THIN ☑
Texas Health
Improvement Network

Facilitating Use of Data to Drive Population Health in Texas

SUMMARY

To enable data-driven population health improvement, the Texas Health Improvement Network (THIN) gathered information on, and developed recommendations for, modernizing policies and regulations related to the use of public health data in Texas. THIN convened a data workgroup with representation from Texas academic and health science institutions, state agencies, and policy institutes. The workgroup conducted 25 interviews with diverse data users and custodians within and outside Texas and convened a day-long meeting of three expert panels. The panels covered 1) data use to inform practices and policies, 2) legal use and sharing of data, and 3) procedures and processes for data sharing. This report summarizes key issues identified in the interviews and panels and provides recommendations for policy makers and others committed to the responsible use of data resources for health improvement in Texas.

RECOMMENDATIONS

The following recommendations are intended to be further researched and evaluated by state agencies and will hopefully inform interim charges to help shape future legislation.

The Texas Legislature should acknowledge through statute Texas's vested interest in using and sharing health data to improve public health, improve health care delivery, and reduce healthcare costs.

- Give explicit permission to the Executive Commissioner of Health and Human Services Commission (HHSC) and commissioners of other health state agencies to encourage and approve data sharing within and across state agencies, with local health departments (LHDs), and with academic research institutions in alignment with the fulfillment of their social, health service delivery, and research roles, and in compliance with state and federal statutes and rules.

Remove statutory barriers for sharing identified public health data within and across state health agencies and LHDs.

- Improve data-sharing between and within state health agencies, including HHSC and the Department of State Health Services (DSHS), to maximize data use in providing health and social services and managing public health, specifically for populations they serve.

  - For vital statistics data:

    - Add to Chapter 192.002 (section b) of the Health and Safety Code (Title 3) related to the medical section of the birth certificate and including fetal deaths, that "...information held by the department under that section of the certificate" will be linked to the demographic section and shared with HHSC in the fulfillment of their social and health service delivery roles. Approved data-sharing should be conducted through an executed memorandum of understanding (MOU) and data use agreement (DUA).

  - For Texas Health Care Information Collection (THCIC) hospital discharge data:

    - Modify under Chapter 108 of the Health and Safety Code to explicitly allow sharing of identified patient-level data within DSHS, and with HHSC for programmatic purposes. Eliminate the need for Institutional Review Board (IRB) approval to access data for programmatic purpose but require assurances of appropriate and limited use. Approved data-sharing should be conducted through an executed memorandum of understanding (MOU) and data use agreement (DUA).

  - For Medicaid data:

    - Clarify under Chapter 108 of the Health and Safety Code the ability to share identified patient-level data within HHSC, and with DSHS, for programmatic use and with agreements ensuring appropriate and limited use for improving public health services and programs. Such uses include assuring completeness of disease registries (cancer, birth defects, etc.) Approved data-sharing should be conducted through an executed memorandum of understanding (MOU) and data use agreement (DUA).

- Remove statutory barriers and establish streamlined processes for sharing individual-level data with LHDs to facilitate their provision of essential local public health services and securing of state and federal grant funding.

  - For vital statistics data:

    - Add to Chapter 192.002 (section b) of the Health and Safety Code (Title 3) related to

the medical section of the birth certificate, that "…information held by the department under that section of the certificate" will be linked to the demographic section and shared with LHDs for programmatic purposes as they fulfill their public health role at the local level. Approved data–sharing should be conducted through an executed memorandum of understanding (MOU) and data use agreement (DUA).

- For Texas Health Care Information Collection (THCIC) hospital discharge data:

  • Modify Chapter 108 of the Health and Safety Code to allow sharing of THCIC data at the census block level with LHDs for programmatic purposes. Eliminate the need for IRB approval to access data for programmatic purposes but require assurances of appropriate and limited use. Approved data-sharing should be conducted through an executed memorandum of understanding (MOU) and data use agreement (DUA).

- Clarify the authority of LHDs to access data required for them to provide essential public health services outlined under section 121.002 of Chapter 121, by adding the following language Sec.121.005 (c) of Chapter 121:

  • A local health unit, local health department, or public health district that provides essential public health services as defined in Sec.121.002 of this Chapter shall be granted access to data, maintained by DSHS, that supports the provision of essential public health services.

  • Each LHD requesting data maintained by DSHS for essential public health services defined in Sec.121.002 shall execute a memorandum of understanding and data use agreement. Health entities requesting data

for research purposes (i.e., data requests not covered in Sec.121.002), shall submit a completed application to the DSHS Institutional Review board for review and approval.

Improve quality, timeliness, and utility of data held by state agencies.

• Request a report from state agencies that identifies statutory changes, resources and timelines needed to establish a master patient index (MPI) for Medicaid, vital statistics, and THCIC data. An MPI would allow the health agencies to share de-identified data, linked across the three datasets and facilitate longitudinal analyses. Discuss in the report strategies that other entities have established to develop MPI policies and procedures and how these strategies can be leveraged by the state agencies.

• Establish mechanisms to increase timeliness of data so that data utilized for decision-making is current and reflective of actual events. Identify ways to reduce disruptions in data processing due to staff turnover and competing priorities. Allow the use of provisional data for data sets when provisional data is sufficiently reflective of the anticipated finalized data.

• Create standardized public reports and data query tools that allow communities, stakeholders, and policy-makers to identify current health patterns and priorities at a local/community level. Utilize the most requested data as a guide for establishing these reports.

• Require that all health state agencies create a streamlined process for receipt, review, response, and sharing of data for programmatic purposes with other health state agencies and LHDs. This process should not require a formal IRB or Open Record Request process. If the data is being used for research, then an IRB process would be required.

- Require that each state agency provide clear, concise instructions on the processes and procedures for accessing public health data and standard agreements for data use, once access is approved. These instructions, policies, and standard agreements must be easily accessible on state agency websites.

Create mutually beneficial partnerships.

- Convene an ongoing data forum—including representatives from state agencies, LHDs, state health institutions, and health policy institutes— to identify and prioritize evaluation and research questions aimed at improving Medicaid programs and services. Partner with academic and health institutions to expand the breadth, number, and quality of evaluations conducted.

- Establish partnerships between state agencies, LHDs, health institutions, and academic institutions to leverage existing infrastructure and meet data operation needs, including data management, data validation, data security, data matching, data sharing, data analysis, and data visualization.

- Identify efficient and sustainable funding models to support data sharing resource needs, including staff time, software, hardware, and contracting costs. Utilize partnerships with universities to align needs, identify and seek grants, and reduce inefficiencies.

- Train future researchers, data scientists, and public health workforce by providing opportunities for students and faculty to access public health data. Create partnerships between state agencies and state health and academic institutions to facilitate this training; include expansion of internship and practicum opportunities for students at state agencies.

BACKGROUND

The Texas Health Improvement Network (THIN) was established by the 84th Texas Legislature to address urgent health care challenges and improve health and health care in Texas. This initiative brings together a diverse, multi-institutional, cross-sector group of leaders focused on catalyzing population health improvement and health equity. The THIN advisory council identified "improved data sharing and use" as central to this work (See Appendix B for the THIN strategic map).

From Data to Outcomes

The use of data can directly affect health outcomes through quality improvement initiatives and feedback with health care providers. In a 2017 study, the California Maternal Data Center was examined to determine whether maternal safety tools can be used to reduce severe maternal morbidity (SMM) in women with obstetric hemorrhage using a large maternal quality collaborative. The data center was designed in partnership with the California state health agencies. The study findings indicated that the data center was critical to the rapid-cycle system that links birth certificate data with hospital discharge data, allowing the collection of

structural, process, and outcome measures. The study reported an approximate 21% reduction in SMM among women with hemorrhage in collaborative hospitals as compared to women in comparison hospitals.[1]

Trends in the U.S. and Texas

In 2017, the U.S. spent the most of any OECD country on health care—both per capita ($10,000+) and as a percentage of GDP (17%)[2]—and yet U.S. life expectancy lags behind many other OECD countries and has decreased for the third year in a row.[3] Texas spends less on health care than the national average,[4] but over $40 billion, almost half of the state budget, goes toward health care.[5] From 2011-15, state health care spending increased by almost 20%, well above the influence of inflation and population growth.[7] In 2017, Texas was 34th in U.S. health rankings, facing distinct challenges, including high uninsured status (50th), shortage of mental health providers (49th), and high prevalence of obesity (43rd).[6] Texas ranks 38th in dollars spent per capita on public health ($67),[8] although research suggests public health interventions provide a median return on investment (ROI) of $14.30 per $1 spent.[7]

1- Main EK, Cape V, Abreo A, Vasher J, Woods A, Carpenter A, and Gould JB. Reduction of severe maternal morbidity from hemorrhage using a state perinatal quality collaborative. Am J Obstet Gynecol, 2017. 216(3): p. 298.e1-298.e11.

2- OECD. Focus on spending on health: Latest trends. 2018 June. http://www.oecd.org/health/health-systems/Health-Spending-Latest-Trends-Brief.pdf

3- Murphy SL, Xu JQ, Kochanek KD, Arias E. Mortality in the United States, 2017. NCHS Data Brief, no 328. Hyattsville, MD: National Center for Health Statistics. 2018.

4- Henry J. Kaiser Family Foundation. Health care expenditures per capita by state of residence. 2014. https://www.kff.org/other/state-indicator/health-spending-per-capita/

5- Minton L, Vela L, Wright B. Counting the cost of Texas health care. Texas Comptroller of Public Accounts. 2017 Mar. https://comptroller.texas.gov/economy/fiscal-notes/2017/march/health-care.php

6- United Health Foundation. America's health rankings: Annual report. 2017. https://assets.americashealthrankings.org/app/uploads/ahrannual17_complete-121817.pdf

7- Masters R, Anwar E, Collins B, Cookson R, Capewell S. Return on investment of public health interventions: A systematic review. Journal of Epidemiology & Community Health. 2017;71:827-834.

8- 85th Texas Legislature. General Appropriations Act for The 2018-19 Biennium. Regular Session, 2017. http://www.lbb.state.tx.us/documents/gaa/general_appropriations_act_2018-2019.pdf

Sound public health investments are impossible without the smart use of data. Texas is a technologically sophisticated state with a wealth of top-notch academic, health and policy institutions and local health departments (LHDs), but Texas falls behind other states in its use of data. An inefficient data-sharing system prevents the strategic and inventive use of data for the benefit of Texans and wastes valuable state resources.

Objective

Per the request of the THIN Advisory Board, a data workgroup was tasked with examining barriers, identifying successful models across the nation, and developing actionable recommendations for efficient health data use and regulation. The workgroup consisted of representatives from academic and health science institutions, state agencies, and policy institutes (See Appendix C for workgroup members).

