

Immunology Center Database Annual Report 2007



A research program of the Brown AIDS Center

The Miriam Hospital

Immunology Center Database (ICDB)

Annual Data Report

1/1/2007 -12/31/2007

Volume III

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Note to Clinic Physician and Staff: Presented in this report is data that passes through the Immunology Clinic Data Entry process (Gabriela Madera's Desk). This same data is used in reports to government agencies. Please make sure that your clinic data/information goes through to the appropriate data entry process. Thanks.

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. However, it does have some limitations to use. ICDB data release policies have been outlined in Section 3 of this report.

1-2) ICDB - History

ICDB was originally created in November 2003, and carries historical treatment data from 1994. ICDB has gone through substantial changes since its inception. There are several data fields added during last 5 years. In Fall 2008, we anticipate that ICDB will be linked to the Lifespan Laboratories database.

1-3) ICDB - Layout

ICDB is a relational database on a SQL server, hosted and maintained by the Lifespan IS department. It contains demographic data, history of Clinic Medical and Social Services visits (from 2003), history of CD4 tests and results (from 1995), history of Viral Load (PVL) tests and results (from 1995), history of all other Annual test (from 2003), history of medical problems or diagnosis, and history of medications used (from 2003). Hepatitis (A/B/C) serology, vaccination, and treatment information is also a part of the ICDB.

An ICDB Data Report will be created every year in April following the annual HIV/AIDS Program Data Report is submitted to HRSA. The ICDB Annual Report provides a summary of the most important and frequently asked data items. In addition, it provides

general information which can be used in grant applications or any presentations where summarizing the clinic population is necessary. When applicable, field definitions with data items are provided. This report has been approved by the Lifespan HIPAA officer and follows all HIPAA regulations. HIPAA audits are performed prior to publication each year.

Section 2

Data Items

2-1) Enrollment

Active Clients: In ICDB, an active client is defined as anyone who has received a service from the clinic during the reporting year. Services include, physician's visit (excluding No Shows and Canceled or rescheduled visits by Physicians or patient), CD4 tests, Viral Load tests, other lab tests, Annual shots, tests or vaccines, Social worker's visits, Hepatitis treatment, Hepatitis Vaccination or if the patient is just newly enrolled in the clinic. Enrollment data has been included in ICDB since the clinic was started. Lists of active clients each year are available beginning in 2002. All reactivated clients are included in our active patient list for the year.

Reactivated Clients are defined as clients who were not active during 2006, but have returned to the clinic in 2007.

Enrollment Status	Clients
Total Active Clients in 2007	1135
New in 2007	127
Reactivated in 2007	27
Deceased in 2007	19
Moved Away in 2007	7
Transferred Care in 2007	7

2-2) Demographics

a) Gender

All gender data are self-reported. For the year 2007, gender distribution is as follows:

Gender	Clients	% of Total
Male	759	66.9
Female	376	33.1
Transgender	0	0.0

b) Age (groups)

Total active clients are grouped together in different age groups. The Immunology Center does not treat clients less than 13 years of age. Age is calculated as of December 31, 2007.

Age Group	Clients	% of Total
13 – 24 Years	34	3.0
25 - 44 Years	536	47.2
45 – 64 Years	549	48.4
Over 65 Years	16	1.4

c) Race/Ethnicity

Race and Ethnicity are classified in two different fields in ICDB. Using both of them together, one can obtain classification or combination of race and Ethnicity together.

Race/Ethnicity	Clients	% of Total
White (not Hispanic)	538	47.40
Black (not Hispanic)	340	29.96
Hispanic or Latino(a)	233	20.53
Asian	19	1.67
Native Hawaiian or Pacific Islander	1	0.09
American Indian or Alaska Native	4	0.35

d) Place of Birth

Place of Birth (POB) is self-reported. The collection of this variable began in 2005, and about 10% of the information is missing.

Country of Birth	Clients	% of Total
US-Born	710	62.56
Foreign-Born	318	28.02
POB Missing	107	9.43

2-3) Socio-Economic Indicators

a) Insurance

Insurance status is collected at the first intake and then continuously updated whenever possible.

Insurance Type	Clients	% of Total
Private	358	31.54
Medicare	191	16.83
Medicaid	304	26.78
Other public	56	4.93
No Insurance	213	18.78
Unknown/Unreported	13	1.14

2-4) Clinical Indicators

a) HIV/AIDS Status

HIV/AIDS Status is defined by CDC as CD4 < 200 or CD4% < 14 plus patients diagnosed with AIDS in the clinic based on any Opportunistic Infections.

