Community Counts

The HTC Population Profile

The HTC Population Profile is a set of twelve data items collected on patients with bleeding disorders or venous thromboembolism. These patients receive care at Hemophilia Treatment Centers (HTCs) that are part of the US Hemophilia Treatment Center Network (USHTCN), a network of 135 HTCs located throughout the United States and its territories. The HTCs practice a model of care delivery called comprehensive (integrated) care. This care includes specialized prevention, diagnostic, and treatment programs. It also includes family-centered education, research, and support services for patients and families living with bleeding disorders. Congress provides support to the HTCs through the Health Resources and Services Administration and the Centers for Disease Control and Prevention (CDC). CDC sponsors Community Counts, a project with the American Thrombosis & Hemostasis Network and the USHTCN that monitors the complications of bleeding disorders. USHTCN centers that participate in the Community Counts project collect data on common health issues, medical complications, and causes of death that affect people with bleeding disorders.

National Center on Birth Defects and Developmental Disabilities
Division of Blood Disorders

The twelve items collected are:

1. Year of birth

2. Sex

3. Ethnicity

4. Race

5. Three-digit zip code of residence

6. Insurance status

7. Primary bleeding disorder diagnosis

8. Baseline factor activity

9. Von Willebrand factory activity (VWF:RCof)

10. Von Willebrand factor antigen level (VWF:Ag)

11. Hepatitis C (HCV) infection status

12. Human immunodeficiency virus (HIV) infection status

Data for the HTC Population Profile component of the Community Counts project are collected as a de-identified data set that is compliant with the Health Insurance Portability and Accountability Act (HIPPA). Authorization from patients for data collection is sought according to the institutional policies of the participating HTCs. HTCs report on patients 89 years of age or younger who receive care either in person or by telemedicine. The data are collected on a calendar-year basis. Most data for a given year are reported by February of the following year, but some records may be received later.

The HTCs began collecting data for the HTC Population Profile in 2012. As of June 30, 2016, 135 individual HTCs have contributed data over time; of these, 113 HTCs have provided data for all five years (2012-2016). The data in these reports are subject to revision.

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HTC Population Profile Patient Characteristics by Calendar Year, data reported from 1/1/2012 through 6/30/2016

		2012	2013	2014	2015	2016	Unique patients[1]	Multi-year patients[2]
		#	#	#	#	#	#	#
	# of HTCs contributing data	125	129**	132	134	122		
	# of patients	25294	26646	29769	29813	9502	58114	31863
Age (years)	**<2**	803	858	1037	1063	309	1974	403
	2–10	5689	5744	6140	6032	2012	10649	6352
	11–19	7025	7356	8056	7949	2491	15664	9200
	20–44	6967	7195	8224	8317	2653	16704	9392
	45–64	3535	3928	4491	4545	1400	9098	4548
	65+	1275	1565	1821	1907	637	4025	1968
Sex†	**Male**	16828	17326	19142	19099	6249	33815	21097
	Female	8466	9320	10627	10714	3253	24299	10766
Ethnicity	**Hispanic, Latino/a, or Spanish origin**	3707	3763	4323	4149	1425	7867	4657
	Not Hispanic, Latino/a, or Spanish origin	21382	22630	25068	25065	7925	49414	26910
	Unknown	205	253	378	599	152	833	296
Race	**American Indian/Alaska Native**	179	170	188	231	94	381	220
	Asian	698	747	883	921	273	1565	958
	Black or African American	2896	3055	3543	3573	1270	6689	3769
	Native Hawaiian or other Pacific Islander	115	94	106	112	18	192	121
	White	21219	22228	24325	24029	7501	47785	26152
	More than one of these	83	144	205	298	140	469	316
	Unknown	104	208	519	649	206	1033	327
Insurance status	**Insured**	23975	25522	28600	28778	9166	55992	30742
	Uninsured	921	899	954	842	263	1674	910
	Unknown	398	225	215	193	73	448	211
Diagnosis	**Blood coagulation disorder without specific diagnosis**	186	305	281	252	60	813	181
	Ehlers-Danlos syndrome	45	44	57	49	7	131	46
	Factor I, hereditary	56	76	73	80	24	163	86
	Factor II, hereditary	18	14	18	17	5	41	18
	Factor V, hereditary	97	108	117	109	28	296	89
	Factor VII, hereditary	458	473	493	519	132	1167	533
	Factor VIII, hereditary	9398	9281	10230	10010	3571	15474	11707
	Factor IX, hereditary	2828	2806	3167	3053	1009	4857	3564
	Factor X, hereditary	68	59	68	66	20	139	66
	Factor XI, hereditary	268	249	308	317	86	745	284
	Factor XIII, hereditary	71	84	99	100	37	153	101
	Factors V & VIII, combined	*	*	*	*	*	14	*
	Alpha-2 antiplasmin deficiency	*	*	*	*	*	5	*
	Platelet function disorder	1494	1612	1841	1902	587	4173	2084
	PAI-1 deficiency	106	83	52	58	40	213	69
	Thrombocytopenia, hereditary	133	113	108	139	27	347	104
	Venous thromboembolism (VTE)	3515	4847	5957	6319	1842	14461	4967
	Von Willebrand disease, type 1	5153	5072	5246	5098	1490	11702	6168
	Von Willebrand disease, type 1C	10	15	23	34	7	48	30
	Von Willebrand disease, type 2A	323	333	340	361	126	673	424
	Von Willebrand disease, type 2B	195	192	212	212	80	402	250
	Von Willebrand disease, type 2M	150	170	204	204	82	337	244
	Von Willebrand disease, type 2N	34	45	52	51	16	101	58
	Von Willebrand disease, type 2, type unknown	83	114	160	179	59	333	189
	Von Willebrand disease, type 3	230	231	247	253	82	359	280
	Von Willebrand disease, unknown	321	281	367	378	78	859	270
	Von Willebrand disease, type other	43	30	39	43	7	108	36
History of HCV infection	**Yes**	3013	2882	3159	3106	1076	4673	3724
	No	14545	14078	15625	15758	5095	28987	18252
	Unknown	4221	4839	5028	4630	1489	9993	4920
	Not Applicable‡	3515	4847	5957	6319	1842	14461	4967
History of HIV infection	**Yes**	931	880	961	928	320	1388	1126
	No	16324	15707	17472	17719	5751	31833	20556
	Unknown	4524	5212	5379	4847	1589	10432	5214
	Not Applicable‡	3515	4847	5957	6319	1842	14461	4967

