

HP2020 DATA SUMMARY - NATIONAL

End of Cycle Report
Data through 12/2021



OVERVIEW

This report displays national summary statistics for bleeding disorder HP2020 measures:

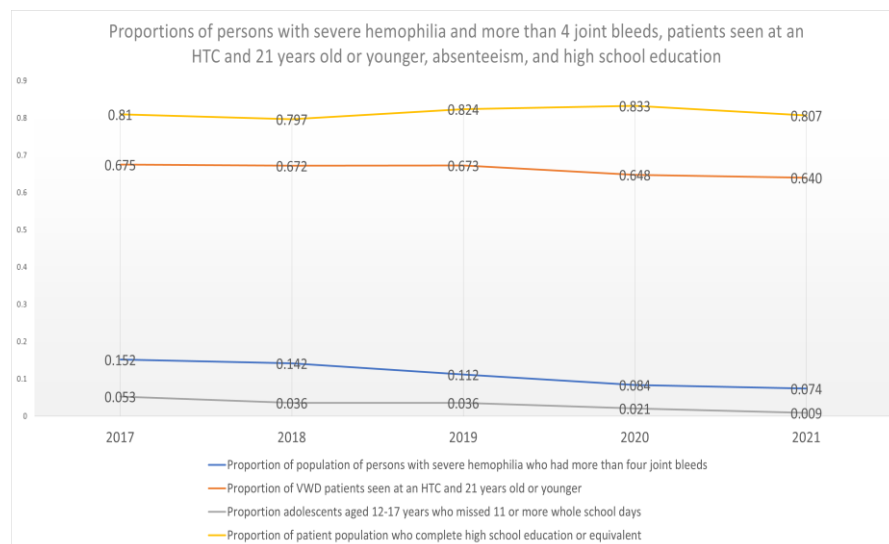
1. Reduce the proportion of people with severe hemophilia who have more than 4 joint bleeds each year (BDBS-01, now labeled as BDSBS-16)
2. Increase the proportion of persons with von Willebrand disease (VWD) seen in specialty care centers who were diagnosed by 21 years of age (BDBS-15)
3. Increase the proportion of persons with a diagnosis of hemoglobinopathies who complete high school education or a General Education or Equivalency Diploma (GED) by 25 years of age (BDBS-8)
4. Decrease school absenteeism among adolescents due to illness or injury (AH-5.6)

Methods

After drafting an initial analysis plan, deidentified data was requested from the CDC using a “data shell” or excel spreadsheet outlining all requested measure and contextual variables. Data cleaning and summary statistics were conducted using Stata 17.0 and Microsoft Excel. No data has been removed for this report or from the data provided to Regional Leadership. Reported here are national summary statistics only. Region-level reports were provided to Regional Leadership as a separate document.

Results

- The proportion of patients with severe hemophilia who had more than 4 joint bleeds decreased from 8.4% in 2020 to 7.4% in 2021. (target met)
- The proportion of persons with von Willebrand disease (VWD) seen in specialty care centers who were diagnosed by age 21 (BDBS-15) demonstrated little change between 2020 and 2021.
- The proportion of age-eligible (18-25) patients who completed their high school education or GED by 25 years of age was 80.7% in 2021.
- The proportion of adolescents aged 12-17 years who missed 11 or more whole school days decreased from 2.1% in 2020 to 0.9% in 2021. (target met)



Limitations

Data cleanup is ongoing at the CDC which can lead to small discrepancies from previous reporting periods. This reporting period also includes data collected during the COVID-19 pandemic, which may limit the number of patients represented in this data. Data for this report was pulled on August 3, 2022 and includes data through the December 2021.