The entities best positioned to use health data for the benefit of Texans are state health agencies (DSHS and HHSC), LHDs, and academic and policy research institutions. Thus, the THIN data workgroup focused on data access and sharing within and among these organizations. The workgroup also concentrated on data sets with the greatest public health utility:

- Vital statistics (includes birth, death, and fetal death data; maintained by DSHS);

- Hospital discharge data (known as the Texas Health Care Information Collection (THCIC); maintained by DSHS); and

- Medicaid data (maintained by HHSC).

Each dataset is covered by discrete federal and state statutes, as well as agency-specific policies (See Appendixes D, E, & F). Some statutes have not been updated in many years and are susceptible to varying interpretations.

Data Security

In taking on this task, the workgroup recognizes that the Texas Legislature has taken aggressive steps to protect individual patient privacy over the last 10 years, which has earned the state a national reputation as a

leader in this area. The passage of HB 300 in 2011, which strengthened the existing Medical Records Privacy Act in Chapter 181 of the Texas Health and Safety Code, addresses patient data sharing and the need for patient consent in many circumstances before patient data is shared. Chapter 181 also includes a long-standing prohibition on re-identification of de-identified data without individual patient consent. Other recent decisions by the Texas Legislature related to data privacy include: requiring that patients be provided information regarding the use of their hospital discharge data [HB 764, 84th] and THCIC modernization [SB 2104 85th]). These provisions and ongoing conversations regarding data privacy must be prioritized as data sharing approaches are designed in order to clearly communicate to the public and to the Legislature that individual privacy rights are being respected.

Existing Efforts to Improve Data Access

The 2018-19 General Appropriations Act included Rider 182, which directed HHSC to collaborate with a third-party entity to identify opportunities for improving the efficiency of behavioral health care delivery.[8] Rider 182 asked that HHSC provide necessary, non-individually identifiable health information for this purpose. Although Rider 182 was a positive step forward, further work is needed.

The Texas Association of City and County Health Officials (TACCHO) has worked for several years to increase access to vital statistics for LHDs (See Appendix G). LHDs interviewed felt that they had greater access to vital statistics data in the past and that their access has become more restricted due to changes in statute interpretations.

Both DSHS and HHSC are actively working to improve their data sharing systems, and representatives from both agencies were involved in the THIN Data workgroup. The workgroup sought to complement these and other co-occurring efforts related to data access in Texas.

A key DSHS initiative is to evaluate and improve data acquisition and utilization practices, both with internal and external partners. DSHS began this process in the

of spring of 2018 by hosting full day data workshops where staff who oversee the most used datasets presented mechanisms for accessing the data. These staff are available for live consultation and technical assistance regarding current and future requests and projects. In the summer of 2018, DSHS started a data sharing initiative that included a detailed review of legal authority relating to sharing the most requested datasets. The effort involves reviewing their policies and processes relating to data sharing and the institutional review board (IRB). This effort was based in part on feedback DSHS received from its local public health partners through a series of regional meetings that occurred in 2018.

Also, DSHS launched a new vital records system on January 1, 2019, that will improve the state's vital records. The system moves the state to a current technology platform and provides upfront quality assurance that should improve data quality and timeliness. During the 2019 legislative session, DSHS is also seeking to upgrade its infectious disease surveillance and response system - the National Electronic Disease Surveillance System (NEDSS), as well as enhancing its Center for Health Statistics' data analytics capabilities. The system upgrades will help improve data sharing capabilities and processes.

HHSC is in the early pilot and assessment phases of a long-term effort to develop a fully-automated, seamlessly interoperable, HHS-wide performance management and data analytics system. This system will streamline and systematize HHSC's ability to access data. HHSC is also exploring the development of an enhanced system-wide business enablement platform that will provide a foundation to expedite new system requests and allow for greater standardization of system data collection.

In its 2020-2021 Legislative Appropriation Request, HHSC is requesting funding for these initiatives. Each would support a more integrated, client-centric approach to health and human services delivery and management through shared service elements and resources, effective data management, and mission specific applications capable of supporting multiple programs. In the short and long-term, these efforts will support data-driven decision making and better position HHSC to identify and leverage potential efficiencies within a wide variety programs and systems. These initiatives should also enhance HHSC's ability to more effectively collaborate with academic and policy institutions on research that could benefit Texans.

HHSC is seeking additional resources to expand and develop a more robust system of risk assessments, security plans, and enhanced monitoring solutions to prevent data breaches and ensure access to sensitive data is adequately controlled.

PROJECT OVERVIEW

In fall 2018, the THIN data workgroup conducted 25 interviews with a diverse group of data users and data custodians. Users included LHDs, a policy institute, Texas academic and health institutions, and out-of-state health institutions, among others.. Custodian interviews were conducted with several organizations, including state health agencies within and outside of Texas, institutions within and outside of Texas, organizations within Texas, states with all-payer claims databases (APCDs), and federal and national organizations.

On November 13, 2018, THIN convened an all-day meeting, focusing on issues and potential solutions for sharing and using data to inform health practice and policies. The time was divided between three expert panels:

1) data use to inform practices and policies
2) legal use and sharing of data and
3) procedures and processes for data sharing

(See Appendixes H & I for agenda and expert panelists).

Panels were moderated by the THIN advisory committee and members of the THIN data workgroup, and the format included short prepared remarks from each panelist, followed by 60 minutes for audience questions and discussion. This report summarizes key issues identified through this process and provides a set of actionable recommendations for policy makers and others committed to the responsible use of our data resources for health improvement in Texas.

SUMMARY OF FINDINGS

Themes fell into two broad categories: 1) the need for data, and 2) systems and factors impacting data sharing. The first covers the benefits and needs related to data sharing, and the second covers policy, infrastructure, and societal values related to data sharing.

1) THE NEEDS FOR DATA

Data Uses and Applications

1. Responding to Urgent Health Needs at a State and Community Level

The local health departments and DSHS regional offices are the front line of public health response. Data-informed LHDs can respond effectively to local issues, and in turn, inform state action. For example, in 2014 there was a rise in syphilis cases in Bexar County. At that time, women were routinely screened for syphilis at the beginning of prenatal care, but not during late pregnancy. The San Antonio Metropolitan Health District (SAMHD), using data shared by DSHS, determined that many women were becoming re-infected during pregnancy, leading to poor birth outcomes. This information led to a SAMHD policy to test pregnant women again during the third trimester, which in turn led to a reduction in negative birth outcomes. In 2015, Texas began requiring third trimester screening for syphilis,[9] and is now one of 17 states with such a policy.[10]

2. Planning and Focusing Efforts to Address Chronic and Emerging Health Needs

Researchers and LHDs depend on disease registries (e.g., cancer, birth defects) to understand, treat, and prevent these conditions, while also identifying trends and clusters or

"hotspots." Currently, the cancer registry has difficulties accessing Medicaid claims data. Access to Medicaid data would improve the quality and comprehensiveness of the registry, to the benefit of all Texans.

LHDs also need access to infectious disease data. Notifiable conditions include HIV, hepatitis A, and tuberculosis. Identified case information flow from the local level to the county or regional level and then to the state level. In interviews, LHDs reported that once they submitted information about notifiable infectious diseases, it was difficult for the data to flow "back" to the LHDs. LHDs use infectious disease data to indentify and find cases as they link them to needed services. However, LHDs shared that public health workers have been hindered in their case finding because data has become difficult to access. DSHS continues to work with the LHD to identify issues and resolve them.

3. Evaluating Programs and Services

Public health data is critical in evaluating programs and providing efficient services. Accurate data helps to determine if programs are working as planned, if people are healthier because of interventions, and if programs are cost-effective. For example, linking individuals across datasets helps programs clarify who is receiving specific services and the outcomes being achieved. Currently, access to matched Medicaid data (housed within HHSC) to death records (housed within DSHS) is not always allowed in Texas, although other states have identified ways to navigate this task. A similar roadblock arises when attempting to access matched Medicaid and CHIP Perinatal recipients (HHSC) to birth outcomes (DSHS).

9- Changes to syphilis testing requirements for pregnant women. https://www.texmed.org/Template.aspx?id=34463

10- Warren HP, Cramer R, Kidd S, Leichliter JS. State requirements for prenatal syphilis screening in the United States, 2016. Maternal and Child Health Journal. 2018 Sep 1;22(9):1227-32.

4. Supporting Funding Proposals and Subsequent Reporting Requirements

Data, especially timely and local data, is essential for successful grant proposals. For example, to apply for Healthy Start funding, HRSA requires infant mortality rates at the ZIP code level. Funders also expect grantees to have access to data for progress and outcomes reporting. Two interviewees from LHDs expressed concerns that they would not receive renewed national grant funding because of lack of timely and local data, putting service providers at risk of being underfunded. Texas is less competitive than other states for federal dollars due to poor data access.

5. Conducting Health Research

Researchers need data to answer questions related to health outcomes, program evaluation, service provision, and cost-effectiveness. In interviews, data users at academic institutions shared that the inaccessibility of health data has hampered their research. During the panel session, the Meadows Mental Health Policy Institute expressed concerns with their inability to get in the queue for refreshed Medicaid and Medicare data, leaving them dependent on national prevalence estimates and unable to accurately estimate the incidence of first episode psychosis in Texas communities. The delay in getting updated data has been an impediment for responding to the needs of patients with serious mental illness.

Characteristics of Data Needed

1. Individual-level or aggregated to small geographic areas

Per Chapter 121 of the Health and Safety Code, LHDs serve an essential function in providing public health services at the local level. These functions are listed in Appendix J. Therefore, to perform these functions, LHDs need timely access to granular data. LHDs need to understand the needs of individuals, respond to local health emergencies, and link individuals to needed services.

Accessing geographically specific data was a challenge identified by all LHDs interviewed. For example, Dr. Anita Kurian of SAMHD shared that in Bexar County they are working to place mobile units into neighborhoods with high rates of congenital syphilis infection. However, they need data with precise geographic information for rapid-response work.

2. Current and Timely Data

"Without current data, we have become data historians." — David Lakey, MD

Panelists and interviewees identified multiple challenges in accessing timely data[11] to inform policy, identify health priorities, and support program evaluation. Of the 12 data users interviewed, the majority found the processes for requesting data were not clear. Data users experienced changes in practices, rules, and personnel when requesting data from state agencies, contributing to lengthy delays. For data users interviewed, the time between request and delivery of data ranged from 2-24 months.[12] Delayed data was a challenge identified by all 4 LHDs interviewed. For LHDs, the lack of "fresh," accessible data makes it harder to follow cases of communicable diseases (STDs, HIV); respond to urgent community health needs (opioid overdoses, teen pregnancies); share timely information with the public; and compete in national grants. Users from LHDs described workarounds to access timely data, including requesting STD/HIV data through open records requests after data had been delayed by more than 6 months. DSHS

11- Refers to both the availability of recent data and the time it takes to acquire data after a request has been made.

