

Date: July 1, 2024

To: Honorable Members of the Illinois General Assembly

From: Sameer Vohra, MD, JD, MA Director, *Department of Public Health*

Re: Data Governance and Organization to Support Equity and Racial Justice Act Section 20-15(a) Report

This report is issued pursuant to the provisions of Section 20-15(a) of the Data Governance and Organization to Support Equity and Racial Justice Act (“the Act”) (20 ILCS 65/20-1). The Act requires the *Illinois Department of Public Health* to report statistical data on the racial, ethnic, age, sex, disability status, sexual orientation, gender identity, and primary or preferred language demographics of program participants for each major program the *Illinois Department of Public Health* administers.

Introduction

In the first Annual March Data Governance and Organization to Support Equity and Racial Justice Act Report, *Department of Public Health* identified the following “major programs” and corresponding 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

For each major program identified in the *Illinois Department of Public Health* March 2022 report, this report will provide statistical data where available for each of demographic dispositions enumerated in the Act: race, age, sex, disability status, sexual orientation, gender identity and primary or preferred language.

[Section 20-15(e) of the Act states “if the Board or Department is unable to begin reporting the data required by subsection (a) by July 1, 2022, the Board or the Department shall state the reasons for the delay under the reporting requirements.” As of the date of this report Illinois Department of Public Health was unable to begin reporting the following data:

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.

Change Management Efforts and Potential Challenges

Provide a brief narrative detailing efforts being made to gather data currently not collected.

If applicable, provide a brief narrative detailing potential challenges in data collection, such as timing concerns, corresponding federal reporting, shifts in population, etc.

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.

Methodology

The information contained in this report is based solely on the data reported to the provided by program participants and collected by programming personal for the various major programs. The data provided by program participants has not been audited for completeness and quality, therefore, no baseline for comparison has been established.

For this report, program participants are defined as *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 that have been identified as program participants regardless of demographic category.

Race and Ethnicity

The Act provides that *Illinois Department of Public Health* “shall use the same racial and ethnic classifications for each program.” 20 ILCS 65/20-15(a). The enumerated classifications are:

- (1) American Indian and Alaska Native alone.
- (2) Asian alone.
- (3) Black or African American alone.
- (4) Hispanic or Latino of any race.
- (5) Native Hawaiian and Other Pacific Islander alone.
- (6) White alone.
- (7) Some other race alone.
- (8) Two or more races.

Conclusion

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 endeavor.

Very Sincerely and Respectfully,



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Director
Illinois Department of Public Health

For additional copies of this report or more specific information, please contact:

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RACE (06/24/2024)											
Program Name	Program Count	American Indian / Alaskan Native	Asian / Asian American	African American / Black	Native/ Indigenous Peoples	Middle Eastern North African	Native Hawaiian or Other Pacific Islander	White/European American	Some Other Race Alone	Two or More Races	No Race Specified
COVID-19 Community Based Testing and Interventions Targeting Minority Population Expansion - FY 2023	133,212	1,587	2,555	46,442	55	387	166	49,054	1,162	14,011	17,793
Genetic Counseling 2024	7,915	35	349	1,419	x	18	75	5,184	217	170	441
Illinois Breast and Cervical Cancer Program - 2024-25	25,394	365	1,887	925	x	0	110	19,159	366	25	2,549
Illinois Family Planning Program 2024-25	83,158	600	1,757	19,904	x	229	168	47,791	3,673	1,409	7,621
Illinois Tobacco Quitline 2024	11,486	73	84	2,830	0	0	x	7,970	301	0	221
Illinois Wisewoman Program 2024	27	0	0	0	0	0	0	27	0	0	0
RACE TOTALS	261,192	2,660	6,632	71,520	55	634	519	129,185	5,719	15,615	28,625

ETHNICITY (06/24/2024)				
Program Name	Program Count	Latina / Latino / Latinx / Hispanic	Other category not specified	Indigenous
COVID-19 Community Based Testing and Interventions Targeting Minority Population Expansion - FY 2023	90,269	64,282	25,799	188
Genetic Counseling 2024	4,523	1,664	2,559	300
Illinois Breast and Cervical Cancer Program - 2024-25	22,946	19,685	3,258	x
Illinois Family Planning Program 2024-25	74,951	36,345	36,898	1,708
Illinois Tobacco Quitline 2024	1,402	69	1,332	x
Illinois Wisewoman Program 2024	33	15	18	0
ETHNICITY TOTALS	194,124	122,060	69,864	2,196

	AGE (06/24/2024)							
Program Name	Program Count	18 and Under	19 - 24	25 - 34	35 - 44	45 - 54	55 - 64	65+
COVID-19 Community Based Testing and Interventions Targeting Minority Population Expansion - FY 2023	141,991	28,857	13,758	24,753	27,025	19,578	14,534	13,486
Genetic Counseling 2024	7,793	3,825	571	1,512	1,035	348	314	188
Illinois Breast and Cervical Cancer Program - 2024-25	24,576	0	491	2,736	6,829	9,600	4,681	239
Illinois Family Planning Program 2024-25	83,501	11,065	22,650	30,614	13,697	4,587	813	75
Illinois Tobacco Quitline 2024	12,406	54	193	1,537	880	3,949	1,559	4,234
Illinois Wisewoman Program 2024	27	0	0	0	5	11	11	0
AGE TOTALS	270,294	43,801	37,663	61,152	49,471	38,073	21,912	18,222