Questions regarding this summary report or the data provided should be directed to Justine Kaplan at jkaplan@athn.org and Skye Peltier at speltier@athn.org. **We would like to thank our CDC partners for their help in creating this report.**

HP2020 BLOOD DISORDER MEASURES

→ Reduce the proportion of people with severe hemophilia who have more than 4 joint bleeds each year (BDBS-01)

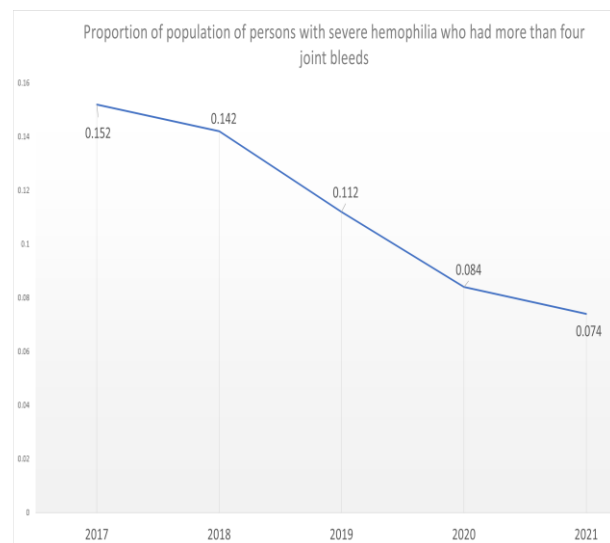
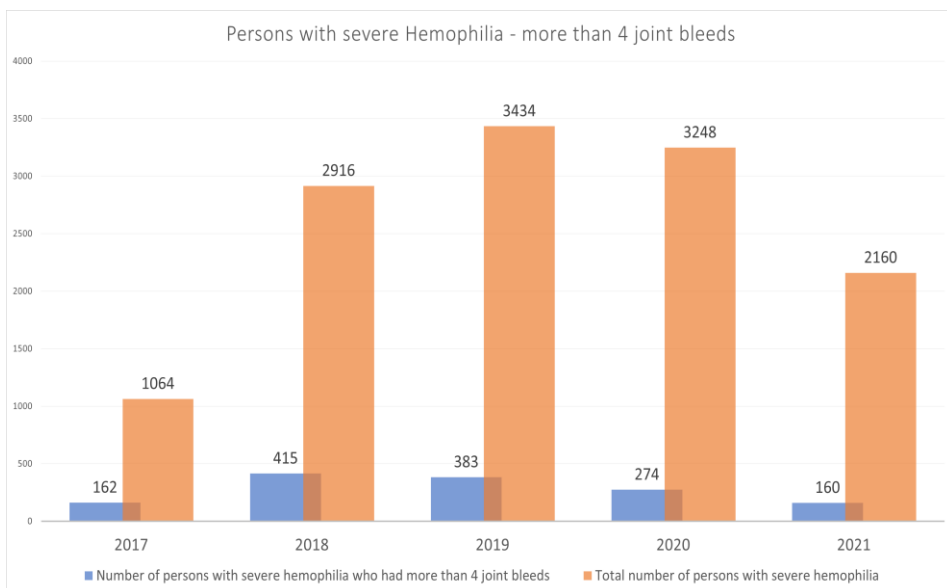
Baseline	16.9 percent of persons with severe hemophilia had more than 4 joint bleeds in 2016
Target	13.3 percent
Source	CDC Registry
Result	The proportion of people with severe hemophilia who had more than 4 joint bleeds dropped from 15.2 percent in 2017 to 7.4 percent across 125 HTC in 2021.

Data Year	2017	2018	2019	2020	2021
HTC responses	115	124	133	134	125

Total HTCs represented*: 140

*Data for this measure was not captured for all years for all HTCs. Example: HTC_XX provided data for 2017, 2019, 2020, and 2021. Data for 2018 was not provided.

	2017	2018	2019	2020	2021
Number of persons with severe hemophilia who had more than 4 joint bleeds	162	415	383	274	160
Total number of persons with severe hemophilia	1064	2916	3434	3248	2160
Proportion of population of persons with severe hemophilia who had more than four joint bleeds	0.152	0.142	0.112	0.084	0.074



HP2020 BLOOD DISORDER MEASURES

→ Increase the proportion of people with von Willebrand disease (VWD) seen in specialty care centers who were diagnosed by age 21 (BDBS-15)