12- Texas Health Care Information Collection (THCIC) data (DSHS) takes 10-12 months before it is available for sharing. Vital statistics (DSHS) take 15 months to be cleaned and made ready for sharing. The most current finalized data available for request from vital statistics is from 2015.

continues to work with LHDs to address these data delays, but statutory changes and clarifications related to LHD access to data would reduce these challenges.

3. Data Integration

Integrating public health data sets with one another—and with other data sets—helps us understand information in context and develop focused, innovative interventions. Despite the power of data integration to drive effective interventions, social determinants of health (SDoH) data tends to be siloed, not centralized. Examples of data integration can be found across Texas; Appendix K includes four examples from the panel sessions.

2) SYSTEMS AND FACTORS IMPACTING DATA SHARING

Policies and Laws

1. Guiding Principles

In general, for HHSC and DSHS, data sharing must align with programmatic purposes. The guiding principles for HHSC related to access to data are:

- Does this request meet a program administration purpose?
- Does this research help us identify who is eligible for services?
- Does this research improve or provide services?
- Does this research establish benefits enforcement and stop fraud, waste, and abuse?

If a data request does not answer one or more of the above questions, it can be refused, leaving researchers with a narrow path to data access.

DSHS considers public health purpose, legal

authority through federal and state laws, individual privacy, the security and handling of the data, and, where applicable, human subjects research.

2. Individual Privacy Protections

At the provider level, individuals give informed consent, allowing or disallowing their data to be shared while maintaining confidentiality. Rural areas present special challenges in protecting individual privacy while allowing data sharing. In places with small populations, like West Texas, it could be possible to identify a single person from "de-identified data." To preserve privacy, DSHS has created data suppression workgroups, looking to guidelines from the Centers for Disease Control and Prevention (CDC) and the National Center for Health Statistics (NCHS). Challenges remain in sharing data when areas are small, or diseases are rare, because agencies must balance privacy needs with service provision. Additionally, it is important to protect data systems from cyber-attacks that can place data integrity and privacy at risk. Each day, HHSC repels millions of cyber-attacks that have the potential if successful to place personal client data at risk.

3. Sharing Process from the Legal Perspective

Even as data sharing could improve services and lower costs, governmental bodies like HHSC and DSHS have their own risks to manage. Programs whose role is described by statute as "custodian of the data" tend to be conservative in sharing that data, lest it be misused, misinterpreted, or compromised. Records at HHSC, in particular, are under scrutiny from multiple federal organizations.

In fact, all data custodians are subject to state and federal statutes. For example, the Dallas-Fort Worth Hospital Council (DFWHC) must comply with HIPAA, HI-TEC, FISMA, and

FEDRAMP. Across data custodians, some sensitive data (e.g. newborn screening) are subject to further state and federal restrictions to secure PHI. What makes HHSC unique is their role as both a service provider and a data custodian. In contrast, an organization like DFWHC maintains a layer of independence by aggregating data from partner hospitals.

4. Interagency Sharing

Data sharing between state agencies can be a challenge. For example, HHSC and DSHS cannot always share data with one another. Even within the same health agency, sharing data can be difficult. For example, in completing an IRB proposal for DSHS, one might be able to obtain birth data and hospital discharge data separately, but having both these datasets matched can be prohibited or require resources that do not currently exist at the state agency. Given the concerns outlined above, there are well-founded reasons for being conservative with data sharing. However, with clear, concise terms and conditions for use of protected data, included on agreements within and between agencies, such concerns can be minimized. Currently, the Texas Department of Information Resources (DIR) has an initiative to facilitate interagency data sharing, including among entities like HHSC and DSHS.

5. Statutory Interpretation

Some data use statutes have been written broadly, leading to varying interpretations, while other statutes have been written narrowly. Pre-HIE statutes are also challenging for consistent legal interpretation. Inconsistent interpretation impacts service provision. For example, although LHDs serve the public health function at the local level, they are not specifically named as an entity that can access vital statistics data. Currently, the interpretation is that LHDs are entitled to birth data "above the

line,"[13] which impedes their work. Panelists recommended a survey of legal issues pertaining to data access, to allow statutory alignment.

Data Infrastructure

1. Necessary Components

While it can take years for new knowledge to reach practice, technology that facilitates data sharing can help close the gap. Yet technology is just one piece of the puzzle. Data infrastructure includes:

- Hardware (e.g., servers);
- Software (e.g., business intelligence tools that allow for query and analysis); and
- Trained workforce (e.g., knowledgeable in data management, validation, security, matching, sharing, analysis, and/or visualization).

Workforce retention remains a challenge for many data custodians, with staff turnover contributing to delays in data sharing.

2. Data Sharing Process

Sharing practices vary across data custodians. In interviewing custodians and users from around the country, we found a few key steps, illustrated in Figure 1.[17] Some steps depend on the custodian or the level of data requested. For example, some data requests that require IRB approval. Some custodians have a review committee, to address data requests involve sensitive information. Some models include requestors paying custodians for access. Finally, after analysis, some requestors share findings with data custodians. For an example of one data sharing process see appendix L.

3. Models of Data Sharing

From the expert panel sessions and interviews with data custodians, several models for data

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13- "Above the line" refers to demographic information only—not details of birth/maternal outcomes because these are considered medical records.
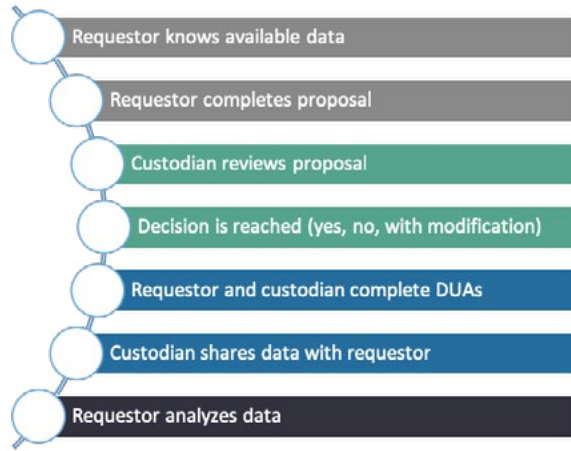
Figure 1. Basic Steps in Data Sharing Process

sharing emerged. Some custodians share data via extractions or ad-hoc reports, while others have business intelligence tools that allow researchers to query data for themselves. Inundation of individual data requests can create an impasse for custodians, flooding those on data management teams with complicated analyses to perform; both HHSC and DSHS identified such impasses in their systems. Self-service analytics and query systems offer a path around data-request logjams.

APCDs in states like Washington and Colorado are exemplary models, balancing public governance with external expertise.[14] Other notable models for data sharing include public data custodians, like the Washington State Department of Health, and data integrators, like Actionable Intelligence for Social Policy, which assist government entities in combining diverse data systems (See Appendix O for a list of data custodians; Appendix P for a comparison of models).

4. Leveraging Existing Infrastructure

In Texas, HHSC and DSHS are in a time of transition. In the past two years, the volume of data requests to HHSC has increased by 20%. To keep pace with requests and respond to urgent needs, DSHS is making an exceptional item request this legislative session to address their antiquated data system, create a portal/tracking system for data requests, and support a GIS server. DSHS's goal is to increase transparency and reduce ad-hoc work in order to expand bandwidth for answering larger questions.

Both DSHS and HHSC are working to determine which datasets are most frequently requested and which reports can be aggregated and updated regularly. To maximize impact, HHSC and DSHS could coordinate as they modernize their existing infrastructure.

5. Improving Infrastructure

Improving data infrastructure in Texas requires more than updates to hardware and software. The data management workforce must be trained in maintaining public health datasets, and researchers and LHDs must be trained in how to access needed data. Universities have a need to expand student training and research, while state agencies have a need to utilize data and research to inform programs. By aligning these needs, universities and state agencies can use data to inform public health, social services, and health services. There are many models for data sharing; as plans for infrastructure improvement move forward, DIR could compare national models and vet the ones best suited for Texas.

Values Related to Data Sharing

1. Current Drivers of Data Sharing Environment

It is easy for data policies and practices to revolve around fear. The landscape includes inherent risks—potential security breaches, compromised personal privacy, and legal consequences. Nevertheless, states like Colorado, Washington, Arkansas, and Florida have implemented All-Payer Claims Databases (See Appendixes N & O), prioritizing public health and data sharing.

14- Currently, there are 16 states with existing state-mandated APCDs. See Appendix M for a nationwide map of APCDs; Appendix N for examples of state statutes mandating APCDs.

Closer to home, DFWHC has tracked patients for over a decade, capturing millions of encounters and safely sharing data with partner hospitals, academic institutions, state agencies, and community health organizations. Kristin Jenkins, President of the DFWHC Foundation, framed DFWHC as a "vast data reservoir," with data flowing in and out; valuable in sharing, not just collecting.

With the advent of THCIC, it was more cost-effective for hospitals in North Texas to share a single data repository through DFWHC. What began out of thrift has persisted and thrived because a group of visionary leaders believed in the power of data sharing. DFWHC's model is replicable and inexpensive. Data sharing among regional hospitals could be nurtured by the state, using existing infrastructure, cultivating trust in long-term relationships, and gradually scaling up.

So, what is stopping data sharing? Several themes emerged from the panels and interviews:

- Risk aversion among lawyers, doctors, hospitals, and safety net providers, who fear liability, inaccuracy, and penalization;
- Generational wariness; and
- Lack of understanding between users and custodians, with each unaware of the pressures the other is under.

2. Additional Important Values

Texas holds many values that support the efficient sharing of data. Most high-value health data is funded by taxpayers and should be harnessed to the benefit of Texans. The current inefficiencies waste limited public health resources.

Data sharing also allows local communities to create local solutions. Texas is home to diverse communities whose health needs vastly differ. Even data at a county level may not be reflective of the experiences of all residents within that county, as has been shown through small area mapping generated by the University of Texas System in collaboration with The University of Texas Health Science Center at Tyler.

The infant mortality rates for neighboring zip codes in the same county can vary dramatically, even within the same racial group (http://www.utsystempophealth.org/imr-texas/). Without data at varying geographic levels, those disparities—and opportunities for intervention—are missed.