[1] “Unique patients” is the total number of individual patients reported by the HTCs since January 2012. This includes individuals reported in only a single calendar year, as well as those reported in more than one calendar year. Individuals reported in more than one calendar year were counted only once in this column.

[2] “Multi-year patients” is the total number of individual patients who were reported by the HTCs in more than one calendar year since January 2012. Patients reported in only a single calendar year are not included in this count.

†The HTC Population Profile contains nineteen transsexual individuals. For confidentiality purposes, the number of transsexual patients is too small to report by year or other characteristics. Transsexual patients have been included in the counts of male and female according to the sex assigned to them at birth since hemophilia and von Willebrand disease, the most common congenital bleeding disorders, affect the sexes differently.

*Except for cells in which the value of the descriptor is “unknown,” counts greater than zero but less than five have been suppressed to protect patient confidentiality. Additional cells may be suppressed to prevent derivation of these counts by subtraction.*Except for cells in which the value of the descriptor is “unknown”, counts greater than zero but less than five have been suppressed to protect patient confidentiality. Additional cells may be suppressed to prevent derivation of these counts by subtraction.

‡HCV and HIV status are not recorded for VTE patients.

**The number of HTCs contributing data for 2013 includes six HTCs that did not contribute data for 2012; two HTCs that contributed data for 2012 did not contribute data for 2013.

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HTC Population Profile Patient Characteristics, Factor VIII and Factor IX, data reported from 1/1/2012 through 6/30/2016

