



March 31, 2023

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 Illinois Department of Public Health (IDPH) hereby submits a progress report detailing the action steps and progress made to enable the collection and cataloging of data described in Section 20-15 of the act, which have been standardized and, to the extent possible, the data sets and programs that are planned for the coming year.

The act requires the report of “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 (GOMB): *a major program is a program with an enacted appropriation of greater than \$1 million in 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.*¹

With direction from GOMB, IDPH has further defined “program participants” as *any individual who receives program services or interventions either directly from state agency staff or indirectly through contractors or grantees.*

Using these definitions, the agency has identified the following 11 programs and program participant populations for analysis:

1. *Disease Control – Illinois Ryan White Part B Program, Acquired Immunodeficiency Syndrome (AIDS) Drug Assistance Program*
2. *Health Promotion – Genetic Counseling*
3. *Health Promotion – Illinois Tobacco Quitline*
4. *Health Protection – Illinois Lead Program*
5. *Minority Health – COVID-19 Community-Based Testing and Intervention Targeting Minority Populations*
6. *Minority Health – COVID-19 Migrant Workers Mobile Testing and Outbreak Response*
7. *Racial and Cultural Health Equity – Underserved Health Care Provider Workforce Loan Repayment Program*
8. *Women’s Health – Family Planning*
9. *Women’s Health – Illinois Breast and Cervical Cancer Program*

¹ Programs with anonymous reporting of violations, those which utilize tele-help lines, and regulatory/licensure programs have been excluded from this definition.

10. *Women's Health – Illinois WISEWOMAN Program*

11. *Women's Health – University of Illinois at Chicago Division of Specialized Care for Children*

Since the July 2022 statistical report, IDPH has taken the following actions to assess the changes needed to catalogue demographic data for each of the aforementioned programs.

Following its initial statistical report, IDPH determined the following demographic categories have been defined and standardized across all “major programs” identified in this report:

Ethnicity

Biological Sex/Sex Assigned at Birth

Gender Identity

Sexual Orientation

Age

Primary or Preferred Language

In the coming year, IDPH will utilize the Office of Equity’s guidance to further refine and standardize definitions for the remaining three demographic categories (i.e., *Race, Indigeneity, and Disability Status*). Once the remaining categories are defined, IDPH will work in partnership with the Department of Innovation and Technology (DoIT) and GOMB to streamline data collection and gather the relevant data from major program participants.

IDPH has also determined that additional work needs to be done to define and to standardize the demographic categories enumerated in the statute. However, program experience and federal requirements and guidance will limit the scope of data standardization in the following programs:

1. *Disease Control – Illinois Ryan White Part B Program, AIDS Drug Assistance Program*
 - a. IDPH staff believe that collecting information for *Sexual Orientation* would substantially impact the ability to deliver services to program participants. Feedback from grantees and program participants shared in 2019 suggests that collecting information on sexual orientation “may deter some [program participants] from seeking services if they are required to report this information.” Further, when this information was previously required on program forms, grantees reported that the question “upset some [program participants] and caused them to withdraw from testing (especially when testing in places in the community that were not exclusively LGBT-friendly areas).”² As such, IDPH will maintain its program policy to not collect this information.
 - b. Use of the “Prefer not to answer” category for *Biological Sex/Sex Assigned at Birth* and *Gender Identity* threatens program compliance with federal requirements. As such, IDPH will not include this category or any other that conflicts with federal regulations or guidance.

Since the initial progress report, IDPH has outlined the following technical and paper process changes required to streamline data collection and reporting on “major program” participants.

1. *Disease Control – Illinois Ryan White Part B Program, AIDS Drug Assistance Program*

² Illinois HIV Integrated Planning Council. (2019, November 22). *Meeting of the IHIPIC Gender Terminology Workgroup*. Please contact IDPH for more information.

- a. IDPH must modify its contracted data system, Provide Enterprise©, to collect the required demographic data for program participants.
2. *Health Promotion – Genetic Counseling*
 - a. IDPH must educate grantees on the required data collection procedures to ensure complete and accurate reporting.
 - b. IDPH must modify its existing internal electronic grants administration and management system (EGrAMS) to support additional fields to collect the required demographic data for program participants that was reported by grantees.
 - c. IDPH must build and support the capacity to collect the required demographic data for program participants as reported by grantees in the new forthcoming internal grants management system, Amplifund.
3. *Minority Health – COVID-19 Community-Based Testing and Intervention Targeting Minority Populations*
 - a. IDPH must modify its existing EGrAMS system to support additional fields to collect the required demographic data for program participants that were reported by grantees.
 - b. IDPH must educate grantees on the required data collection procedures to ensure complete and accurate reporting.
4. *Racial and Cultural Health Equity – Underserved Health Care Provider Workforce Loan Repayment Program*
 - a. IDPH must program additional fields into the existing online database to collect the required demographic data for program participants.
5. *Women's Health – Family Planning*
 - a. IDPH must modify its contracted data vendor system, Ahlers, to collect the required demographic data for program participants.
 - b. IDPH must revise the Client Visit Record collection tool used by grantees to capture client-level data at intake to include the required demographic data for program participants.
 - c. IDPH must educate grantees on the revised demographic data requirements, including data testing.
 - d. IDPH must procure hardware and software to enable grantees to collect and report the required demographic data for program participants.
6. *Women's Health – Illinois Breast and Cervical Cancer Program*
 - a. IDPH must revise the enrollment and health assessment intake forms used by grantees to collect client-level data to include the required demographic data for program participants.
 - b. IDPH must revise its current request for proposals for a new data and billing system vendor to include the demographic data for program participants as required by statute.
 - c. IDPH must train grantees on the new contracted data and billing system and the demographic data for program participants as required by statute.
7. *Women's Health – Illinois WISEWOMAN Program*
 - a. IDPH must revise the enrollment and health assessment intake forms used by grantees to collect client-level data to include the required demographic data for program participants.
 - b. IDPH must revise its current request for proposals for a new data and billing system vendor to include the demographic data for program participants as required by statute.

- c. IDPH must train grantees on the new contracted data and billing system and the demographic data for program participants as required by statute.
8. *Women's Health – University of Illinois at Chicago Division of Specialized Care for Children*
- a. IDPH must revise the Client Track care coordination software used by the grantee to include the demographic data for program participants required by statute.
 - b. IDPH must educate and train the grantee on the demographic data for program participants required by statute.

As the state works to implement the act, IDPH's data stewards; information and technology staff; and diversity, equity, and inclusion leaders will work together with DoIT and GOMB to analyze currently catalogued data, identify data gaps, and determine how to collect demographic information. Ultimately, we hope to provide valuable data and analysis that will be meaningful and inform program design and policy-making endeavors.

Very Sincerely and Respectfully,

A handwritten signature in black ink that reads "Sameer Vohra". The signature is written in a cursive, flowing style.

Sameer Vohra, MD, JD, MA
Director