

Hemophilia Data Set: Leveraging the ATHNdataset and the Electronic infrastructure for Performance Improvement and Research

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Where can I find out??

- # patients in the US Hemophilia Treatment Center Network? Regionally? Nationally?
- Age? Gender?
- Severity? Diagnoses?
- HIV?
- Home Infusion?
- Selected services
- Trends over time?

What is the HDS?

- National registry compiled by US HTC/N
- 1980's – annually
- HRSA & CDC initiated
- Aggregate, de-identified
- Uses: program planning, needs assessment, evaluation, monitoring trends, advocacy
- Current projects: *HDS Trends 1990-1998* and *HTC Characteristics Survey*

Variables

- Clinical: diagnosis, severity, HIV, inhibitors
- Demographics: age, race/ethnic, gender
- Services: home treatment, annual & diagnostic eval, PCP, outreach clinics, transportation assist, advisory board
- Mortality: diagnosis, age, HIV+/-, cause

Revisions: ad hoc work groups guided by changes in HRSA/CDC priorities

Logistics

- Voluntary but expected by HRSA regional grantees – **100% participation**
- Not research
- Collected by HTC clinicians and data managers: paper ... to web based – increasing quality/integrity
- Resources: limited

Looking forward

Map gaps & redundancies along leading health indicators aligned with disorder specific and national health priorities

Graphic interface for benchmarking & trends

Link data sets – what HTC services are associated with better patient health outcomes

Acknowledgements

- HTC staff from 1990 – present
- HTC Regional Coordinators
- CDC
- HRSA
- Rick Shearer, BA

Assess to and Proposed Changes in HDS

Who Has Access to HDS?

- National
 - Are available to anyone
 - Are sent to HRSA, CDC, HNF, HFA
 - All RCs have it
- Regional
 - Are available through the RCs
- State
 - May be available
- HTC
 - Only available from individual HTCs

Why Change

- ❖ Meet the needs of US HTCN and our partners
- ❖ Allow for better analysis of trends
- ❖ Improve the usefulness of the report
- ❖ Enhance Performance Measurement
- ❖ Remove some unnecessary items
- ❖ All data elements to be available in Web Tracker
- ❖ Minimize burden on HTCs

WHEN Change

- ❖ Possibly for 2012 data
- ❖ We still need to review HDS
 - In relation to the greatly expanded HRSA Performance Measures
 - In relation to HRSA upcoming grant guidance for the US Hemophilia Treatment Center Network

Active patient

- ❖ An active patient is any patient you consider active.
- ❖ They will be classified by when you last had meaningful two-way communication with them:
 - In the past calendar year.
 - Not in the past calendar year.

Inactive patients

- ❖ The number of patients where the HTC changed their status from Active to Inactive in the calendar year

Age Groups

- ❖ Number of age groups increased
 - ❖ Align with other national data including the US Census
- | | |
|---------|---------|
| ➤ 0 - 2 | ➤ 25-29 |
| ➤ 3-4 | ➤ 30-39 |
| ➤ 5-9 | ➤ 40-49 |
| ➤ 10-14 | ➤ 50-59 |
| ➤ 15-19 | ➤ 60-69 |
| ➤ 20-24 | ➤ 70+ |

Race and Ethnicity

- ❖ Based on US Census definitions and to align how the question is asked in Web Tracker

RACE

A. General Demographics: Active patients by age, gender and race.	AGE 0 - 2		AGE 3 - 11	
	Male	Female	Male	Female
American Indian or Alaska Native				
Asian				
Black or African American				
Native Hawaiian or other Pacific Island				
White				
Multi-racial				
TOTAL	0	0	0	0

Ethnicity

	AGE 0 - 2		AGE 3 - 11	
	Male	Female	Male	Female
<i>B. General Demographics: Active patients by age, gender and ethnicity.</i>				
Hispanic				
Non-Hispanic				

Diagnostic Information

- ❖ Still collect
 - A
 - B
 - VWD
 - Other factor deficiencies
 - Acquired VIII
- ❖ Eliminated home Stimate use