		Factor VIII (n=15474)								Factor IX (n=4857)							
		Mild		Moderate		Severe		Severity Unknown		Mild		Moderate		Severe		Severity Unknown	
		#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)
	# of patients	5082	(100)	2711	(100)	7514	(100)	167	(100)	1636	(100)	1832	(100)	1334	(100)	55	(100)
Age (years)	<2	98	(2)	94	(3)	194	(3)	11	(7)	45	(3)	48	(3)	52	(4)	6	(11)
	2–10	900	(18)	566	(21)	1634	(22)	24	(14)	303	(19)	383	(21)	265	(20)	11	(20)
	11–19	1185	(23)	631	(23)	1721	(23)	24	(14)	361	(22)	437	(24)	251	(19)	11	(20)
	20–44	1603	(32)	911	(34)	3049	(41)	78	(47)	518	(32)	557	(30)	532	(40)	16	(29)
	45–64	868	(17)	372	(14)	780	(10)	20	(12)	277	(17)	293	(16)	185	(14)	10	(18)
	65+	428	(8)	137	(5)	136	(2)	10	(6)	132	(8)	114	(6)	49	(4)	1	(2)
Sex[†]	Male	4087	(80)	2669	(98)	7481	(100)	95	(57)	1198	(73)	1818	(99)	1329	(100)	40	(73)
	Female	995	(20)	42	(2)	33	(0)	72	(43)	438	(27)	14	(1)	5	(0)	15	(27)
Ethnicity	Hispanic, Latino/a, or Spanish origin	930	(18)	537	(20)	1225	(16)	40	(24)	118	(7)	119	(6)	230	(17)	8	(15)
	Not Hispanic, Latino/a, or Spanish origin	4103	(81)	2163	(80)	6260	(83)	125	(75)	1454	(89)	1702	(93)	1098	(82)	46	(84)
	Unknown	49	(1)	11	(0)	29	(0)	2	(1)	64	(4)	11	(1)	6	(0)	1	(2)
Race	American Indian/Alaska Native	94	(2)	27	(1)	54	(1)	5	(3)	*		19	(1)	13	(1)	1	(2)
	Asian	116	(2)	104	(4)	353	(5)	9	(5)	26	(2)	19	(1)	66	(5)	0	(0)
	Black or African American	303	(6)	367	(14)	1177	(16)	18	(11)	147	(9)	72	(4)	197	(15)	3	(5)
	Native Hawaiian or other Pacific Islander	5	(0)	13	(0)	41	(1)	2	(1)	*		12	(1)	10	(1)	0	(0)
	White	4428	(87)	2125	(78)	5730	(76)	128	(77)	1418	(87)	1693	(92)	1022	(77)	49	(89)
	More than one of these	50	(1)	32	(1)	90	(1)	1	(1)	*		6	(0)	14	(1)	1	(2)
	Unknown	86	(2)	43	(2)	69	(1)	4	(2)	35	(2)	11	(1)	12	(1)	1	(2)
Insurance status	Insured	4880	(96)	2618	(97)	7277	(97)	145	(87)	1402	(86)	1485	(81)	1297	(97)	43	(78)
	Uninsured	163	(3)	85	(3)	197	(3)	15	(9)	178	(11)	338	(18)	29	(2)	9	(16)
	Unknown	39	(1)	8	(0)	40	(1)	7	(4)	56	(3)	9	(0)	8	(1)	3	(5)
History of HCV infection	Yes	687	(14)	591	(22)	2033	(27)	17	(10)	162	(10)	315	(17)	452	(34)	6	(11)
	No	3646	(72)	1892	(70)	4850	(65)	93	(56)	1132	(69)	1214	(66)	760	(57)	26	(47)
	Unknown	749	(15)	228	(8)	631	(8)	57	(34)	342	(21)	303	(17)	122	(9)	23	(42)
History of HIV infection	Yes	105	(2)	168	(6)	858	(11)	7	(4)	17	(1)	40	(2)	120	(9)	0	(0)
	No	4155	(82)	2287	(84)	5954	(79)	101	(60)	1253	(77)	1448	(79)	1078	(81)	32	(58)
	Unknown	822	(16)	256	(9)	702	(9)	59	(35)	366	(22)	344	(19)	136	(10)	23	(42)

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HTC Population Profile Patient Characteristics, von Willebrand Disease (VWD), data reported from 1/1/2012 through 6/30/2016

		VWD (n=14922)							
		Type 1		Type 2		Type 3		Type other and Type unknown	
		#	(%)	#	(%)	#	(%)	#	(%)
	# of patients	11750	(100)	1846	(100)	359	(100)	967	(100)
Age (years)	<2	99	(1)	22	(1)	*		23	(2)
	2–10	2709	(23)	435	(24)	65	(18)	239	(25)
	11–19	4787	(41)	527	(29)	73	(20)	313	(32)
	20–44	2872	(24)	483	(26)	129	(36)	215	(22)
	45–64	965	(8)	240	(13)	71	(20)	107	(11)
	65+	318	(3)	139	(8)	*		70	(7)
Sex[†]	Male	4118	(35)	795	(43)	180	(50)	326	(34)
	Female	7632	(65)	1051	(57)	179	(50)	641	(66)
Ethnicity	Hispanic, Latino/a, or Spanish origin	1834	(16)	228	(12)	30	(8)	152	(16)
	Not Hispanic, Latino/a, or Spanish origin	9790	(83)	1521	(82)	328	(91)	776	(80)
	Unknown	126	(1)	97	(5)	1	(0)	39	(4)
Race	American Indian/Alaska Native	68	(1)	13	(1)	*		3	(0)
	Asian	272	(2)	55	(3)	19	(5)	22	(2)
	Black or African American	832	(7)	156	(8)	24	(7)	87	(9)
	Native Hawaiian or other Pacific Islander	51	(0)	8	(0)	*		0	(0)
	White	10218	(87)	1541	(83)	308	(86)	809	(84)
	More than one of these	92	(1)	14	(1)	*		7	(1)
	Unknown	217	(2)	59	(3)	0	(0)	39	(4)
Insurance status	Insured	11458	(98)	1687	(91)	347	(97)	931	(96)
	Uninsured	201	(2)	101	(5)	8	(2)	19	(2)
	Unknown	91	(1)	58	(3)	4	(1)	17	(2)
History of HCV infection	Yes	102	(1)	76	(4)	87	(24)	12	(1)
	No	7997	(68)	1303	(71)	240	(67)	648	(67)
	Unknown	3651	(31)	467	(25)	32	(9)	307	(32)
History of HIV infection	Yes	25	(0)	8	(0)	8	(2)	2	(0)
	No	7934	(68)	1354	(73)	313	(87)	655	(68)
	Unknown	3791	(32)	484	(26)	38	(11)	310	(32)

