The Miriam Hospital Immunology Center, Providence, RI

Immunology Center Database (ICDB)

Annual Data Report

1/1/2024 -12/31/2024

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Note to Clinic Physicians and Staff:
With the implementation of a new EMR (EPIC), the scope of the Immunology Center Database (ICDB) has increased significantly. Presented in this report are data that passed through the Immunology Center 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, Providence, RI; however, it does have many limitations for its use. ICDB data release policies have been outlined in Section 3 of this report.

1-2) ICDB – History

The ICDB was originally created in November 2003 with CFAR funding for the purposes of 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 eClinical Works (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 mostly populated from direct downloads of the ECW backend data system, known as ECW-EBO.

The Miriam Immunology Center (MIC) started utilizing EPIC, the current EMR system of Lifespan, in March 2015. During EPIC implementation, CFAR/Lifespan staff worked in collaboration with the Lifespan IS department to adjust and redesign the ICDB system to start downloading data from EPIC system specifically for Ryan White reporting, CFAR research, and reporting to other funding agencies. At lifespan, Epic data is stored in Caboodle Data Warehouses (CDWs) that can be accessed using SAP Business Objects (BO) via Business Intelligence (BI) Launch Pad. Currently, we access these CDWs using SAP Business Analytics techniques and BI to populate the ICDB system with clinical data related to HIV care. MIC also created a customized HIV Case Management Flowsheet within EPIC to collect other program-specific data items not already present in EPIC. Presently, only 5% of the data elements 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, labs 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 the annual Ryan White Services Report (RSR: includes patient level data) submission to the HIV/AIDS Bureau (HAB) of the Health Resources and Services Administration (HRSA). This annual report provides a summary of essential data items that are most frequently requested. It also provides general demographic profiles that can be used in grant applications or presentations in which summarizing the clinic population may be necessary. When applicable, field definitions with data items are provided. This report has been approved by the Lifespan HIPAA office and 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 who was diagnosed within the last 12 months of their registration to clinic date.

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

Enrollment Status	Patients
Total Active Patients (with any kind of service)	2141
New to clinic	133
New diagnoses	66
Transfers In	67
Deceased during the year	24
Moved Away/Transferred Care	48
Reactivated during the year	22
Active patients with at least 1 Core Medical Service during the year	2087
Active patients with at least one Outpatient/Ambulatory Health Services (OAHS) during the year	1982

2-2) Demographics

a) Sex at Birth

This is the very first year that we are reporting this data item. In all previous reports, current Gender was included.

Gender	Patients	% of Total
Male	1585	74.0*
Female	556	25.9*

* Percentage of total active patients (n=2141).

b) Age (groups)

The total active patients are grouped together in different age groups (Note: We changed the age group ranges and date of age calculation as compared to previous years to accommodate HRSA's definitions of special groups). The Immunology Center does not treat patients less than 18 years of age. Age is calculated as of January 1st, 2024.

Age Group	Patients	% of Total
18 – 25 Years	43	2.0*
26 - 44 Years	618	28.9*
45 – 64 Years	1080	50.4*
65 and over	400	18.9*

* Percentage of total active patients (n=2141).

The average age of active patients as of January 1st, 2024, was 52.1 years (standard deviation 13.5 years) with a minimum of 19 and maximum age of 88 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 the purposes of this report, we include only the primary race reported by the patient on the intake form.

Race	Patients	% of Total
White	1297	60.5*
Black or African American	654	30.5*
Asian	40	1.9*
Native Hawaiian or Pacific Islander	13	0.6*
American Indian or Alaska Native	12	0.6*
More than 1 Race/Unknown/Not Reported	125	5.8*

* Percentage of total active patients (n=2141).

Ethnicity	Patients	% of Total
Hispanic/Latino	590	27.6*
Non-Hispanic/Latino	1551	72.4*

* Percentage of total active patients (n=2141).

d) Place of Birth

Place of Birth (POB) is self-reported, and country of birth is derived from the Place of birth information. US-born category includes only persons born in all 50 states, US-Puerto Ricans are reported as a separate category and all others are grouped together into Foreign-Born category.

Country of Birth	Patients	% of Total
US-Born	1343	62.7*
US–Puerto Rico Born	134	6.3*
Foreign-Born	661	30.8*
POB Missing	3	0.14*

* Percentage of total active patients (n=2141).

2-3) Socio-economic Indicators

a) Insurance

The following table shows the insurance data for 2024. Medicaid/CHIP/Other public includes VA, Tri-Care, and other Military insurance. Private Insurance includes private insurance provided by an employer or individual. The table represents all unique insurance instances all active patients had during the year (unlike previous years' reports where insurance information provided was as of their last medical or other core services visit during the calendar year).

Insurance Type	Patients	% of Total
Private (Individual)**	1015	48.6%*
Private (Employer) **	95	4.6%
Medicare	493	23.6*
Medicaid, CHIP/Other Public	607	29.1*
No Insurance/Uninsured	175	8.4*

* Percentage of total unique insurance instances (n=2385).
**Private Insurance includes insurance purchased by the individual/family

b) Housing status

Housing status is the housing status as of the last visit until December 31st, 2024, entered via HIV-Flow Sheet OR updated by the clinic staff in the ICDB.