HIV/AIDS Status	Clients	% of Total
HIV+, not AIDS	529	46.61
CDC-defined AIDS	606	53.39

b) Risk Factors

Risk Factors as self-reported, and generally collected at time of Intake.

Primary Risk Factors	Clients	% of Total
MSM	378	33.30
IDU	264	23.26
MSM/IDU	15	1.32
Heterosexual contact	370	32.60
Hemophilia/coagulation disorder	1	0.09
Receipt of transfusion	11	0.97

Mother with/at risk	5	0.44
Other	21	1.85
Unknown/ Unreported	70	6.17

2-5) Treatment

a) Tests

Following table presents the number of tests performed in the reporting year. Column 2 represents the total number of test completed on the active clients. Column 3 presents the number of unduplicated clients who had at least one test done, and Column 4 represents the *number of unduplicated clients who had the test as percentage of total active clients for the year 2007* (except for Pap Smear test, where last column is percentage of females who had Pap Smear test done out of total active females in 2007).

Lab Test	# of Tests Done	# of Unique Clients	% of Active Clients
CD4 Test	3042	1050	92.51
PVL Test	3007	1044	91.98
PPD Tests			
No. of PPD Negative clients as of 1/1/2007			1028
PPD Planted	418	375	36.47
PPD Read	333	321	31.23
Pap Smears	217	200	53.13
Other STDs			
GC	900	703	62.11
CHLY	895	699	61.94
RPR	639	458	40.35

b) Hepatitis Tests

Following table reports Hepatitis A and C test results performed in the reporting year.

	Hep A Serology	Hep C Serology
Positive	118	40
Negative	105	347
Unknown	0	1
Total Tests done	223	388

Following table presents number of Hepatitis B test results performed in the reporting year.

Results	Hep B
Chronic HBV	11
Vaccinated	57
Negative	98
Prior HBV Infection	68
Unknown	22
Total Test Performed	256

c) Medicines

Medicine data has been determined by the current medicines usage. "On HAART" means, that the client used at least one HIV/AIDS medicine during 2007.

Medicine Status	Clients	% of Total
Not on Medicines	193	17.00
On HAART	891	78.50
Other (mono or dual)	5	0.44
Unknown/ Unreported	46	4.05

d) Services Provided

Service provided by the clinic medical staff within the reporting period. Ambulatory Outpatient visits include Physician's first visit, Follow-up exams, Hepatitis C visit, and any patient checked into the ACI and Nursing homes by our Immunology Clinic Physicians. Psychosocial visits include any Case management and Mental Health visits attended by Immunology Clinic social workers.

Type of Visit	Total # of Visits	# of Unduplicated Clients
Ambulatory /Outpatient Visits	4407	1049
Psychosocial Support Encounters	2441	898

Section 3

Immunology Clinic Database System: Data Release Policies

Data presented in the ICDB annual report are for clinical and government reporting purposes only. The data may be used to summarize the Immunology Clinic population (for presentations and grant applications), but this information cannot be published without obtaining appropriate IRB approval. If you intend to use the data for a research paper, please make sure you follow the procedure as noted below:

- 1) All requests for data from ICDB must be done through the completion of a “Data Request Form (DRF) the forms are located on the CFAR website (<http://www.lifespan.org/cfar/icdb-guidelines.htm>)
- 2) Researcher forwards the COMPLETELY filled DRF to rdicesare@lifespan.org
- 3) If the data requested is purely for research purposes, IRB approval information must be completely filled in and a copy of the IRB approval form (<http://www.lifespan.org/research/irb/>) should be attached to the DRF. If the request is for clinical use at the Immunology Center or is for government reporting, IRB approval is not needed.
- 4) The DFR 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 one committee member is required). If approval is granted, the data will be provided and sent to the requestor.

- 5) Data, which includes individual identifiers, will not be sent via e-mail. Requestor must contact Gabriela Madera (gmadera@lifespan.org) at the Immunology Center to obtain the data.
- 6) 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. Identifiable data obtained for research purposes must meet HIPAA’s Accounting of Disclosure requirements. See ORA website for information on Accounting of Disclosures.
<http://www.lifespan.org/research/irb/docs/accountingofdisclosureinformation-instructions.pdf>
- 7) Each requestor is responsible for the confidentiality, privacy and proper use of the data released to him/her (specifically when the data includes patient identification variables).
- 8) Each individual performing human subject research must have educational training in the protection of study volunteers.
(<http://www.lifespan.org/research/irb/mandatoryedguidance.htm>) It is each requestor’s responsibility to make sure any colleagues who utilize the data are authorized to do so. It is also the researcher’s responsibility to properly discard or file the data after use.