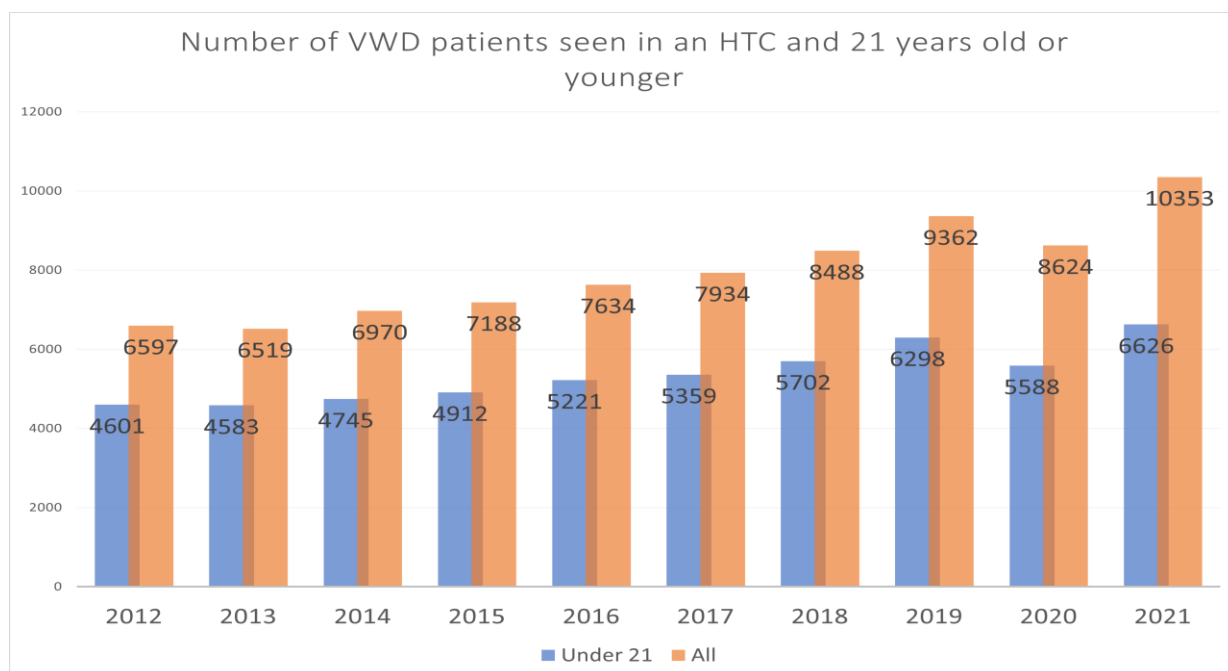
Baseline	69.7 percent (established using data from 2012)
Target	76.7 percent (established using standard 10 percent improvement)
Source	Population Profile
Result	6626 patients with von Willebrand Disease under the age of 21 were seen at specialty care clinics in 2021.

Data Year	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021
HTC responses	123	125	133	131	134	134	139	137	137	133

Total HTCs represented*: 147

*Data for this measure was not captured for all years for all HTCs. Example: HTC_XX provided data for 2017, 2019, 2020, and 2021. Data for 2018 was not provided.

	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021
Number of VWD patients seen in an HTC and 21 years old or younger	4601	4583	4745	4912	5221	5359	5702	6298	5588	6626
Total number of VWD patients seen	6597	6519	6970	7188	7634	7934	8488	9362	8624	10353



HP2020 BLOOD DISORDER MEASURES

→ Increase the proportion of patients who complete high school education or a General Education or Equivalency Diploma (GED) by 25 years of age (BDBS-8) **Archived in 2015 due to lack of viable data source*

