



March 15, 2024

To the Honorable Members of the Illinois General Assembly:

In compliance with the requirements set forth in the Data Governance and Organization to Support Equity and Racial Justice Act (20 ILCS 65 *et. al*) (the “Act”), the *Illinois Department of Public Health (IDPH)* hereby submits a progress report detailing the action steps and progress made since the last annual report dated July 1, 2023, to enable the collection and cataloguing of data described in Section 20-15 of the Act have been standardized and, to the extent possible, the data sets and programs that are planned for the coming year.

The Act requires *IDPH* to “report statistical data on racial, ethnic, age, sex, disability status, sexual orientation, gender identity, and primary or preferred language demographics of program participants for each major program” administered by *IDPH*.

While “major program” is not defined in the statute, the agency has adopted the following definition provided by the Governor’s Office of Management and Budget: *a major program is a program with an enacted appropriation of greater than \$1 million in the prior fiscal year; direct services provided to individuals and/or a reasonable expectation that demographic information can be aggregated via proxy data without substantial cost or disruption to program delivery.*

IDPH has further defined “program participants” *any individual who receives program services or interventions directly from state agency staff, contractors, or grantees.* The program participants count is the number of distinct individuals who have been identified as program participants regardless of demographic category.

Using these definitions, the Agency has identified the following programs and program participant populations for analysis:

FY23 Major Programs:

1. Children and Youth with Special Health Care Needs Grant Program - FY 2021
2. Communities of Color Special at Risk Population 2023
3. Comprehensive Health Protection Grant - FY 2023 (Lead Poisoning Prevention and Response)
4. COVID-19 Community Based Testing and Interventions Targeting Minority Population
5. COVID-19 Community Based Testing and Interventions Targeting Minority Population Expansion - FY 2023
6. Genetic Counseling 2023
7. Illinois Breast and Cervical Cancer Program – 2023
8. Illinois Family Planning Program 2023
9. Illinois Tobacco Quitline 2023
10. Illinois Wisewoman Program 2022 - 2023

IDPH had previously included the following programs in the definition of major program, however after additional discussions it was decided for various reasons the following will not be included at this time:

1. Communities of Color Special At Risk Population 2023
2. Comprehensive Health Protection Grant - FY 2023 (Lead Poisoning Prevention and Response)
3. COVID-19 Community Based Testing and Interventions Targeting Minority Population

FY24 Major Programs:

1. Children and Youth with Special Health Care Needs Grant Program - FY 2021
2. COVID-19 Community Based Testing and Interventions Targeting Minority Population Expansion - FY 2023
3. Genetic Counseling 2023
4. Illinois Breast and Cervical Cancer Program – 2023
5. Illinois Family Planning Program 2023
6. Illinois Tobacco Quitline 2023
7. Illinois Wisewoman Program 2022 – 2023
8. COVID-19 Migrant Workers Mobile Testing & Outbreak Response FY 2021 (new program added)
9. Wellness on Wheels (WOW) (new program added)

Since the July 2023 statistical report, IDPH has taken the following actions to assess the changes needed to catalogue demographic data for each of the aforementioned programs.

Children and Youth with Special Health Care Needs Grant Program – 100% Compliant

COVID-19 Community Based Testing and Interventions Targeting Minority Population Expansion – This program is 75% compliant, but it will be ending at the end of FY24. Technology is not utilized to capture their data; instead, paper systems are utilized.

Genetic Counseling - Reviewed ERJA reporting requirements with Genetic Counseling grantees to establish status on their ability to collect required data. Majority of patient populations are specific to newborns and pediatric populations. Genetic Counseling electronic management systems do not currently collect demographic information on sexual orientation, gender identity, with some not collecting disability status or the same race/language categories listed on the ERJA report form. The primary focus of this grant program is to provide genetic counseling services to Illinois' pediatric populations. The grantees vary on their ability to collect the specific data sets listed on the ERJA form. It is uncertain how to address their varying system needs to support all ERJA data required. Some genetic counselors are requesting a waiver from collecting gender identity and sexual orientation categories due to their infant/child patient populations. They currently report these categories only if it is brought up by the patient. For genetic counseling grantees to collect all required data, they would need to have their EMR build those missing categories or data sets within their system. Also, due to the short turnaround time to gather responses, The Department has received feedback from 67% of grantees.

Illinois Breast and Cervical Cancer Program – Secure a new data and billing system to compile and report program data (including participant enrollment data) for CDC funders and grantee reimbursement. The IBCCP an RFP process is planned to address this issue.

Illinois Family Planning Program - The Family Planning program has an existing data system that would have to create an upload or a bridge into EGrAMS. This program uses technology and can capture 50% of the requirements.

Illinois Tobacco Quitline – 100% Compliant. IDPH collects demographic data of callers to the Illinois Tobacco Quitline (ITQL), operated under an IDPH grant to the American Lung Association (ALA). Demographic data reports are submitted monthly, quarterly, and annually. During caller enrollment for telephone tobacco cessation counseling, the Grantee asks callers 16 demographic questions, including gender, race, ethnicity, sexual orientation, disabilities, primary language, secondary language, education level, income level, primary health insurance, military status, public housing residence status, pregnancy status, chronic disease status, and behavioral health conditions. Additional demographic questions may be added at the recommendation of the Centers for Disease Control and Prevention (CDC), Office on Smoking and Health or the North American Quitline Consortium (NAQC).

Illinois Wisewoman Program - Grantees were able to comply with the last report using existing Cornerstone data.

COVID-19 Migrant Workers Mobile Testing & Outbreak Response (new program added) – This program uses a paper system and was able to meet 100% of the data collection requirements. However, for this grant, which began in FY22 and ended 5 months into FY24, the Department may not be able to gather data from grantees as the program has come to an end.

Wellness on Wheels (WOW) (new program added) – This program uses a paper system to collect data and can collect 70% of the requirements.

Following the July 2023 statistical report IDPH has determined that racial, ethnic, age, sex, disability status, sexual orientation, gender identity, and primary or preferred language have been defined and standardized for the following programs:

1. Children and Youth with Special Health Care Needs Grant Program - FY 2021
2. COVID-19 Community Based Testing and Interventions Targeting Minority Population Expansion - FY 2023
3. Genetic Counseling 2023
4. Illinois Breast and Cervical Cancer Program – 2023
5. Illinois Family Planning Program 2023
6. Illinois Tobacco Quitline 2023
7. Illinois Wisewoman Program 2022 – 2023
8. COVID-19 Migrant Workers Mobile Testing & Outbreak Response FY 2021 (new program added)
9. Wellness on Wheels (WOW) (new program added)

In the coming year, the agency will utilize the Office of Equity’s guidance to further refine and standardize definitions for the remaining demographic categories and ensure standardization exists across all programs identified in this report. *IDPH* will work with the Department of Innovation and Technology and the Governor’s Office of Management and Budget in the coming months to streamline its data collection and collect the relevant data from major program participants.

As the State works to implement the Act, IDPH data stewards, information and technology staff, and diversity, equity, and inclusion leaders will work with the Department of Innovation and Technology and the Governor’s Office of Management and Budget to analyze currently catalogued data, identify data gaps, and determine how to collect demographic information. As we continue to implement the process and infrastructure changes necessary to collect the data required, we will

continue to work to provide the required demographic data to inform program design and policy-making endeavors.

Very Sincerely and Respectfully,

Sameer Vohra, MD, JD, MA (he/him/his)

Director