HEMOPHILIA A / FACTOR VIII DEFICIENCY

C. Current year patients by age, gender and bleeding disorder.	MILD		MODERATE		SEVERE		TOTAL Hemophilia A	
	Male	Female	Male	Female	Male	Female	Male	Female
	Age 0 - 2							0
Age 3 -4							0	0
Age 10-14							0	0
Age 15-19							0	0
Age 20-25							0	0
Age 25-29							0	0
Age 30-39							0	0
Age 40-49							0	0
Age 50-59							0	0
Age 60-69							0	0
Age 70 +							0	0
TOTAL	0	0	0	0	0	0	0	0
Home IV Therapy							0	0
Inhibitor							0	0

HIV Risk Reduction

K. Number of HIV patients and partners	Number	
Number of active patients who are HIV positive and currently living		
Number of sexual partners who seroconverted to HIV in this CY		Eliminate
Number of pregnancies among HIV positive and at risk couples in this CY		Eliminate
Number of HIV positive infants born in this CY		Eliminate
Number of Hepatitis C Positive Patients		Will not collect

Comprehensive Evaluations

- ❖ Increased specificity of unduplicated patients
- ❖ Changed Number with PCP, only applies to patients with comp
- ❖ Changed sent summary to PCP, only applies to patients receiving comp

J. Number of unduplicated patients that received comprehensive evaluation

					A		
					Mild	Moderate	Severe
Age 0 - 2							
Age 3 -4							
Age 10-14							
Age 15-19							
Age 20-25							
Age 25-29							
Age 30-39							
Age 40-49							
Age 50-59							
Age 60-69							
Age 70 +							
TOTAL					0	0	0
How many of these patients have a PCP							
How many of these PCP's have access to a summary of the evaluation via an EMR, written summary sent to them or other mechanism							

Total Comprehensive Evaluations

❖ Eliminated

<i>M. Number of comprehensive evaluations conducted</i>	0
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~~Please refer to the HDS Glossary for the definition of this data element.~~

Diagnostic Evaluations

- ❖ Remains unchanged

N. Diagnostic Evaluations (unduplicated patients)	0
Please refer to the HDS Glossary for the definition of this data element.	

Not in the past calendar year

- ❖ Used to collect as a single number
- ❖ Needed more information about who these individuals are

H. Patients whose last documented contact was greater than one year ago.

	2 years ago	3 years ago	4 years ago	5+ years ago	Total
Hemophilia A					
Severe					0
Moderate					0
Mild					0
Hemophilia B					
Severe					0
Moderate					0
Mild					0
VWD					
Type I					0
Type II					0
Type III					0
Type Unknown					0
Other					0
Total	0	0	0	0	0

Deaths

DEATHS THAT OCCURRED IN PAST YEAR

K. Primary Cause of Death

	Hemophilia A		Hemophilia B		vWD		Other Factor deficiency		TOTAL		TOTAL
	HIV -	HIV +	HIV -	HIV +	HIV -	HIV +	HIV -	HIV +	HIV -	HIV +	
HIV Related											0
Liver disease related											0
Bleeding related											0
Cardiac related	NEW										0
Cancer related	NEW										0
Accident & Trauma	NEW										0
Other											0
Unknown											0
TOTAL	0	0	0	0	0	0	0	0	0	0	0

	AGE 0 - 2		AGE 3 - 4		AGE 5-9		AGE 10-14		AGE 15-19	
	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
A. General Demographics: Current year patients by age, gender and race.										
HIV Related										
Liver disease related										
Bleeding related										
Cardiac related										
Cancer related										
Accident & Trauma										
Other										
Unknown										
TOTAL	0	0	0	0	0	0	0	0	0	0

Data Fields Required

- ❖ Diagnosis – Diagnosis tab
- ❖ Severity, VWD type -Diagnosis tab
- ❖ Date of Birth - Demographics Tab
- ❖ Race and Ethnicity - Demographics Tab
- ❖ PCP – Providers Tab
- ❖ Home Factor Therapy – Bleeds/Infusions Tab/
 - Who infuses
- ❖ HIV status – Diagnosis Tab
- ❖ Visits – Visits Tab
 - Date
 - Type
 - PCP sent summary if a comp visit

SUMMARY -- HDS

- ❖ Only report that captures information on all patients in US HTC Network
- ❖ 100% participation for over 2 decades
- ❖ Useful -- trends for program planning and (some) monitoring/evaluation
- ❖ Evolved to address changing priorities
- ❖ Can help answer questions
- ❖ Report can be generated by Web Tracker.