CONCLUSIONS AND NEXT STEPS

All stakeholders, including the health state agencies, agreed that more streamlined processes are needed to improve appropriate access to health data, as it is not currently used to its full potential to improve health care and the health of Texans. Stakeholders identified three major issues:

1. Many of the rules governing data are antiquated. The rules and statutes used to determine data sharing in Texas, have not been updated for many years. Federal policies dictating access to Medicaid data are 8 years old, while rules covering vital statistics data are over 20 years old. And yet the processes for using and sharing data are being reassessed, making it harder to access data even among state agencies and LHDs.

2. State agencies lack sufficient resources (hardware, software, and workforce) to track data requests, fulfill data requests, or create standardized data reports and queries. Most requests come from state agencies, LHDs, and state universities, and many are denied due to resource scarcity. Even requests that are rejected due to data security issues could in some instances be shared as de-identified data, were additional resources available. Many requests are reoccurring, which could be fulfilled by developing standardized reports or public use data files.

3. There are not standardized, publicly documented data sharing processes. Without consistency, stakeholders and data custodians face frustrations, delays, and compromised trust. Most statutes dictating how public health data are shared have not changed in many years. Yet every 2-5 years, custodians reconsider internal processes. Depending on staff turnover, familiarity with statutes, and health data breaches (even if unrelated to the data in question), the path to sharing is widened or narrowed.

To address these issues and others identified within this report, current statutes need to be examined and updated, to assure consistent interpretation and allowances for state agencies and LHDs to provide essential public health and welfare services. Specific additions to current statutes are outlined in the Recommendations section. While specific recommendations for statutes are identified, state agencies along with their partners and stakeholders should continue to conduct a deep dive into the complexity of the data sharing, including discussions of issues related to resources and statutes.

Additionally, it is recommended that state agencies receive Exceptional Items funding that they requested, to allow them to modernize their data processing and analytics capability. However, increased funding alone will not meet state and community needs for data-driven programs and services. Although state agencies have excellent and dedicated staff, they are still understaffed with high turnover rates, especially in data and analytics sections.

To supplement the ongoing improvement activities by DSHS and HHSC, we recommend fostering, strengthening and increasing partnerships with Texas universities collaborating with faculty who are familiar with state data sets and researchers who use innovative techniques to manage, analyze, and interpret health data. Most Texas universities have access to advanced technology and secure operating platforms. In fact, the 17th most powerful computing system in the world —the Texas Advanced Computing Center (TACC)—is operated and maintained by The University of Texas at Austin. Using existing university resources, state agencies can expand technological capabilities and access to experts while reducing costs. Universities also offer the opportunity to train and provide student workers, increasing the workforce and capacity for state agencies to expand data management, analytics, and dissemination.

Finally, all data custodians need to identify their processes for data sharing, protecting data while

providing it to those who need it for programmatic or research purposes. Processes and procedures need to be clear, public, consistent, and understood by all staff within the agency. Changes to processes should be minimal, reasoned, and inclusive of stakeholder input. Documents like DUAs and MOUs should be mostly standardized and easily accessible.

These recommendations are not expected to solve all issues identified by stakeholders during this effort.

There are hundreds of health data sets, and we addressed just three, albeit the most commonly used. Rather, these recommendations offer a starting point. Certain concrete changes—updating statutes, clarifying policies and procedures at state health agencies, and creating partnerships—can significantly increase the use of public health data to improve services and programs, gain federal funding, and inform health and social policies.

APPENDICES

Appendix A: Glossary

Academic/basic research: Scientific inquiry that is theoretical and seeks to legitimize the field and profession.

Aggregate-level: Data about individuals that has been grouped, so that any single person may not be identified; useful for planning and disease prevention (e.g. the number of babies born with very low birth weight in a given county).

Applied research: Scientific inquiry that is practical and seeks to find solutions to immediate problems and issues.

All-Payer Claims Database (APCD): Statewide repository of data—aggregated, encrypted, and protective of individual patient identity—from health insurance claims (private, public, and self-insured); APCDs are useful in containing cost and improving quality and care. http://www.ncsl.org/research/health/collecting-health-data-all-payer-claims-database.aspx

Claims data: Patient information from health insurers, including demographic characteristics (e. g., age, sex), diagnoses, treatments, and costs. https://www.cdc.gov/workplacehealthpromotion/model/healthcare-cost-data/interpreting.html

Census tract level data: Data pertaining to "small, relatively permanent statistics subdivisions of a county or equivalent entity that are updated by local participants prior to each decennial census... The primary purpose of census tracts is to provide a stable set of geographic units for the presentation of statistical data. Census tracts generally have a population size between 1,200 and 8,000 people, with an optimum size of 4,000 people." (https://www.census.gov/geo/reference/gtc/gtc_ct.html)

Data management: Stewardship throughout the data life-cycle; includes implementing architecture, policies, and practices to make data accessible and timely for organizational needs.

Data use agreement (DUA): Contract used to define terms and conditions for transmitting data; includes limitations on use and publication, privacy rights, responsibilities to protect data, and liabilities for harm. https://research.unc.edu/files/2013/04/CCM3_039360.pdf

De-identified data: Information that could be used to single out a particular person is de-coupled from other data; sometimes referred to as public use data file (PUDF) (e.g., identifying information, like names, birthdates, and addresses are removed from a data file listing cases of heart disease).

Encounter data: Claims records for health services paid for by managed care organizations (MCOs); used by the U.S. Department of Health & Human Health Services (HHS) and Centers for Medicare & Medicaid Services (CMS) to inform risk-adjusted and incentive payments to MCOs. https://www.mathematica-mpr.com/~/media/publications/pdfs/health/max_encounterdata.pdf

Health Insurance Portability and Accountability Act of 1996 (HIPAA): Requires regulations to protect privacy and security of health information:

- Per HHS, "a major goal of the Privacy Rule is to assure that individuals' health information is properly protected while allowing the flow of health information needed to provide and promote high quality health care and to protect the public's health and well-being." https://www.hhs.gov/hipaa/for-professionals/privacy/index.html

- Per HHS, "a major goal of the Security Rule is to protect the privacy of individuals' health information while allowing covered entities to adopt new technologies to improve the quality and efficiency of patient care." https://www.hhs.gov/hipaa/for-professionals/security/laws-regulations/index.html

Hospital discharge data: Includes inpatient stays, admission and discharge dates, demographic characteristics of patients, and primary/secondary diagnoses. https://www.nahdo.org/data_resources

Fully identified data: Information that could be used to single out a particular person is not suppressed or de-coupled from other data (e.g., identifying information, like names, birthdates, and addresses, included in a data file listing cases of tuberculosis).

Institutional Review Board (IRB): Established by the National Research Act of 1974, IRBs review research proposals to ensure that the rights and welfare of participants are protected. https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html

Limited data set: Excludes direct identifiers, like names, birthdates, addresses, etc. per the HIPAA Privacy Rule, may be used/disclosed for research, public health, or health care operations, "without obtaining either an individual's Authorization or a waiver or an alteration of Authorization for its use and disclosure, with a data use agreement." https://privacyruleandresearch.nih.gov/pr_08.asp

Memorandum of understanding (MOU): An agreement between two or more parties outlining terms and conditions of cooperation; not necessarily binding.

Open records request: Set out in the Texas Public Information Act (Chapter 552, Texas Government Code), the process of petitioning governmental bodies to gain access to public information; within 10 days of the petition, if the governmental body believes the information is not public, it must ask the Attorney General for a decision to withhold records (decision generally rendered within 45 days); if the governmental body does not seek a ruling within 10 days of being petitioned for information, "the information is presumed to be public," unless there are compelling arguments for withholding it. https://foift.org/resources/texas-public-information-act/

Personally identifiable information (PII): Data that can be used to identify, contact, or locate a specific person.

Population health: "The health outcomes of a group of individuals, including the distribution of such outcomes within the group… the field of population health includes health outcomes, patterns of health determinants, and policies and interventions that link these two" (Kindig & Stoddart, 2003). https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1447747/

Program evaluation: Assessment of activities, measuring implementation, effectiveness, efficiency, cost-effectiveness, and attribution (in other words, are outcomes related to the activities, or something else?); one of the ten essential public health services. https://www.cdc.gov/eval/guide/introduction/index.htm#ftn5

Programmatic Use: use by an agency to meet its program functions.

Protected health information (PHI): Per HIPAA regulations, PHI is any data in a medical record, generated or used in health care service provision, that could use used to identify a person; includes names, geographic location smaller than state, birthdates, discharge dates, death dates, Social Security numbers, contact information, medical record numbers, etc. https://cphs.berkeley.edu/hipaa/hipaa18.html

Public health: A commonly used definition is: "The science and art of preventing disease, prolonging life, and promoting health through the organized efforts and informed choices of society, organizations, public and private communities, and individuals," from Charles-Edward Amory Winslow, Founder of Yale School of Public Health. https://www.cdc.gov/publichealth101/public-health.html

Sociodemographic characteristics: Includes age, ethnicity, sex, socioeconomic status, marital status, sexual orientation, family size, education, etc.

Social determinants of health (SDoH): Per Healthy People 2020, environmental conditions "in which people are born, live, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks"; for example, access to safe, affordable housing is a SDoH. https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health

