



The Miriam Hospital Immunology Center, Providence, RI

Immunology Center Database (ICDB)

Annual Data Report

1/1/2025 -12/31/2025

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Note to Clinic Physicians and Staff:

Since the implementation of the EMR (EPIC) in 2015, the scope of the Immunology Center Database (ICDB) has expanded significantly. Presented in this report are data that passed through the Electronic Medical Records (EPIC) and the ICDB direct data entry process. These same data are used in reports to government agencies.

Section 1

Introduction and History

1-1) ICDB - Usage

The Immunology Center Database (ICDB) is one of the best healthcare databases available for research at The Miriam Hospital in Providence, RI; however, it has many limitations in its use. ICDB data release policies have been outlined in Section 3 of this report.

1-2) ICDB - History

The ICDB was created in November 2003 with CFAR funding for patient tracking, Ryan White program reporting, and CFAR research activities. Calendar year 2011 was the last year that data elements were manually entered into the ICDB database. With the acquisition of electronic medical records (EMRs) from the vendor eClinicalWorks (ECW) in December 2011, manual entry of data elements was no longer required for most data items. For the period December 2011 through March 2015, ICDB was populated primarily through direct downloads from the ECW backend data system, known as ECW-EBO.

The Miriam Hospital Immunology Center (TMHIC) began using EPIC, Lifespan's current EMR system, in March 2015. During EPIC implementation, CFAR/Lifespan staff collaborated with the Lifespan IS department to adjust and redesign the ICDB system to begin downloading data from EPIC, specifically for Ryan White reporting, CFAR research, and reporting to other funding agencies. At the lifespan, Epic data is stored in Caboodle Data Warehouses (CDWs) and can be accessed via SAP BusinessObjects (BO) through the Business Intelligence (BI) Launchpad. Currently, we access these CDWs using SAP Business Analytics techniques and BI to populate the ICDB system with clinical data related to HIV care. TMHIC also created a customized HIV Case Management Flowsheet in EPIC to collect other program-specific data items not already present in EPIC. Currently, only 5% of data related to current enrollment and some baseline HIV-specific information are manually entered into ICDB. The rest of the data elements are drawn down directly through EPIC's CDWs.

1-3) ICDB - Layout

ICDB is a relational (longitudinal) database on a secure SQL server that is hosted and maintained by the Lifespan IS department. It contains demographic data; the history of medical and social service visits to the clinic; lab results, including CD4 and HIV viral load tests; HIV-specific history of medical ailments or diagnoses; HIV treatment histories; and vaccinations.

The ICDB annual report is created each April following submission of the annual Ryan White Services Report (RSR: includes patient-level data) to the HIV/AIDS Bureau (HAB) of the Health Resources and Services Administration (HRSA). This annual report summarizes essential data items most frequently requested. It also provides general demographic profiles that can be used in grant applications or presentations where summarizing the clinic's population is necessary. When applicable, field definitions with data items are provided. The Brown University Health IRB office has approved this report, which follows all HIPAA regulations.

Section 2

Data Items

2-1) Enrollment

Active Patients: Starting from 2012, an active patient is defined as a patient who had at least one visit (medical or other core medical service, including an Intake visit) recorded in the EMR; OR a patient who is newly registered to the clinic; OR a patient who died (without any visit) during the calendar year. All reactivated patients are included in the active patients list for the year. New diagnoses are defined as any patient diagnosed within the 12 months preceding their registration at the clinic.

Reactivated Patients: A reactivated patient for the current calendar year is defined as a patient who was not active during the previous calendar year but returned to the clinic in the current calendar year. This data item is entered into ICDB via the clinic staff's Activation/Reactivation processes.

Enrollment Status	Patients
Total Active Patients (with any service)	2138
New to the clinic	123
New diagnoses	42
Transfers In	81
Deceased during the year	20
Moved Away/Transferred Care	57
Reactivated during the year	33
Active patients with at least 1 Core Medical Service, or EHE initiative service during the year	2106
Active patients with at least one Outpatient/Ambulatory Health Service (OAHS) during the year	2002

2-2) Demographics

a) Sex at Birth

Starting in 2024, we began reporting Sex at Birth instead of self-reported Gender. In reports before 2024, self-reported current gender was included.

Gender	Patients	% of Total
Male	1568	73.3*
Female	570	26.7*

* Percentage of total active patients (n=2138).

b) Age (groups)

The total number of active patients is grouped into different age categories (Note: We changed the age group ranges and the date used for age calculation compared to previous years to align with HRSA's definitions of special groups). The Immunology Center does not treat patients under 18 years of age. Age is calculated as of January 1st, 2025.

Age Group	Patients	% of Total
18 - 25 Years	41	1.9*
26 - 44 Years	599	28.0*
45 - 64 Years	1055	49.3*
65 and over	443	20.7*

* Percentage of total active patients (n=2138).

