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HEALTH INFORMATION AND DATA SHARING

**ISSUE BRIEF**

# Chronic Disease and Data Modernization – Opportunities (and Safeguards) For Enhanced Public Health Data Collection

In the aftermath of COVID-19, public health has improved and modernized both federal and state data collection for the prevention of infectious disease. Renewed federal and state focus on chronic disease creates the potential for similar enhancements to public health data collection for non-communicable diseases (NCDs). Jurisdictions can empower their public health agencies to expand reporting requirements for clinical data to improve surveillance and support interventions against chronic disease within the most vulnerable populations. At the same time, as jurisdictions expand reporting requirements for NCDs, they should also maintain appropriate safeguards for individually identifiable data collected and used for prevention initiatives.

## Chronic Disease Prevalence and Burden

The CDC reports that "*chronic diseases such as heart disease, cancer, and diabetes are the leading causes of death and disability in the United States. They are also leading drivers of the nation's $4.5 trillion in annual health care costs.*" Direct expenditures for diabetes treatment alone are estimated at $306 billion annually, with heart disease and cancer also contributing to hundreds of billions in care costs. Treatments for chronic conditions are also heavily dependent on prescription drugs that are expensive both for patients and their private and governmental insurers, Moreover, for a Medicaid population in which a majority of patients have at least one chronic condition, federal and state governments share the costs of increased chronic diseases. Increased attention to the impacts of chronic disease in the United States reflects a similar worldwide shift in public health focus to the prevention of NCDs, which in turn has led to heightened epidemiological focus on monitoring risk factors.

In the United States, the prevalence of chronic diseases such as heart disease, diabetes, and cancer vary substantially based on geography, socioeconomic status, and degree of health care access:

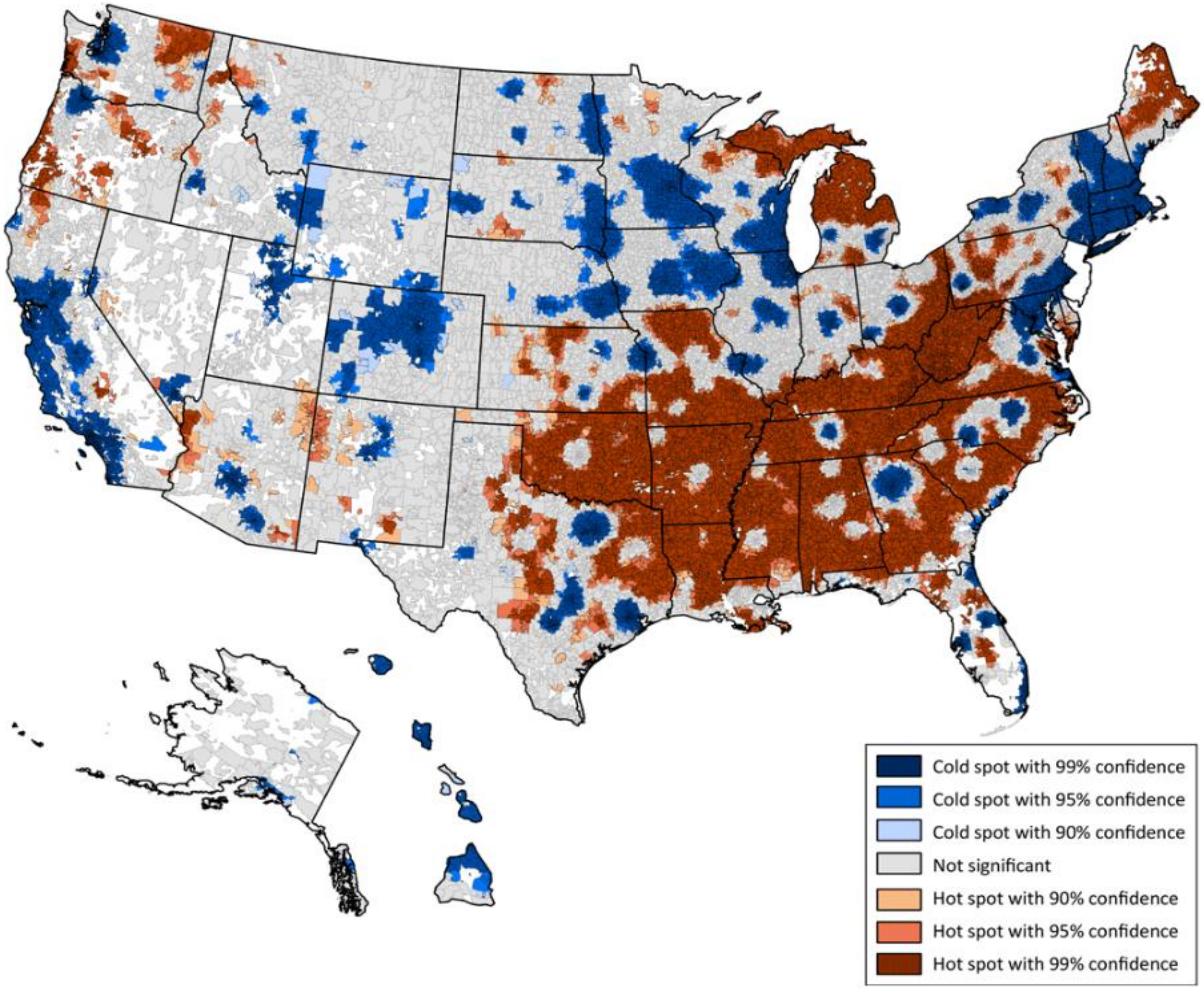

Figure 1: Hot Spot analysis of chronic disease prevalence scores throughout the US showing significant spatial clusters of high chronic disease prevalence scores (red clusters = hot spots) and low chronic disease prevalence scores (blue clusters = cold spots). Source: Chronic Disease Prevalence in the US: Sociodemographic and Geographic Variations by Zip Code Tabulation Area (2024)

Significant disparities in chronic disease prevalence are well documented for rural communities and according to income; based on race and ethnicity; and in particular among American Indian and Alaska Native tribes. Consequently, both existing and emerging strategies to remediate NCDs (such as precision public health) depend significantly on the completeness of data collection to identify the most vulnerable populations for interventions.

## Expanding Public Health Data Collection for Chronic Disease

### Public Health Authority for Chronic Disease Reporting

In the United States, the states exercise primary authority for public health data collection under their police power. Health care providers and laboratories are generally required to report cases of infectious disease and may do so without patient authorization consistent with HIPAA. Reportable conditions are enumerated by regulation and revised on a continuing basis not just by states and territories, but also by localities and Tribes ("STLT"s)—for example, as in California, Pennsylvania, Texas and Los Angeles County. After cases of reportable conditions are evaluated by public health departments, the federal government is in turn notified by relevant STLT authorities of a more limited subset of notifiable diseases. The Centers for Disease Control and Prevention (CDC) tabulates information about notifiable diseases and publishes condition-specific insights on a regional and national basis.

However, jurisdictions' exercise of their police power for disease reporting is not necessarily limited to infectious disease and can also encompass chronic disease surveillance. The 2003 Model State Public Health Act notably envisioned broad public health authority to address chronic disease to the extent it defines that power to include the prevention, control or amelioration of all "*conditions of public health importance."* The Model Act defined a condition of public health importance as any "*disease, syndrome, symptom, injury, or other threat to health that is identifiable on an individual or community level and can reasonably be expected to lead to adverse health effects in the community*." Section 5-102 of the Model Act in turn proposed expansive state or local public health authority to collect data relating to risk factors, morbidity and mortality, community indicators, and "*any other data needed*" about such conditions of public health importance.

The World Health Organization's 2017 Guidelines on Ethical Issues in Public Health Surveillance similarly emphasize how public health authority justifiably extends to the reporting of NCDs. The WHO defines public health surveillance to encompass the collection of "*data . . . pertaining to communicable and NCDs, injuries and conditions and their related risks and determinants."* The WHO Guidelines also stress an ethical responsibility to gather such information to combat disparities in the burden of chronic disease, as well as to counteract the potential invisibility of chronic disease among vulnerable populations.

### Chronic Disease Data Reporting in Practice

Jurisdictions have implemented widely varying approaches in law and regulation for public health surveillance of chronic disease. Some states, like Alaska and Florida, have aligned with the Model Public Health Act to generally empower their public health departments to require data collection for any condition of public health importance—but have not adopted corresponding implementing regulations for reporting of some of the most common chronic diseases (as Florida's health care provider and lab reporting requirements reflect).

States more often target their chronic disease reporting requirements to registries focused on a limited subset of conditions. For cancer, all fifty states require reporting to public health agency-operated centralized registries. By contrast, for Alzheimer's disease, just a handful of states—including Georgia, South Carolina and West Virginia—have implemented reporting requirements to a dedicated registry. For diabetes, only one jurisdiction—New York City—has mandated reporting of lab blood sugar tests to a registry designed to combat pre-diabetes and diabetes. At the same time, not all chronic disease reporting is tied to registries: some types of chronic disease may separately be recorded in connection with occupational disease surveillance, such as for workplace-related asthma in Washington and Massachusetts.

Jurisdictions' comparative lack of emphasis on comprehensive NCD reporting requirements is partly explicable based on the availability of survey-based data sources that address the same surveillance objectives. Both STLT public health and the federal government strongly emphasize such survey-based collection. With STLT assistance, the CDC's Behavioral Risk Factor Surveillance System (BRFSS) conducts more than 400,000 interviews with adults each year to measure health-related risk behaviors, chronic conditions and use of preventative services. The BRFSS supports estimation of chronic disease prevalence data for state and major metropolitan areas, as well as similar data estimates for localities (CDC Places). The BRFSS and similar survey data also underpin the CDCs Chronic Disease Indicator (CDI), which reports chronic disease prevalence across the jurisdictions according to uniform definitions. Despite its reliance on self-reporting, the BRFSS' survey-based approach offers certain advantages for collection of health-related behaviors and longitudinal aspects of chronic disease that may not be fully documented in health care records.