Texas Health Care Information Collection (THCIC): Per Texas Department of State Health Services, THCIC was created by the 74th Texas Legislature in 1995, "to collect data and report on health care activity in hospitals and health maintenance organizations operating in Texas. The goal is to provide information that will enable consumers to have an impact on the cost and quality of health care in Texas." https://dshs.texas.gov/thcic/
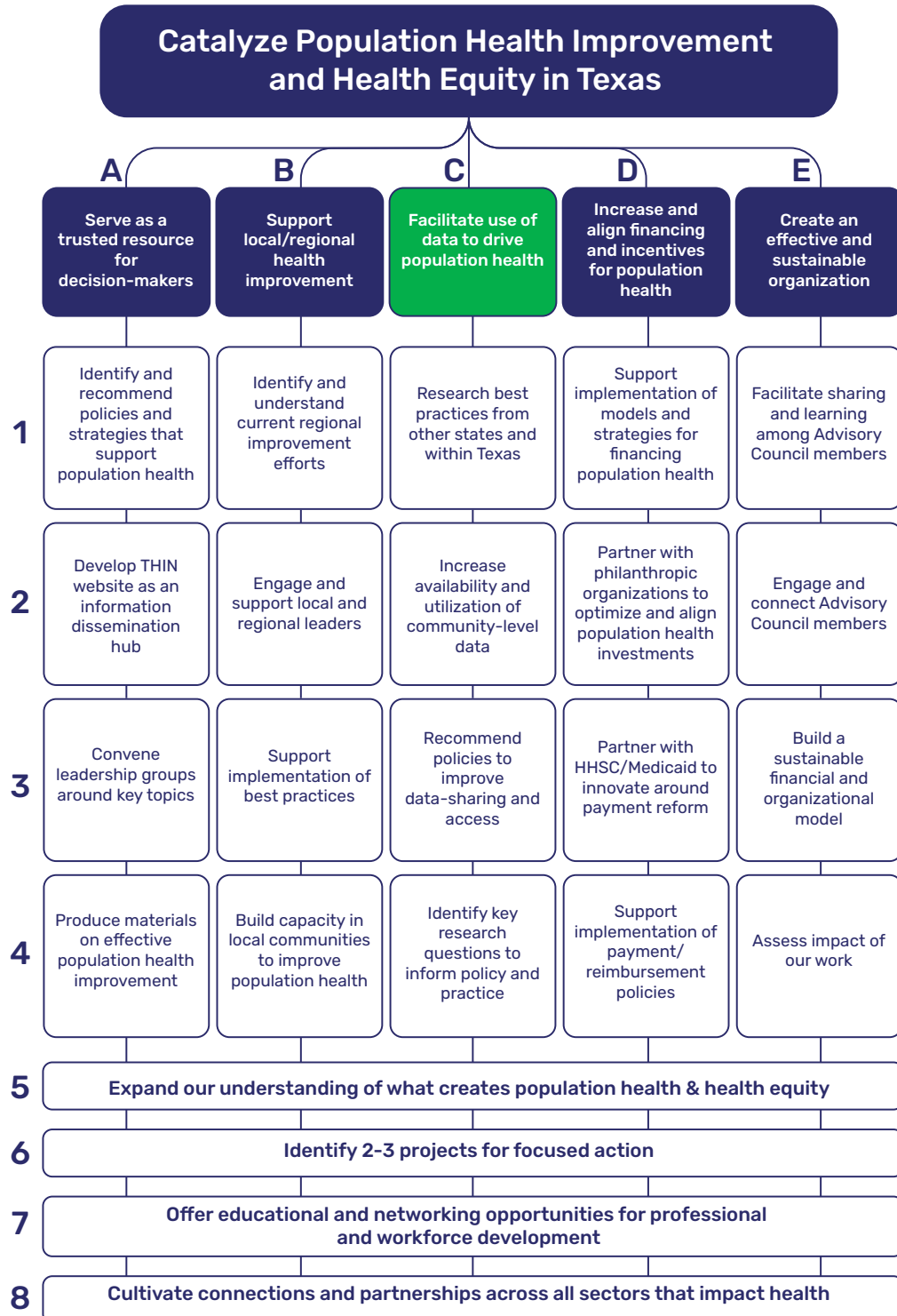
Vital statistics: Data on life events (birth, fetal death, death), including related medical data and demographic information.

Appendix B: Texas Health Improvement Network Strategic Map

Texas Health Improvement Network

STRATEGIC MAP

Catalyze Population Health Improvement and Health Equity in Texas

	A Serve as a trusted resource for decision-makers	**B** Support local/regional health improvement	**C** Facilitate use of data to drive population health	**D** Increase and align financing and incentives for population health	**E** Create an effective and sustainable organization
1	Identify and recommend policies and strategies that support population health	Identify and understand current regional improvement efforts	Research best practices from other states and within Texas	Support implementation of models and strategies for financing population health	Facilitate sharing and learning among Advisory Council members
2	Develop THIN website as an information dissemination hub	Engage and support local and regional leaders	Increase availability and utilization of community-level data	Partner with philanthropic organizations to optimize and align population health investments	Engage and connect Advisory Council members
3	Convene leadership groups around key topics	Support implementation of best practices	Recommend policies to improve data-sharing and access	Partner with HHSC/Medicaid to innovate around payment reform	Build a sustainable financial and organizational model
4	Produce materials on effective population health improvement	Build capacity in local communities to improve population health	Identify key research questions to inform policy and practice	Support implementation of payment/reimbursement policies	Assess impact of our work

5	Expand our understanding of what creates population health & health equity
6	Identify 2-3 projects for focused action
7	Offer educational and networking opportunities for professional and workforce development
8	Cultivate connections and partnerships across all sectors that impact health

Appendix C: Texas Health Improvement Network Data Workgroup

David Lakey, MD
Vice Chancellor for Health Affairs
Chief Medical Officer
The University of Texas System

Jessica Cance, PhD, MPH
Agency Analytics Unit Manager
Texas Department of State Health Services

Cecilia Ganduglia Cazaban, MD, DrPH, MPH
Assistant Professor / Co-Director
UTHealth School of Public Health / Center for
Healthcare Data

Kirk Cole, MUP
Senior Advisor to the Commissioner
Texas Department of State Health Services

Maria Cooper, PhD, MA
Research Specialist
Office of Science and Population Health
Texas Department of State Health Services

Jordan Dixon, MPP
Deputy Executive Commissioner
Office of Transformation and Innovation
Texas Health and Human Services Commission

Nagla Elerian, MS
Director of Strategic Initiatives
UT System Population Health

Calvin Green, MPA
Deputy Executive Commissioner
Office of Performance
Texas Health and Human Services Commission

Travis Hanson, JD, MS
Executive Director
West Texas Health Information Technology Regional
Extension Center (WTxHITREC)
Texas Tech University

Anjum Khurshid, MD, PhD
Assistant Professor / Co-Chief
Department of Population Health / Data Integration
Dell Medical School, The University of Texas at Austin

Lisa Kirsch, MPAff
Senior Policy Director
Dean's Office
Dell Medical School, The University of Texas at Austin

Trudy Krause, DrPH, MBA, CPHQ
Associate Professor / Co-Director
UTHealth School of Public Health / Center for
Healthcare Data

Hye-Chung Kum, PhD, MSW, MS
Associate Professor
Texas A&M University

Mike Johnsrud, PhD, RPh
Executive Director
Texas Center for Health Outcomes Research &
Education (TxCORE)
The University of Texas College of Pharmacy

Robert Morgan, PhD
Professor and Chair of Management, Policy, and
Community Health
UTHealth, School of Public Health

Eileen Nehme, PhD, MPH
THIN Program Director
UT System Population Health

John Petrila, JD
Vice President of Adult Policy
Meadows Mental Health Policy Institute

Stephen Pont, MD, MPH
Medical Director
Office of Science and Population Health
Texas Department of State Health Services

Karen Rascati, PhD, RPh
Professor, Graduate Advisor
The University of Texas College of Pharmacy

Kristin Richards, PhD, RPh, MS
Associate Director of the Texas Center for Health
Outcomes Research (TxCORE)
The University of Texas College of Pharmacy

Eduardo Sanchez, MD, MPH, FAAFP
Chief Medical Officer for Prevention
American Heart Association

Appendix D: Statutes Governing Vital Statistics

Texas Government Code Section 552.115

Sec. 552.115. EXCEPTION: CONFIDENTIALITY OF BIRTH AND DEATH RECORDS.

(a) A birth or death record maintained by the vital statistics unit of the Department of State Health Services or a local registration official is excepted from the requirements of Section 552.021, except that:

- (1) a birth record is public information and available to the public on and after the 75th anniversary of the date of birth as shown on the record filed with the vital statistics unit or local registration official;

- (2) a death record is public information and available to the public on and after the 25th anniversary of the date of death as shown on the record filed with the vital statistics unit or local registration official, except that if the decedent is unidentified, the death record is public information and available to the public on and after the first anniversary of the date of death;

- (3) a general birth index or a general death index established or maintained by the vital statistics unit or a local registration official is public information and available to the public to the extent the index relates to a birth record or death record that is public information and available to the public under Subdivision (1) or (2);

- (4) a summary birth index or a summary death index prepared or maintained by the vital statistics unit or a local registration official is public information and available to the public; and

- (5) a birth or death record is available to the chief executive officer of a home-rule municipality or the officer's designee if:
    - (A) the record is used only to identify a property owner or other person to whom the municipality is required to give notice when enforcing a state statute or an ordinance;
    - (B) the municipality has exercised due diligence in the manner described by Section

54.035(e), Local Government Code, to identify the person; and

- (C) the officer or designee signs a confidentiality agreement that requires that:

    - (i) the information not be disclosed outside the office of the officer or designee, or within the office for a purpose other than the purpose described by Paragraph (A);
    - (ii) the information be labeled as confidential;
    - (iii) the information be kept securely; and
    - (iv) the number of copies made of the information or the notes taken from the information that implicate the confidential nature of the information be controlled, with all copies or notes that are not destroyed or returned remaining confidential and subject to the confidentiality agreement.

Full statute available at: https://statutes.capitol.texas.gov/Docs/GV/htm/GV.552.htm

Texas Health and Safety Code

Title 3. Vital Statistics
Chapter 192. Birth Records.
Sec. 192.002. FORM OF BIRTH CERTIFICATE.

- (a) The department shall prescribe the form and contents of the birth certificate.

- (b) The section of the birth certificate entitled "For Medical and Health Use Only" is not part of the legal birth certificate. Information held by the department under that section of the certificate is confidential. That information may not be released or made public on subpoena or otherwise, except that release may be made for statistical purposes only so that no person, patient, or facility is identified, or to medical personnel of a health care entity, as that term is defined in Subtitle B, Title 3, Occupations Code, or to a faculty member at a medical school, as that term is defined in Section 61.501, Education

Code, for statistical or medical research, or to appropriate state or federal agencies for statistical research. The executive commissioner may adopt rules to implement this subsection.

- (c) The form must include a space for recording the social security numbers of the mother and father and the signatures of the biological mother and biological father. These social security numbers and signatures are not a part of the legal birth certificate, shall be made available to the agency administering the state's plan under Part D of Title IV of the federal Social Security Act (42 U.S.C. Section 651 et seq.), and may not be used or disseminated for any purpose other than the establishment and the enforcement of child support orders.

- (d) The social security numbers of the mother and father recorded on the form shall be made available to the United States Social Security Administration.

Full statute available at: https://statutes.capitol.texas.gov/Docs/HS/htm/HS.192.htm

Texas Administrative Code

Title 25. Health Services
Part 1. Department of State Health Services
Chapter 181. Vital Statistics
Subchapter A. Miscellaneous Provisions
Rule § 181.11. Requests for Personal Data

- (a) The purpose of this section is to describe the criteria that the Committee on Requests for Personal Data will use in reviewing and recommending disposition when an application for personal data is received.

- (b) The Commissioner and/or his designee shall appoint a Committee on Requests for Personal Data (Committee) that serves in an advisory capacity. The committee reviews and makes recommendations regarding requests for personal data to be used for research purposes or for the official use of governmental agencies.

- (c) Procedures.

    - (1) If the department receives a request for personal data, the release of which has been determined to be legally discretionary, and there is a question as to whether the data

should be released, the request shall be referred to the committee for its review and recommendation. The committee will review the request and make a recommendation regarding release to the commissioner or his designee.