The Miriam Immunology Center Database Annual Report 2025

The average age of active patients as of January 1st, 2025, was 52.6 years (standard deviation 13.5 years) with a minimum age of twenty and a maximum of 89 years.

c) Race/Ethnicity

Race and ethnicity are classified in two different fields in the ICDB; as a result, any classifications or combinations of race and ethnicity together can be obtained. This data item is entered directly into the ICDB via new patient intake forms. For this report, we include only the patient's primary race reported on the intake form.

Race	Patients	% of Total
White	1277	59.7*
Black or African American	651	30.4*
Asian	42	2.0*
Native Hawaiian or Pacific Islander	11	0.5*
American Indian or Alaska Native	11	0.5*
More than 1 Race/Unknown/Not Reported	146	6.8*

* Percentage of total active patients (n=2138).

Ethnicity	Patients	% of Total
Hispanic/Latino	596	27.9*
Non-Hispanic/Latino	1542	72.1*

* Percentage of total active patients (n=2138).

d) Place of Birth

Place of Birth (POB) is self-reported, and the country of birth is derived from the Place of Birth information. The US-born category includes only persons born in all fifty states, US-Puerto Ricans are reported as a separate category, and all others are grouped into the Foreign-Born category.

Country of Birth	Patients	% of Total
US-Born	1338	62.6*
US-Puerto Rico Born	131	6.1*
Foreign-Born	666	31.2*
POB Missing	3	0.14*

* Percentage of total active patients (n=2138).

2-3) Socio-economic Indicators

a) Insurance

The following table shows the insurance data for 2025. Medicaid/CHIP/Other public includes VA, Tri-Care, and other Military insurance. Private Insurance includes coverage provided by an employer or an individual. The table represents all unique insurance instances held by all active patients during the year (unlike previous years' reports, which provided insurance information as of their last medical or other core services visit during the calendar year).

Insurance Type	Insurances	% of Total
Private (Individual)**	1028	43.2*
Private (Employer) **	81	3.4*
Medicare	535	22.5*

The Miriam Immunology Center Database Annual Report 2025

Medicaid, CHIP/Other Public	570	23.9*
No Insurance/Uninsured	160	6.7*
Missing	6	0.3

* Percentage of total unique insurance instances (n=2380).

**Private Insurance includes insurance purchased by the individual/family

Note: Clients can report more than one value for this item; therefore, the total client count may exceed the number of unique clients.

b) Housing status

Housing status is the status as of the last visit through December 31st, 2025, entered via the HIV Flow Sheet or updated by clinic staff in the ICDB.

Housing Status	Patients	% of Total
Stable/Permanent Housing	1809	87.7*
Temporary housing	189	9.2*
Unstable Housing Arrangements	65	3.2*

* Percentage of total active patients (n=2138).

2-4) Clinical Indicators

a) HIV/AIDS Status

The CDC defines AIDS Status as a CD4 count < 200 or CD4% < 14 and includes any diagnosis with AIDS in the clinic based on the presence of opportunistic infections. The data reported in the table below is the HIV/ AIDS status of patients as of December 31, 2025.

HIV/AIDS Status	Patients	% of Total
HIV+, not AIDS	1271	61.6*
CDC-defined AIDS	792	38.4*

* Percentage of total active patients (n=2138).

b) Risk Factors

All risk factors are self-reported and are collected at the time of new patient intake by clinic staff. This data item is manually entered into ICDB and is the Primary HIV Risk Factor reported by the patient.

Primary Risk Factors	Patients	% of Total
MSM	1025	47.9*
Heterosexual contact	849	39.7*
IDU	154	7.2*
MSM/ IDU	24	1.2*
Perinatal transmission	23	1.1*
Blood Transfusion	17	0.8*
Hemophilia/ coagulation disorder	3	0.1*
Others/ Unknown/ Unreported	43	2.0*

* Percentage of total active patients (n=2138).

2-5) Clinical Care

a) Lab Tests

The following table displays the most important lab tests performed in the current reporting year. Column 2 represents the total number of tests completed on active patients who had at least one Outpatient Ambulatory Medical Care (OAMC) visit in the year; Column 3 represents the number of unique patients who had at least one test completed; and Column 4 represents the percentage (%) of total active patients who had at least one OAMC visit in the reporting

The Miriam Immunology Center Database Annual Report 2025

year, except for the Pap smear test, where the last column is % of females who had a Pap smear test performed in the past 3 years (per latest guidelines), out of the female patients who had at least one medical visit during the calendar year and were eligible for Pap smear. This table shows the total number of patients with at least one OAMC visit who had tests done during the year and are not adjusted for any additional criteria.

Lab Test	# of Tests Done	# of Unique Patients	% of Active Patients
CD4 Test done in the year	1030	828	41.4*
PVL Test done in the year	3535	1921	96.0*
Other Annual Tests			
Screened for Cervical Cancer (PAP) in the last 3 years (per new standards)		400	89.1**
Screened for Syphilis in the year		1207	60.3*

*Percentage is out of the total number of patients who had at least one OAHs during 2025 (n=2002).