Baseline: 79 percent

Target: 87 percent

Source: CDC Registry

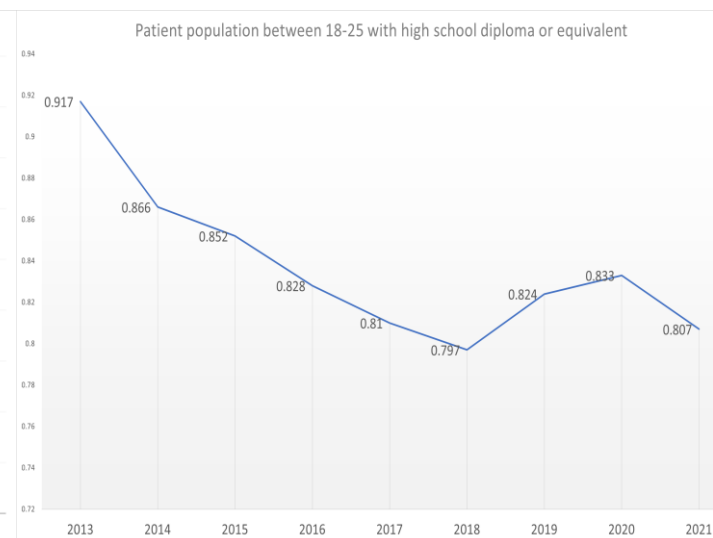
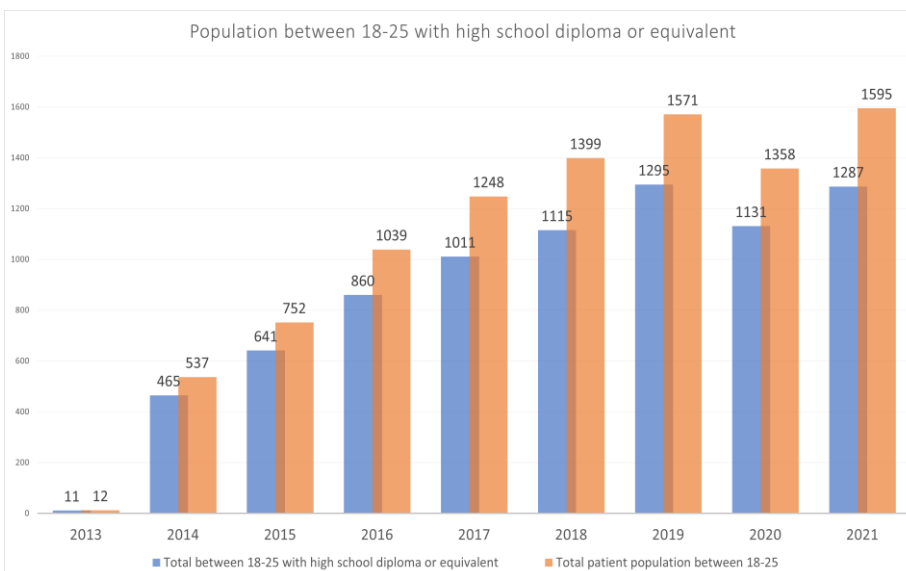
Result: 80.7 percent of eligible persons aged 18-25 completed high school education or equivalent in 2021.

Data Year	Missing	2013	2014	2015	2016	2017	2018	2019	2020	2021
HTC responses	4	5	69	99	119	122	127	130	123	110

Total HTCs represented*: 147

*Data for this measure was not captured for all years for all HTCs. Example: HTC_XX provided data for 2017, 2019, 2020, and 2021. Data for 2018 was not provided.

	Missing	2013	2014	2015	2016	2017	2018	2019	2020	2021
Total population between 18-25 with high school diploma or equivalent	--	11	465	641	860	1011	1115	1295	1131	1287
Total population between ages 18-25	--	12	537	752	1039	1248	1399	1571	1358	1595
Proportion of patient population between 18-25 with high school diploma or equivalent	--	0.917	0.866	0.852	0.828	0.810	0.797	0.824	0.833	0.807



HP2020 BLOOD DISORDER MEASURES

→ Decrease school absenteeism among adolescents due to illness or injury (AH-5.6)

Baseline	5.0 percent of adolescents aged 12-17 years missed 11 or more whole school days due to illness or injury in the previous 12 months, as reported in 2008
Target	3.6 percent
Source	CDC Registry
Result	Absenteeism was .9 percent in 2021.