- (2) The committee will require each applicant for personal data to complete the application form as prescribed by the committee.

- (3) If the personal data is released, a copy of the final project report, any publication, or presentation must be furnished to the committee. The department will be given credit as the source of the data.

- (4) It is department policy to disapprove applications involving contact with any person, institution, or agency identified on the record unless the committee determines that there are substantial overriding reasons for the contact.

- (5) It is department policy to disapprove applications involving research that does not serve a valid scientific or public health purpose.

- (6) The Vital Statistics Unit shall charge the statutory fee for each vital record research copy as provided in the Health and Safety Code, §191.0045.

- (7) Personal data application requests need to be submitted to the department's Institutional Review Committee if any of the following apply to the requested research:

    - A. sponsored by the department;

    - B. conducted by or under the direction of department employees or agents;

    - C. conducted by or under the direction of department employees or agents using department property of facilities, or;

    - D. involves the use of department nonpublic information to identify or contact human research subjects or prospective subjects.

Full statute available at: https://texreg.sos.state.tx.us/public/readtac$ext.TacPage?sl=R&app=9&p_dir=&p_rloc=&p_tloc=&p_ploc=&pg=1&p_tac=&ti=25&pt=1&ch=181&rl=11

Appendix E: Statute Governing Texas Health Care Information Collection (THCIC) Data

Texas Health and Safety Code, Chapter 108

Sec. 108.006. POWERS AND DUTIES OF EXECUTIVE COMMISSIONER AND DEPARTMENT.

- (a) The department shall develop a statewide health care data collection system to collect health care charges, utilization data, provider quality data, and outcome data to facilitate the promotion and accessibility of cost-effective, good quality health care. The executive commissioner or department, as applicable, shall perform the following duties:

  - (1) the department shall direct the collection, dissemination, and analysis of data under this chapter;

  - (2) the department shall collect the data under this chapter;

  - (3) the executive commissioner shall adopt policies and rules necessary to carry out this chapter, including rules concerning data collection requirements;

  - (4) the department shall build on and not duplicate other data collection required by state or federal law, by an accreditation organization, or by department rule;

  - (5) working with appropriate agencies, the department, with the approval of the executive commissioner, shall review public health data collection programs in this state and recommend, where appropriate, consolidation of the programs and any legislation necessary to effect the consolidation;

  - (6) the department shall assure that public use data is made available and accessible to interested persons;

  - (7) the executive commissioner shall prescribe by rule the process for providers to submit data consistent with Section 108.009;

  - (8) the executive commissioner shall adopt by rule and the department shall implement a methodology to collect and disseminate data reflecting provider quality in accordance with Section 108.010;

  - (9) the department shall make reports to the legislature, the governor, and the public on:

    - (A) the charges and rate of change in the charges for health care services in this state;

    - (B) the effectiveness of the department in carrying out the legislative intent of this chapter;

    - (C) if applicable, any recommendations on the need for further legislation; and

    - (D) the quality and effectiveness of health care and access to health care for all citizens of this state;

  - (10) the department shall develop an annual work plan and establish priorities to accomplish its duties;

  - (11) the department shall provide consumer education on the interpretation and understanding of the public use or provider quality data before the data is disseminated to the public;

  - (12) the department shall work with the commission and each health and human services agency that administers a part of the state Medicaid program to avoid duplication of expenditures of state funds for computer systems, staff, or services in the collection and analysis of data relating to the state Medicaid program;

  - (13) the department shall work with the Department of Information Resources in developing and implementing the statewide health care data collection system and maintain consistency with Department of Information Resources standards; and

  - (14) the department shall develop and implement a health care information plan to:

- (A) support public health and preventative health initiatives;

- (B) assist in the delivery of primary and preventive health care services;

- (C) facilitate the establishment of appropriate benchmark data to measure performance improvements;

- (D) establish and maintain a systematic approach to the collection, storage, and analysis of health care data for longitudinal, epidemiological, and policy impact studies; and

- (E) develop and use system-based protocols to identify individuals and populations at risk.

Full statute available at: https://statutes.capitol.texas.gov/Docs/HS/htm/HS.108.htm

Appendix F: Statutes Governing Texas Medicaid Data

Title IV-A of the Social Security Act—TANF disclosure

SEC. 413. [42 U.S.C. 613] (a) RESEARCH. —The Secretary, directly or through grants, contracts, or interagency agreements, shall conduct research on the benefits, effects, and costs of operating different State programs funded under this part, including time limits relating to eligibility for assistance. The research shall include studies on the effects of different programs and the operation of such programs on welfare dependency, illegitimacy, teen pregnancy, employment rates, child well-being, and any other area the Secretary deems appropriate. The Secretary shall also conduct research on the costs and benefits of State activities under section 407.

Full statute available at: https://www.gpo.gov/fdsys/granule/USCODE-2010-title42/USCODE-2010-title42-chap7-subchapIV-partA-sec613

7 Code of Federal Regulation (C.F.R.) 272.1(c)(i)—SNAP disclosure

In accordance with Section 2020(e)(8), Chapter 51, Title 7, of the United States Code (U.S.C.) [7 C.F.R 272.1(c)(i)], HHSC may share data concerning SNAP applicant or recipient households only for purposes directly connected with the administration or enforcement of the provisions of SNAP, regulations issued pursuant to the SNAP, Federal assistance programs, or federally-assisted State programs, provided there are safeguards restricting the use or disclosure of the Data.

Full statute available at: https://www.gpo.gov/fdsys/granule/CFR-2011-title7-vol4/CFR-2011-title7-vol4-sec272-1/content-detail.html

Section 1902(a)(7)(A) of the Social Security Act [42 U.S.C. 1396a(a)(7)(A)]—Medicaid disclosure

Security Act (42 USC §1396a(a)(7)). The law requires that a "State plan for medical assistance must: (7) provide safeguards which restrict the use or disclosure of information concerning applicants and recipients to purposes directly connected with the administration of the plan." This statutory requirement is implemented in regulations at 42 CFR §431.300 et seq.. 42 CFR §431.302 defines Medicaid program administration to include:

- (A) Establishing Eligibility;
- (B) Determining the amount of Medical Assistance;
- (C) Providing services for recipients; and
- (D) Conducting or assisting an investigation, prosecution, or civil or criminal proceeding related to the administration of the plan.

Full statute available at: https://www.ssa.gov/OP_Home/ssact/title19/1902.htm

Texas Public Information Act

Texas Government Code, Chapter 552, gives you the right to access government records; and an officer for public information and the officer's agent may not ask why you want them. All government information is presumed to be available to the public. Certain exceptions may apply to the disclosure of the information. Governmental bodies shall promptly release requested information that is not confidential by law, either constitutional, statutory, or by judicial decision, or information for which an exception to disclosure has not been sought.

Examples of laws related to different types of PII are listed below:

- HIPAA/HITECH—Health related information
- GLBA—Financial information
- Privacy Act—Fair Information Practices for PII held by Federal Agencies
- COPPA—Protects children's privacy by allowing parents to control what information is collected
- FERPA—Student's personal information

- FCRA—Collection and use of consumer information

Such laws attempt to restrict corporations from inappropriately sharing PII and impose requirements for appropriately protecting such information.

Full statute available at: https://statutes.capitol.texas.gov/Docs/GV/htm/GV.552.htm

Appendix G: The Texas Association of City & County Health Officials (TACCHO) Recommendations

TACCHO Recommendations in the Funding and Policy Committee 2017 Annual Report (December 2017):

The PHFPC recommends DSHS continue to work with the TACCHO workgroup to determine how LHDs can obtain public health data maintained by DSHS. Look at options: 1) evaluate the possibility of governmental transfer of information, 2) identify the statutes creating barriers, and review the language, and 3) review and identify legislative barriers and define the interdependent relationship between LHDs and DSHS removing barriers to data sharing.

The recognition that many activities using public health data are local public health practice as opposed to research and should therefore not be subject to the standard review process by the DSHS Internal Review Board; 4) Recognition that some of the barriers identified may relate to existing statutes and require changes to state statutes or interpretation in the administrative code.

With the goal to resolve barriers to data sharing, including those relating to statutes.

The full report can be found at: https://dshs.texas.gov/legislative/2017-Reports/2017-PHFPC-report.pdf

DSHS response to the recommendations can be found at: https://www.dshs.texas.gov/legislative/2017-Reports/2017-DSHS-Response-PHFPC.pdf

Appendix H: Agenda for THIN Data Expert Panel

THIN Data Panel Discussion

UT System Building, 210 W. 7th St.
Room 2.206 A/B, Austin, TX 78701
November 13, 2018

8:30-9:00	Welcome and Introductions
9:00-9:45	**Panel 1: Data Use to Inform Practice and Policies (9 minutes each)**
	Meadows Policy Institute—John Petrila, JD
	San Antonio Metropolitan Health District—Anita Kurian, MBBS, MPH, DrPH
	UTHealth Science Center at Houston—Robert Morgan, PhD
	Dell Medical School, UT Austin—Lisa Kirsch, MPAff
	Dallas-Fort Worth Hospital Council—Kristin Jenkins, JD, MBA, FACHE
9:45-10:45	**Q&A + Discussion**
10:45-10:55	Break + Snacks
10:55-11:00	Introductions
11:00-11:45	**Panel 2: Legal Use and Sharing of the Data (11 minutes each)**
	HHSC—Cynthia Dollar, JD
	DSHS—Barbara Klein, JD
	Dallas-Fort Worth Hospital Council—Theresa Mendoza
	University of South Florida, College of Public Health Experience—John Petrila, JD
11:45-12:45	**Q&A + Discussion**
12:45-1:15	Lunch
1:15-1:20	Introductions
1:20-2:05	**Panel 3: Procedures and Processes for Data Sharing (7 minutes each)**
	HHSC—Calvin Green, MPA
	DSHS—Lisa Wyman, PhD
	Dallas-Fort Worth Hospital Council—Theresa Mendoza
	Center for Healthcare Data, UTHealth—Trudy Krause, DrPH, MBA, CPHQ
	ResDAC—Faith Asper, MHS, CIPP/G (video conference)
	University of South Florida, College of Public Health Experience—John Petrila, JD
2:05-3:05	**Q&A + Discussion**
3:05-3:15	Break
3:15-4:00	**Synthesis of Main Themes & Priorities**

Appendix I: Texas Health Improvement Network Expert Panelists

DATA USE TO INFORM PRACTICE AND POLICIES

John Petrila, JD
Vice President of Adult Policy
Meadows Mental Health Policy Institute