**Percentage is out of the total females who had at least 1 medical visit in 2025 (n=543) and were eligible for PAP Smear Test or HPV test in 2025 (n=449, excluding 94 Not Medically Indicated category).

b) Treatment

Patients' usage of HIV treatment is determined by current use of medications (as of December 31, 2025). Ever since we started using the new EMR (EPIC), this data item has been available only for ordered medications and is entirely dependent on those medications ordered within EPIC. The table below includes medications ordered from 1/1/2024 to 12/31/2025, as well as a manual chart review (from the physician's notes) for a small number of patients.

Medication Status	Patients	%
Yes - on HIV treatment	1979	98.9*
No - not on HIV treatment/Unknown/Unreported	23	1.1*

* Percentage of total Active patients in the year (n=2138).

c) Clinical Outcomes / Lab Results

Clinical outcomes are based on the last available lab value for the current reporting year. Most of the viral load and CD4 test results are downloaded from EPIC, and results from outside labs are manually entered into ICDB using the scanned documents in EPIC.

Viral Load Suppression (PVL < 200)	Patients	%
Yes (PVL < 200)	1823	91.1*
No (PVL >= 200)	99	4.9*
No PVL result is available for the year	80	4.0*

* Percentage of total patients who have at least one medical visit during the year (n=2002).

Note: CD4 test results are the most recent available lab value for the patient, regardless of whether it was done in 2025 or earlier.

Last available CD4 Test Results	Patients	%
CD4 counts 500 or greater	1493	75.4*

The Miriam Immunology Center Database Annual Report 2025

CD4 count between 200 and 499	412	20.8*
CD4 counts less than 200	75	3.8*

*Percentage of total Active patients who have at least 1 OAHS during 2025 (n=2002) with a documented CD4 test (n=1980).

d) Services Provided

Service encounters provided by TMH IC clinic staff for the year are reported in the table below. Ambulatory/Outpatient visits include all patient visits (e.g., initial visits, follow-up exams, or office visits with a completed visit status) with any prescribing provider, including physicians, Physician Assistants (PAs), Nurse Practitioners (NPs), or Pharmacists. Other encounters include mental health, medical case management, and substance use services (as defined by the Ryan White Program). Of note, specific screenings (health education/risk reduction, mental health, and substance use screens) are tracked through an EMR tool that creates extractable data fields for these data points.

Services Provided	Unique Patients	Total # of Visits
Ambulatory/Outpatient Encounters	2002	6118
Mental Health Services	1388	5609
Medical Case Management (including Treatment Adherence Services)	559	2098
Health Education/Risk Reduction	1263	3605
Medical Transportation	308	1151
Outreach Services	564	1404

END of the Data Section

The Miriam Immunology Center Database Annual Report 2025

Section 3

ICDB System: Data Release Policies

Data presented in the ICDB Annual Data Report are for clinical and government reporting purposes only. This data report may be used to summarize the TMHIC population (for presentations and grant applications) but cannot be published without obtaining appropriate IRB approval. If you intend to use this data or need more detailed data for any research purpose, please follow the procedure noted below:

- 1) After IRB approval, a request for data from ICDB must be made through the completion of a "CFAR Clinical Data Request Form (DRF)", which is located on the CFAR website [Cores Services | Providence/Boston Center for Aids Research \(CFAR\) | Medical School | Brown University](#), and click on the "ICDB Request Form" in left side bar. Or use the following link. [Clinical Data Request Form \(CDR\) - TMH Immunology Center \(formsite.com\)](#).
- 2) If the requester is not a member of the Infectious Diseases Division, then they must collaborate with any faculty member within the Division. Data will be released only to faculty members of the ID Division; we do not release data to staff (i.e., research assistants, project directors).
- 3) If the data requested is purely for research purposes, IRB approval information must be filled in, and a copy of the IRB approval letter must be uploaded with the data request. Your IRB approval letter can be found within your IRBNet study documents. If the request is for clinical use at the Immunology Center or for government reporting, IRB approval is not needed.

The Data Request Form (DRF) will be forwarded to the Data Release Authorization Committee, to review the Data Request (approval from at least two committee members is required). If approval is granted, the data will then be sent to the requester. ***Please Note: research groups can get the data for their research projects by using the above process, but they cannot get access to the actual ICDB SQL Server database.***

- 4) After all requirements outlined above are met, the data, which includes individual identifiers, will not be sent via e-mail. The requester must contact Dr. Fizza Gillani (fgillani@BrownHealth.org) to obtain the identified data for research.
- 5) Names of patients for research purposes will be issued only if appropriate IRB approval is obtained and/or preparatory to research has been arranged with the Lifespan IRB office. See IRBNet Forms and Templates for accounting of disclosure information and instructions.
- 6) Each PI (requester) is responsible for the confidentiality, privacy, and proper use of data that is released to them (specifically when the data includes patient identification).
- 7) Everyone performing human subject research must have educational training in the protection of study volunteers. It is the Principal Investigator's responsibility to make sure any colleague who has access to the data or who uses the data has appropriate training. It is also the researcher's responsibility to properly discard or file the data after the project is completed. Please call the Research Protection Office (RPO) for guidelines.