	SEX (06/24/2024)			
Program Name	Program Count	Female	Male	Other category not specified
COVID-19 Community Based Testing and Interventions Targeting Minority Population Expansion - FY 2023	140,698	62,661	70,265	7,772
Genetic Counseling 2024	7,993	4,811	2,776	406
Illinois Breast and Cervical Cancer Program - 2024-25	24,679	24,632	31	16
Illinois Family Planning Program 2024-25	83,149	71,483	11,662	x
Illinois Tobacco Quitline 2024	12,376	7,650	4,572	154
Illinois Wisewoman Program 2024	61	61	0	0
SEX TOTALS	268,956	171,298	89,306	8,348

	DISABILITY STATUS (06/24/2024)						
Program Name	Program Count	Physical Disability	Blind or Visually Impaired	Deaf or Hard of Hearing	Medical Disability	No Disability	Other category not specified
COVID-19 Community Based Testing and Interventions Targeting Minority Population Expansion - FY 2023	71,013	394	19	34	421	64,185	5,960
Genetic Counseling 2024	1,939	39	x	20	186	1,441	249
Illinois Breast and Cervical Cancer Program - 2024-25	16,241	x	12	20	12	15,885	303
Illinois Family Planning Program 2024-25	74,099	235	88	89	835	71,283	1,569
Illinois Tobacco Quitline 2024	8,694	920	1,723	895	906	3,053	1,197
Illinois Wisewoman Program 2024	x	0	0	0	0	x	0
DISABILITY STATUS TOTALS	171,986	1,588	1,842	1,058	2,360	155,847	9,278

	SEXUAL ORIENTATION (06/24/2024)								
Program Name	Program Count	Bisexual	Gay	Lesbian	Queer	Questioning and/or unsure	Straight (heterosexual)	Additional category/identity not listed	Prefer not to answer
COVID-19 Community Based Testing and Interventions Targeting Minority Population Expansion - FY 2023	104,034	549	534	153	287	3,517	54,077	287	44,630
Genetic Counseling 2024	3,705	x	x	x	0	42	598	100	2,944
Illinois Breast and Cervical Cancer Program - 2024-25	17,341	80	x	49	6	315	14,296	341	2,252
Illinois Family Planning Program 2024-25	74,694	4,715	680	391	81	1,419	56,780	2,317	8,311
Illinois Tobacco Quitline 2024	9,126	140	114	49	0	486	8,170	0	167
Illinois Wisewoman Program 2024	x	0	0	0	0	0	x	0	0
SEXUAL ORIENTATION TOTALS	208,900	5,484	1,328	642	374	5,779	133,921	3,045	58,304

	GENDER IDENTITY (06/24/2024)					
Program Name	Program Count	Man	Woman	Non-binary, gender non-conforming	Other	Prefer not to answer
COVID-19 Community Based Testing and Interventions Targeting Minority Population Expansion - FY 2023	99,584	40,234	50,574	152	4,251	4,373
Genetic Counseling 2024	5,743	823	2,173	x	x	2,737
Illinois Breast and Cervical Cancer Program - 2024-25	19,526	10	19,210	x	27	271
Illinois Family Planning Program 2024-25	74,589	8,356	64,445	950	97	741
Illinois Tobacco Quitline 2024	12,456	4,572	7,650	34	21	179
Illinois Wisewoman Program 2024	27	0	27	0	0	0
GENDER IDENTITY TOTALS	211,925	53,995	144,079	1,136	4,396	8,301

	PRIMARY OR PREFERRED LANGUAGE (06/24/2024)										
Program Name	Program Count	English	Non-English Primary Language	Spanish	Polish	Chinese (including Mandarin, Cantonese)	Tagalog (Including Filipino)	Hindi	Arabic	Vietnamese	Korean
COVID-19 Community Based Testing and Interventions Targeting Minority Population Expansion - FY 2023	155,892	85,674	26,245	43,191	x	127	15	63	482	41	49
Genetic Counseling 2024	6,444	5,798	104	461	13	x	x	x	49	x	0
Illinois Breast and Cervical Cancer Program - 2024-25	28,766	4,493	9,576	13,993	35	38	218	285	39	60	29
Illinois Family Planning Program 2024-25	78,291	58,693	4,613	14,855	x	27	x	12	70	12	x
Illinois Tobacco Quitline 2024	9,607	9,565	x	35	x	0	0	0	0	0	x
Illinois Wisewoman Program 2024	27	18	0	9	0	0	0	0	0	0	0
PRIMARY OR PREFERRED LANGUAGE TOTALS	279,027	164,241	40,538	72,544	48	192	233	360	640	113	78