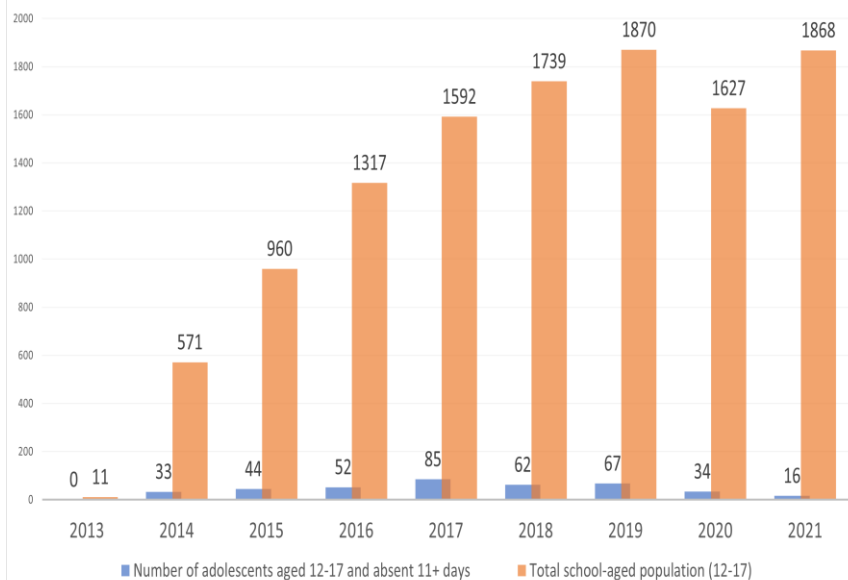
Data Year	Missing	2013	2014	2015	2016	2017	2018	2019	2020	2021
HTC responses	19	4	64	88	103	106	104	111	111	100

Total HTCs represented*: 147

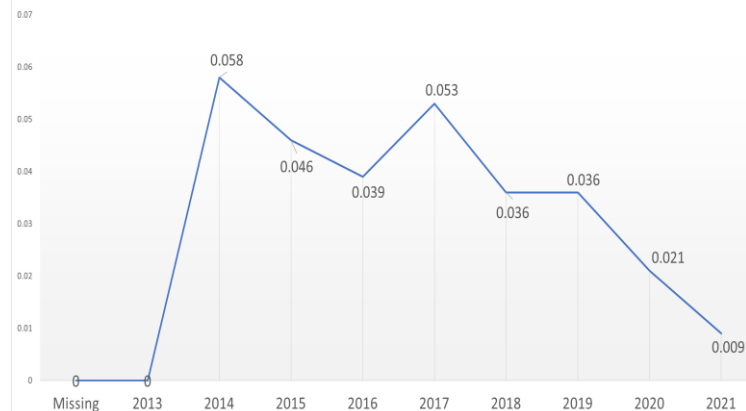
*Data for this measure was not captured for all years for all HTCs. Example: HTC_XX provided data for 2017, 2019, 2020, and 2021. Data for 2018 was not provided.

	Missing	2013	2014	2015	2016	2017	2018	2019	2020	2021
Number of adolescents aged 12-17 and absent 11+ days	--	0	33	44	52	85	62	67	34	16
Total school-aged population (12-17)	--	11	571	960	1317	1592	1739	1870	1627	1868
Proportion adolescents aged 12-17 years who missed 11 or more whole school days	--	--	0.058	0.046	0.039	0.053	0.036	0.036	0.021	0.009

Adolescents aged 12-17 who missed 11+ whole school days



Proportion of adolescents aged 12-17 years who missed 11 or more whole school days



APPENDIX

1. **BDBS-01 (now BDBS-16) Data Details (healthypeople.gov)**
2. **BDBS-15 Data Details (healthypeople.gov)**
3. **BDBS-8 Data Details (healthypeople.gov)**
4. **AH-5.6 Data Details (healthypeople.gov)**
5. **Healthy People 2020 Midcourse Review (HRSA, NIH)**
6. **Community Counts 2020 Infographic (ATHN)**
7. **Healthy People 2020 Indicators and Baseline Measurements for the National Hemophilia Program and Regional Networks based on Community Counts (Jan 2021, NHPCC)**