Anita Kurian, MBBS, MPH, DrPH
Assistant Director
San Antonio Metropolitan Health District

Robert Morgan, PhD
Professor and Chair of Management, Policy, and Community Health
UTHealth, School of Public Health

Lisa Kirsch, MPAff
Senior Policy Director, Dean's Office
Dell Medical School, The University of Texas at Austin

Kristin Jenkins, JD, MPA, FACHE
President
Dallas-Fort Worth Hospital Council Foundation

LEGAL USE AND SHARING OF DATA

Cynthia Dollar, JD
Special Counsel for Information Privacy and Security
Texas Health and Human Services Commission

Barbara Klein, JD
General Counsel
Texas Department of State Health Services

Theresa Mendoza
Director of Quality, BI, & Data Services
Dallas-Fort Worth Hospital Council Foundation

John Petrila, JD
Vice President of Adult Policy
Meadows Mental Health Policy Institute

PROCEDURES AND PROCESSES FOR SHARING DATA

Calvin Green, MPA
Deputy Executive Commissioner
Office of Performance
Texas Health and Human Services Commission

Lisa Wyman, PhD
Director
Center for Health Statistics
Texas Department of State Health Services

Theresa Mendoza
Director of Quality, BI, & Data Services
Dallas-Fort Worth Hospital Council Foundation

Trudy Krause, DrPH, MBA, CPHQ
Associate Professor / Co-Director
UTHealth, School of Public Health / Center for Healthcare Data

Faith Asper, MHS, CIPP/G
Associate Project Director
Research Data Assistance Center (ResDAC)
University of Minnesota, School of Public Health

John Petrila, JD
Vice President of Adult Policy
Meadows Mental Health Policy Institute

Appendix J: Local Health Departments Essential Functions:

From Chapter 121 of the Health and Safety Code, local health departments have essential public health services which include:

1. monitor the health status of individuals in the community to identify community health problems;

2. diagnose and investigate community health problems and community health hazards;

3. inform, educate, and empower the community with respect to health issues;

4. mobilize community partnerships in identifying and solving community health problems;

5. develop policies and plans that support individual and community efforts to improve health;

6. enforce laws and rules that protect the public health and ensure safety in accordance with those laws and rules;

7. link individuals who have a need for community and personal health services to appropriate community and private providers;

8. ensure a competent workforce for the provision of essential public health services;

9. research new insights and innovative solutions to community health problems; and

10. evaluate the effectiveness, accessibility, and quality of personal and population-based health services in a community.

Full statute available at: https://statutes.capitol.texas.gov/Docs/HS/htm/HS.121.htm

Appendix K: Examples of Data Integration from across Texas

Dell Medical School

How can we prevent asthma attacks among children in Austin?

Clinical data
+
SDoH data
+
Environmental data
=
Database and map of asthma "hotspots"

Center for Healthcare Data

How are people with serious mental illnesses accessing care?

Medicare data
+
Medicaid data
+
Local mental health authority data
=
Comparison of services and cost

Parkland Center for Clinical Innovation
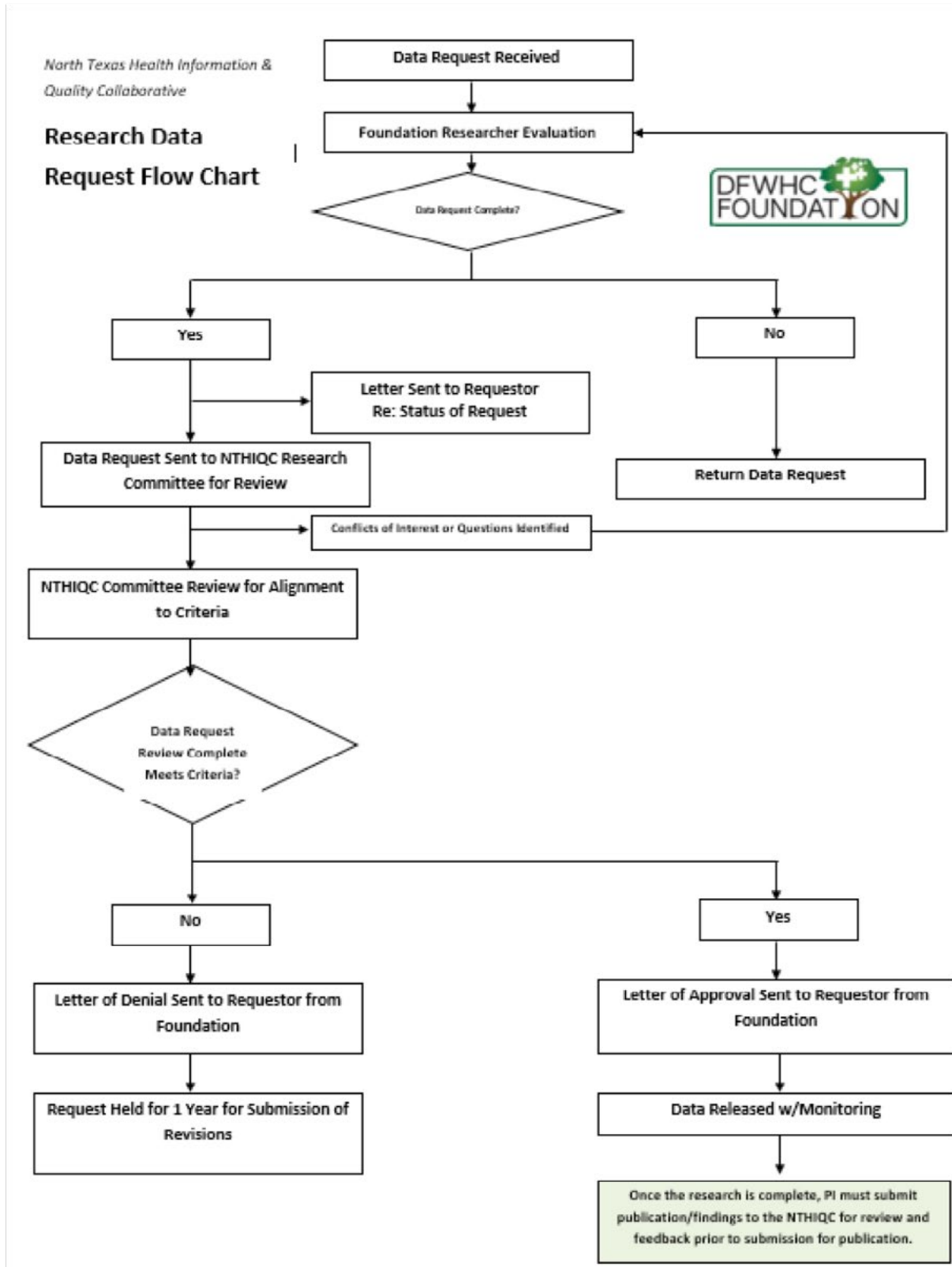
Why are people frequenting the ER in Dallas?

ER visits
+
Map of neighborhood
+
SDoH data
=
Nurse practitioner providing care at apartment complex

San Antonio Metropolitan Health District

**Why are children with asthma frequenting the ER in San Antonio?**

Clinical data
+
EMS trip data from Texas Regional Advisory Council Data Collaborative
=
Families lack transportation

Appendix L: Data Request Process used by Dallas-Fort Worth Hospital Council

North Texas Health Information & Quality Collaborative

Research Data Request Flow Chart

- Data Request Received
- Foundation Researcher Evaluation
- Data Request Complete?
  - Yes
    - Letter Sent to Requestor Re: Status of Request
    - Data Request Sent to NTHIQC Research Committee for Review
    - Conflicts of Interest or Questions Identified
    - NTHIQC Committee Review for Alignment to Criteria
    - Data Request Review Complete Meets Criteria?
      - No
        - Letter of Denial Sent to Requestor from Foundation
        - Request Held for 1 Year for Submission of Revisions
      - Yes
        - Letter of Approval Sent to Requestor from Foundation
        - Data Released w/Monitoring
        - Once the research is complete, PI must submit publication/findings to the NTHIQC for review and feedback prior to submission for publication.
  - No
    - Return Data Request

DFWHC FOUNDATION

Appendix M: States with All Payer Claims Databases

From the APCD Council, available at: https://www.apcdcouncil.org/state/map
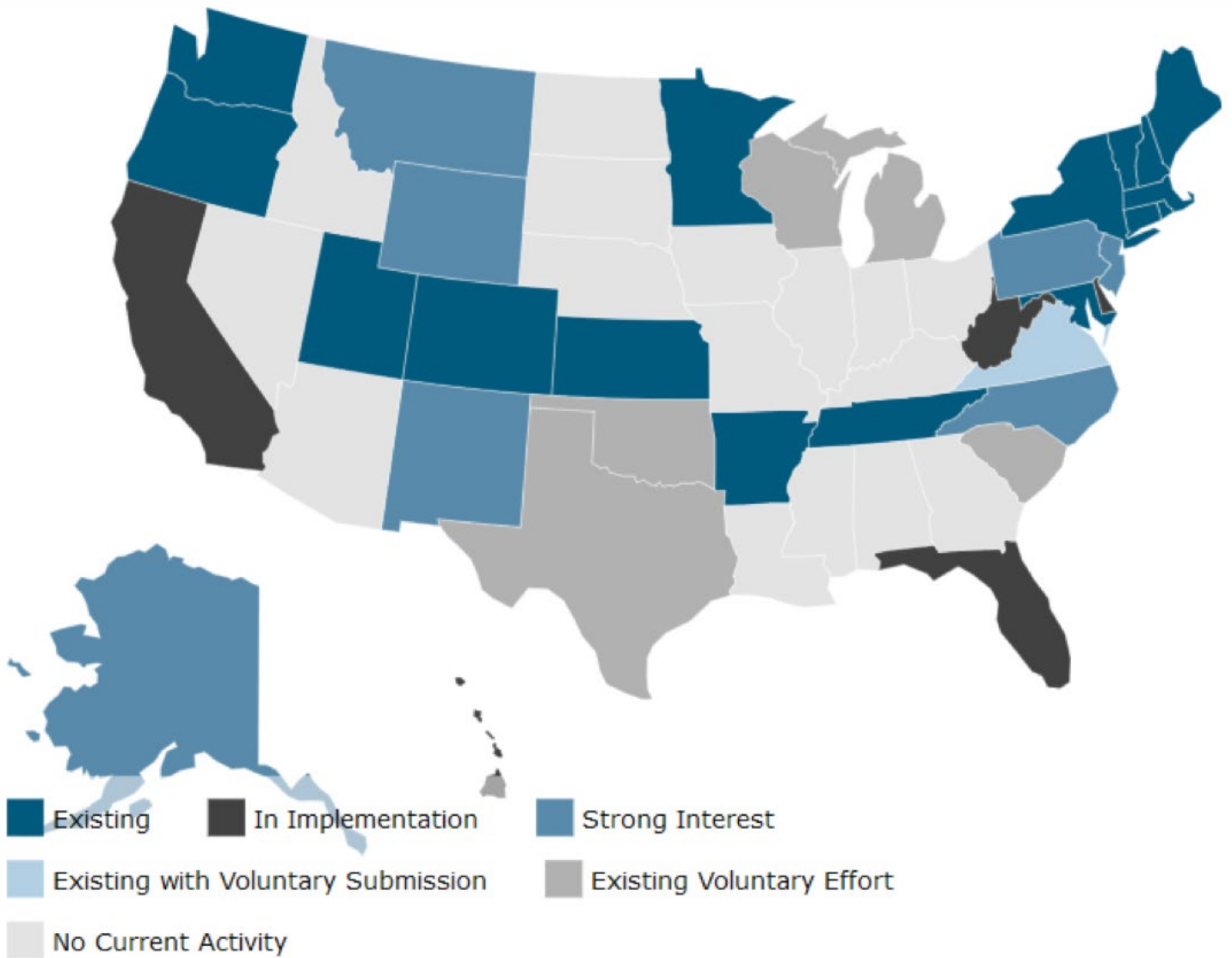
Appendix N: State Statutes Mandating All-Payer Claims Databases