Moreover, non-governmental registries also provide an important source of public health information about chronic diseases. Even as state governments have chartered and funded registries for certain chronic conditions, national physician colleges or health system practice groups also maintain other patient-focused regional and national registries for NCDs, such as for cardiac disease, arthritis, and diabetes. The detailed, customized clinical information collected in such practitioner registries complements self-reported survey information from sources like the BRFSS.

## Potential Enhancements to Public Health Surveillance for Chronic Disease

Although registries and surveys provide meaningful NCD data, clear opportunities exist for improvement in data collection. Current lag times in public health reporting of initial chronic disease information may be two years or more. Survey-based data may also lack the granularity necessary to monitor community-level progress. As a result, recent data modernization initiatives for chronic disease have focused on improved public health access to information contained in electronic health records (EHRs). Just as for infectious disease modernization, these initiatives have also emphasized greater standardization of data elements relating to chronic disease within EHRs and across health information exchanges. At the same time, these new initiatives also recognize the potential under-inclusiveness of chronic disease data in EHRs arising from disparities in health care access.

Michigan has recently established a pilot program for a comprehensive state registry of chronic disease based on improved access to EHR information: the "Chronic Disease Registry Linking Electronic Health Record Data" (CHRONICLE). The CHRONICLE program has initially focused on stroke and hypertension data collection but is eventually intended to support a "*comprehensive chronic disease data system, enabling better disease and comorbidity monitoring across an array of linked data sources.*" Last year, Michigan's Department of Health and Human Services adopted general regulations that will require reporting on a near real-time basis by health care providers and labs. The selection of particular chronic diseases subject to the new reporting requirements will be determined by an advisory board.

## Expanding Public Health Data Collection for Chronic Disease

Prevention initiatives against chronic disease that are based on aggregate and de-identified data about at-risk communities—such as locally-focused data derived from the BRFSS surveys—should not present privacy concerns. Such interventions can be directed to populations with higher risk factors for particular chronic diseases. One example of a community-focused intervention is diabetes education and screening: Sonoma County recently responded to data showing above-average diabetes prevalence by deploying a Mobile Diabetes Education Center that distributed risk questionnaires and offered optional point-of-care blood sugar testing.

However, where public health interventions against chronic disease rely on individually identifiable health information, jurisdictions should ensure adequate privacy protections and limit potentially adverse uses of such data. Even as individual clinical data can help identify those most likely to benefit from preventative interventions, public health reporting requirements for chronic disease data remains subject to constitutional and ethical constraints. Liberty and due process considerations require that jurisdictional reporting is necessary and proportional, uses reasonable means, and avoids harm (and prior initiatives to establish cancer and diabetes-related registries have been understood to meet such requirements). The WHO Guidelines also emphasize that individual data collection should have a legitimate public health purpose; should implement appropriate security to minimize the risk of disclosure; and should not result in sharing with agencies likely to use such data to act against individuals or for uses unrelated to public health. Moreover, particularly sensitive chronic disease data, such as for behavioral health, may require special safeguards.

Just as for infectious diseases, jurisdictions can establish appropriate statutory protections for individual chronic disease data collected by their public health authorities. Although the federal HIPAA privacy rule establishes guardrails for the release of protected health information from health care providers to public health agencies, jurisdictional laws provide the principal source of protection for such information once it is transferred (whether to local or state public health authorities). In some jurisdictions, protection of the confidentiality of chronic disease information may already be addressed under existing general state laws or regulations protecting individual health information held by government agencies (Massachusetts and Virginia, for example). Alternatively, specific jurisdictional regulations for public health reporting may be sufficiently broadly framed to protect confidentiality: existing examples include New York City's protections for all data reporting relating to "*conditions of public health interest*"; Florida's similar protection of reports of both infectious or non-infectious disease, and Texas' confidentiality requirements for all "*cases or suspected cases of diseases or health conditions.*" Jurisdictions with disease reporting confidentiality requirements tied to communicable disease might also usefully revise such provisions to encompass reports of individual chronic disease. As it recently expanded its chronic disease reporting authority, Michigan notably reiterated that such records will be non-public, confidential, and limited to use for epidemiological investigation and evaluation.

Where enhanced reporting of NCDs supports individualized outreach for preventative interventions, jurisdictions will also need to be mindful of public concern about possible employment discrimination based on chronic condition classifications. Recent survey data show that even though more than half of employees in the U.S. report physical chronic conditions, most have not formally disclosed their conditions to their employer. Even though federal and some state antidiscrimination laws require reasonable workplace accommodations for employees with chronic conditions like hypertension or diabetes, public health agencies must address broader public fears of possible stigmatization within their assessment of the likely effectiveness of proposed interventions to combat NCDs.

**4/25/2025**

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**Support for the Network is provided by the Robert Wood Johnson Foundation. The views expressed in this document do not necessarily reflect the views of the Foundation.**

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