Housing Status	Patients	% of Total
Stable/Permanent Housing	1907	89.1*
Temporary housing	166	7.8*
Unstable Housing arrangements	68	3.1*

* Percentage of total active patients (n=2141).

2-4) Clinical Indicators

a) HIV/AIDS Status

HIV/AIDS Status is defined by the CDC as a CD4 count < 200 or CD4% < 14 and including any diagnosis with AIDS in the clinic based on the presence of opportunistic infections. Data reported in the following table are the HIV/AIDS status of patients as of December 31, 2024.

HIV/AIDS Status	Patients	% of Total
HIV+, not AIDS	1226	60.5*
CDC-defined AIDS	801	39.5*

* Percentage of total active patients (n=2141).

b) Risk Factors

All risk factors are self-reported and are generally 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	1030	48.1*
Heterosexual contact	822	38.4*
IDU	163	7.6*
MSM/ IDU	27	1.3*
Perinatal transmission	18	0.8*
Blood Transfusion	19	0.9*
Hemophilia/ coagulation disorder	3	0.1*
Others/ Unknown/ Unreported	59	2.8*

* Percentage of total active patients (n=2141).

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 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 represents the total number of patients with at least one OAMC visit that were tested during the year and is not adjusted for any additional criteria.

Lab Test	# of Tests Done	# of Unique Patients	% of Active Patients
CD4 Test done in the year	1454	1117	56.4*
PVL Test done in the year	3620	1959	98.8*
Other Annual Tests			
Screened for Cervical Cancer (PAP) in last 3 years (per new standards)		384	88.3**
Screened for Syphilis in year		1207	60.9*

* Percentage is out of the total number of patients who had at least one OAHS during 2024 (n=1982).
**Percentage is out of the total females who had at least 1 medical visit in 2024 (n=523) and were eligible for PAP Smear Test or had HPV test in 2024 (n=435 excluding 88 Not Medically Indicated category).

b) Treatment

Patients' usage of HIV treatment is determined by current use of medications (as of December 31, 2024). Ever since we started using the new EMR (EPIC), this data item is only available through a query for medications ordered and are completely dependent on medications ordered within the EMR. The following table includes the medications ordered in last 2 years (within Epic) from 1/1/2023-12/31/2024 as well as a manual chart review (from physician's notes) for a small number of patients.

Medication Status	Patients	%
Yes – on HIV treatment	2099	98.0*
No – not on HIV treatment/Unknown/Unreported	42	2.0*

* Percentage of total Active patients in the year (n=2141).

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 generally manually entered into ICDB using the scanned documents in EPIC.

Viral Load Suppression (PVL < 200)	Patients	%
Yes (PVL < 200)	1841	94.0*
No (PVL >= 200)	118	6.0*
No PVL result available for the year	23	1.2**

* Percentage of total patients who have at least one viral load test done in 2024 (n=1959).
**Percentage of total patients who have at least one OAHS visit during 2024 (n=1982).

Note: CD4 test results are the last available lab value for the patient, irrespective of if it was done in 2024 or earlier.

Last available CD4 Test Results	Patients	%
CD4 counts 500 or greater	1487	75.0*
CD4 count between 200 and 499	415	20.9*
CD4 counts less than 200	80	4.1*

* Percentage of total Active patients who have at least 1 OAHS during 2024 with a documented CD4 test (n=1982).

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 visit, follow-up exams, or office visit with a completed visit status) with any prescribing provider including physicians, Physician Assistants (PAs), Nurse Practitioners (NPs), or Pharmacists. Other encounters include services such as mental health services, medical case management services 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 via the implementation of an EMR tool that creates extractable data fields for these data points.

Services Provided	**Total # of Visits**	**Unique Patients**
Ambulatory/Outpatient Encounters	5577	1982
Mental Health Services	4808	1198
Medical Case Management (including Treatment Adherence Services)	2106	456
Health Education/Risk Reduction	5074	1539
Medical Transportation	1518	375
Outreach Services	1271	556

END of the Data Section

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 Immunology Center population (for presentations and grant applications) but cannot be published without obtaining appropriate IRB approval. If you intend to use these data or need more detailed data for any research purpose, please follow the procedure noted below:

1) After IRB approval, request for data from ICDB must be done 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) I Medical School I 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 requestor is not a member of Infectious Diseases Division, then he/she must collaborate with any faculty member within the Division. Data will only be released to faculty members of the ID Division; we are not authorized to provide 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 (A group of senior physicians from the Immunology Center at The Miriam Hospital). The committee will 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 requestor.

4) After all requirements outlined above are met, the data which includes individual identifiers will not be sent via e-mail. Requestor must contact Dr. Fizza Gillani (fgillani@lifespan.org) at the Miriam Immunology Center to obtain this 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 (requestor) is responsible for the confidentiality, privacy and proper use of data that is released to him/her (specifically when the data includes patient identification variables).

7) Everyone performing human subject research must have educational training in the protection of study volunteers. It is the Principal Investigator's (PI's) responsibilities to make sure any colleague who has access to the data or who uses the data have appropriate training. It is also the researcher's responsibility to properly discard or file the data after project is completed. Please call the Research Protection Office (RPO) for guidelines.