Colorado, HOUSE BILL 10-1330, 2010

25.5-1-204. Advisory committee to establish an all-payer health claims database - creation - members - duties - creation of all-payer health claims database - rules - repeal.

- (1) (a) WITHIN FORTY-FIVE BUSINESS DAYS AFTER THE EFFECTIVE DATE OF THIS SECTION, THE EXECUTIVE DIRECTOR SHALL APPOINT AN ADVISORY COMMITTEE TO MAKE RECOMMENDATIONS REGARDING THE CREATION OF THE FRAMEWORK AND IMPLEMENTATION PLAN FOR A COLORADO ALL-PAYER CLAIMS DATABASE FOR THE PURPOSE OF FACILITATING THE REPORTING OF HEALTH CARE AND HEALTH QUALITY DATA THAT RESULTS IN TRANSPARENT AND PUBLIC REPORTING OF SAFETY, QUALITY, COST, AND EFFICIENCY INFORMATION AT ALL LEVELS OF HEALTH CARE. THE EXECUTIVE DIRECTOR SHALL APPOINT AN ADMINISTRATOR OF THE DATABASE.

- (b) THE EXECUTIVE DIRECTOR SHALL APPOINT THE MEMBERS OF THE

ADVISORY COMMITTEE (listed in statute)...

Full statute available at: http://www.leg.state.co.us/CLICS/CLICS2010A/csl.nsf/fsbillcont3/7772E-FE1E998E627872576B700617FA4?Open&file=1330_enr.pdf

Washington, RCW 43.371.020, 2014

Statewide all-payer health care claims database—Selection and duties of lead organization—Certification as qualified entity pursuant to 42 C.F.R. Sec. 401.703(a)—Contract with data vendor.

- (1) The office shall establish a statewide all-payer health care claims database to support transparent public reporting of health care information. The database must improve transparency to: Assist patients, providers, and hospitals to make informed choices about care; enable providers, hospitals, and communities to improve by benchmarking their performance against that of others by focusing on best practices; enable purchasers to identify value, build expectations into their purchasing strategy, and reward improvements over time; and promote competition based on quality and cost. The database must systematically collect all medical claims and pharmacy claims from private and public payers, with data from all settings of care that permit the systematic analysis of health care delivery.

Full statute available at: http://app.leg.wa.gov/RCW/default.aspx?cite=43.371.020

Arkansas, Senate Bill 956, 2015

23-61-902. Legislative intent and purpose.

- (a) It is the intent of the General Assembly to create and maintain an informative source of healthcare information to support consumers, researchers, and policymakers in healthcare decisions within the state.

- (b) The purpose of this subchapter is to:
  - (1) Empower Arkansans to drive, deliver, and seek out value in the healthcare system;
  - (2) Create the Arkansas Healthcare Transparency Initiative;
  - (3) Establish governance of the Arkansas Healthcare Transparency Initiative;
  - (4) Provide authority to collect healthcare information from insurance carriers and other entities; and
  - (5) Establish appropriate methods for collecting, maintaining, and reporting healthcare information, including privacy and security safeguards.

23-61-903. Definitions.
As used in this subchapter:

- (1) "Arkansas Healthcare Transparency Initiative" means an initiative to create a database, including

ongoing all-payer claims database projects fund-
ed through the State Insurance Department, that
receives and stores data from a submitting entity
relating to medical, dental, and pharmaceutical and
other insurance claims information, unique identifi-
ers, and geographic and demographic information
for covered individuals as permitted in this sub-
chapter, and provider files, for the purposes of this
subchapter.

Full statute available at: https://www.arkansasapcd.
net/Docs/95/

Florida, House Bill 1175, 2016

An act relating to transparency in health care; ...

requiring a facility to provide a written or electronic
good faith estimate of charges to a patient or prospec-
tive patient within a certain timeframe; ...

requiring that certain records be made available
through electronic means that comply with a specified
law; ...

revising requirements for the collection and use of
health-related data by the agency; requiring the agency
to contract with a vendor to provide an Internet-based
platform with certain attributes; requiring potential
vendors to have certain qualifications; ...

requiring a health insurer to make available on its
website certain methods that a policyholder can use to
make estimates of certain costs and charges; providing
that an estimate does not preclude an actual cost from
exceeding the estimate; ...

requiring a health insurer that participates in the state
group health insurance plan or Medicaid managed
care to provide all claims data to a contracted vendor
selected by the agency by a specified date; exclud-
ing from the contributed claims data certain types of
coverage; ...

requiring a health maintenance organization that
participates in the state group health insurance plan
or Medicaid managed care to provide all claims data
to a contracted vendor selected by the agency by a

specified date; excluding from the contributed claims
data certain types of coverage; amending S. 409.967,
F.S.; requiring managed care plans to provide all claims
data to a contracted vendor selected by the agency; ...

requiring the Department of Management Services to
provide certain data to the contracted vendor for the
price transparency database established by the agen-
cy; requiring a contracted vendor for the state group
health insurance plan to provide claims data to the
vendor selected by the agency; amending SS. 20.42,
80 381.026, 395.602, 395.6025, 408.07, 408.18, and 81
465.0244, F.S.; conforming provisions to changes made
by the act; providing legislative intent; providing an
appropriation; providing an effective date...

Full statute available at: https://www.flsenate.gov/
Session/Bill/2016/1175/BillText/er/PDF

Appendix O: National Examples of Data Custodians

Actionable Intelligence for Social Policy (AISP), Philadelphia, PA

American Hospital Association (AHA), Washington, DC

Center for Healthcare Data, UTHealth Science Center at Houston, Houston, TX

Center for Improving Value in Health Care (CIVHC), Denver, CO

Center for State Child Welfare Data, Chapin Hall, University of Chicago, Chicago, IL

Dallas-Fort Worth Hospital Council (DFWHC), Irving, TX

Institute for Precision Cardiovascular Medicine Platform, American Heart Association, Dallas, TX

Louis de la Parte Florida Mental Health Institute (FMHI), University of South Florida, Tampa, FL

Research Assistance Center (ResDAC), University of Minnesota, Minneapolis, MN

Washington All-Payer Claims Database (WA-APCD), Oregon Health & Science University, Portland, OR

Washington State Department of Health (WA-DOH), Tumwater, WA

Appendix P: Models of Data Sharing in Texas and in Other States

Data Sharing in Texas

Model Type	Example	Data	Description
Public Data Custodian	Health and Human Services Commission (HHSC), Department of Health and Human Services (DSHS)	Medicaid, vital statistics, hospital discharge data	Currently in a time of transition; now, process is lengthy for users, resource-intensive for data custodians; users request access to data and research must align with agency priorities; MOUs and DUAs must be completed and are under revision.
Voluntary All-Payer Claims Database	Center for Healthcare Data at UTHealth	75% of commercial claims, for 80% of Texas with health insurance	Qualified researchers, with IRB approval and signed DUAs, request access to data extracts; IT department monitors use.
Academic-Public Partnership	University of Texas College of Pharmacy (UTCOP)	Medicaid data	UTCOP has collaborated with HHSD on research.
Independent Data Aggregator	Dallas-Fort Worth Hospital Council (DFWHC)	Inpatient/outpatient encounters in North Texas (64 million encounters, 12 million unique patients, from 98 hospitals); includes unblinded physician data, readmission rates, etc.	DFWHC has a template used for data sharing with hospitals; hospitals decide at monthly meetings to release data to outside entities; hospitals use self-service analytics to answer questions; can also request ad-hoc report.

Data Sharing in Other States

Model Type	Example	Data	Description
Public Data Custodian	Washington State Department of Health (WA-DOH)	Birth, death, fetal death, hospital discharge, BRFSS, abortion, marriage/ divorce, death with dignity program	De-identified public use files available for birth, hospital discharge data; limited data sets available for purchase with DUAs; confidential birth records are shared with IRB approval; death records are open; WA-DOH created a blanket data sharing agreement with LHDs, allowing access to limited data sets via secured portal.
All-Payer Claims Database	Washington State All-Payer Claims Database (WA-APCD); Center for Improving Value in Health Care (CIVHC)	Insurance claims, including private and public payers	State-mandated by statute; WA-APCD and CIVHC have public-facing websites for consumers to compare health care costs; data request policies and timelines are clear for researchers; requests including PHI require input from stakeholders.
Academic-Public Partnership	Florida Mental Health Institute at University of South Florida (FMHI)	Medicaid, death, civil/ involuntary commitment data	Houses some original data; serves as intermediary for other public health data, through partnerships and agreements with other organizations to house/process data.
Resource for Data Requests	Research Data Assistance Center at University of Minnesota (ResDAC)	Does not house data but serves as resource for researchers requesting access to CMS data	ResDAC helps researchers with getting started, submitting a request to CMS, and understanding data once it is obtained (help desk); has several online tools to guide researchers through tailored request process.
Data Integrator	Actionable Intelligence for Social Policy at University of Pennsylvania (AISP)	Does not house data but assists organizations in integrating administrative datasets.	Integrated data systems (IDS) link data extracts, for approved projects, during an approved time; data custodians retain oversight of data; potential solution to "siloed" datasets for organizations serving similar or overlapping populations (e.g., mental health, substance abuse, child welfare, juvenile justice, lead exposure, emergency shelter use, and local incarceration.)