach included:

1.Stakeholder Engagement:

Interviews with healthcare providers, policymakers, payers, state agencies, and community-based organizations to identify data-sharing challenges and key priorities

2. Regulatory & Legal Analysis:

Review of state and federal data-sharing laws to identify policy barriers.

3. Technological Infrastructure Assessment:

Evaluation of North Carolina's health and social services data systems to identify gaps and integration opportunities.

4. Comparative Evaluation:

Analysis of HDU models in other states to inform North Carolina's approach.

This multi-pronged analysis provided insights into technical, policy, and governance considerations for building a scalable, regulatory compliant HDU.

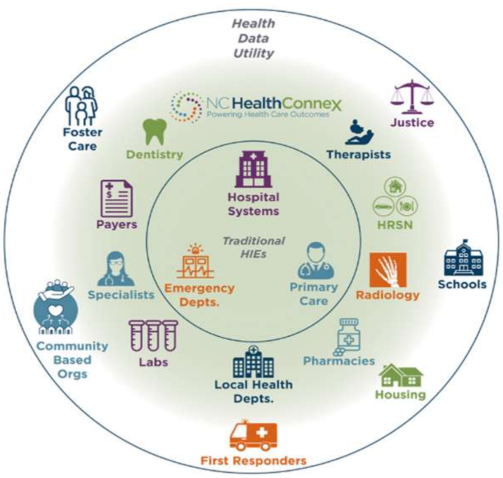

Figure 1: Overview of the expanding scope as one moves from a traditional HIE (center circle) to NC HealthConnex today (green shading) to a full health data utility or HDU (outer circle).

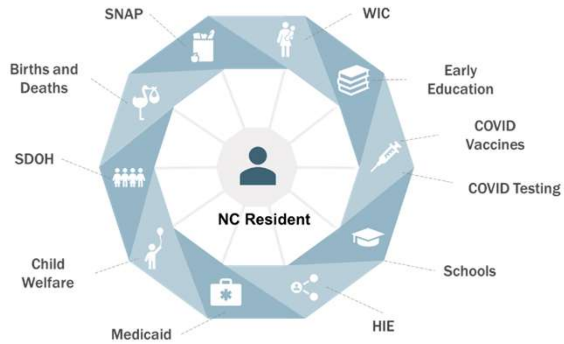

Figure 2: Motivation for a Health Data Utility: Integration of data sources beyond clinical care gives a fuller picture of an individual's needs and experiences, better enabling a "whole person health" approach.

Principal Findings

Stakeholders widely support a unified data-sharing framework to reduce care fragmentation and administrative burden. Key initial use cases include:

- **Food Insecurity Screening:** Enabling providers to determine SNAP enrollment status for patients screening positive for food insecurity.
- **High-Risk Child Case Management:** Providing care managers with contextual insights into a child's existing services and school attendance, with guardian consent.
- **Medication Adherence Support in Homeless Shelters**: Provide shelter staff with limited, role-based access to medication lists (with client consent), to help with post-discharge medication adherence.

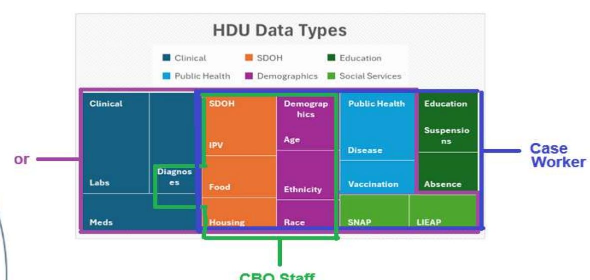

Figure 3: Data types will have role-based access that facilitates interoperability but prioritizes granular consent and data security. A sophisticated, use case–driven consent framework will determine what data can be shared, with whom, and under what conditions—ensuring legal compliance while supporting appropriate collaboration.

Policy challenges center on aligning state privacy laws with federal requirements. Current regulations on social services data restrict information-sharing with healthcare providers, while HIPAA limits sharing with non-clinical entities, hindering cross-sector collaboration.

Technology and governance alone are insufficient; addressing workflow integration, economic incentives, and staff bandwidth is critical to ensuring the HDU's adoption and sustainability.

Conclusions

An HDU in North Carolina can bridge critical gaps in data-sharing between healthcare, social services, and community organizations. This assessment focuses on best practices such as:

- Early and broad stakeholder engagement
- Stakeholder use-case driven design and prioritization
- Addressing governance and legal issues up front
- Building relationships to proceed at the speed of trust

Implications for Policy /Practice

NC's HDU initiative provides a framework for improving data-sharing across healthcare and social service sectors to advance care coordination. From a practice perspective, an HDU can help reduce administrative burden, improve service coordination, and enhance data accessibility for providers and care managers. Key policy considerations include reconciling privacy laws with evolving data-sharing needs while minimizing administrative burdens. The lessons learned from this process can inform other states considering similar approaches to improving cross-sector data-sharing and care integration.

Acknowledgements

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References

1. https://www.civitasforhealth.org/wp-content/uploads/2023/03/Civitas-HDU-Framework-Final-2023-03-26.pdf