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HTC Population Profile Patient Characteristics, Rare Factor Deficiencies (excluding Factor VIII and Factor IX), data reported from 1/1/2012 through 6/30/2016

		FI		FII		FV		Factors V & VIII, combined		FVII		FX		FXI		FXIII		Alpha-2 Antiplasmin Deficiency		PAI-1 Deficiency	
		#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)
	# of patients	163	(100)	41	(100)	296	(100)	14	(100)	1167	(100)	139	(100)	745	(100)	153	(100)	5	(100)	213	(100)
Age (years)	**<2**	6	(4)	*		6	(2)	*		18	(2)	*		24	(3)	7	(5)	*		6	(3)
	2–10	46	(28)	10	(24)	41	(14)	*		381	(33)	30	(22)	127	(17)	28	(18)	*		52	(24)
	11–19	44	(27)	16	(39)	90	(30)	*		448	(38)	43	(31)	216	(29)	32	(21)	*		92	(43)
	20–44	46	(28)	9	(22)	108	(36)	6	(43)	223	(19)	38	(27)	181	(24)	64	(42)	*		40	(19)
	45–64	15	(9)	*		36	(12)	*		68	(6)	19	(14)	110	(15)	16	(10)	*		15	(7)
	65+	6	(4)	*		15	(5)	*		29	(2)	*		87	(12)	6	(4)	*		8	(4)
Sex[†]	**Male**	71	(44)	21	(51)	118	(40)	7	(50)	578	(50)	59	(42)	354	(48)	79	(52)	*		79	(37)
	Female	92	(56)	20	(49)	178	(60)	7	(50)	589	(50)	80	(58)	391	(52)	74	(48)	*		134	(63)
Ethnicity	**Hispanic, Latino/a, or Spanish origin**	21	(13)	13	(32)	47	(16)	0	(0)	253	(22)	37	(27)	86	(12)	26	(17)	*		34	(16)
	Not Hispanic, Latino/a, or Spanish origin	141	(87)	28	(68)	244	(82)	14	(100)	898	(77)	100	(72)	655	(88)	127	(83)	*		177	(83)
	Unknown	1	(1)	0	(0)	5	(2)	0	(0)	16	(1)	2	(1)	4	(1)	0	(0)	*		2	(1)
Race	**American Indian/Alaska Native**	*		*		0	(0)	0	(0)	8	(1)	0	(0)	0	(0)	*		0	(0)	0	(0)
	Asian	*		*		6	(2)	*		31	(3)	10	(7)	32	(4)	15	(10)	*		*	
	Black or African American	7	(4)	*		13	(4)	*		234	(20)	20	(14)	41	(6)	18	(12)	0	(0)	19	(9)
	Native Hawaiian or other Pacific Islander	0	(0)	0	(0)	0	(0)	0	(0)	*		0	(0)	0	(0)	*		0	(0)	*	
	White	138	(85)	35	(85)	270	(91)	10	(71)	843	(72)	101	(73)	659	(88)	114	(75)	*		180	(85)
	More than one of these	*		*		*		0	(0)	*		*		*		*		0	(0)	*	
	Unknown	9	(6)	1	(2)	*		*		40	(3)	*		*		*		0	(0)	4	(2)
Insurance status	**Insured**	156	(96)	39	(95)	290	(98)	13	(93)	1142	(98)	138	(99)	735	(99)	151	(99)	5	(100)	194	(91)
	Uninsured	5	(3)	*		*		*		15	(1)	*		7	(1)	*		0	(0)	11	(5)
	Unknown	2	(1)	*		*		*		10	(1)	*		3	(0)	*		0	(0)	8	(4)
History of HCV infection	**Yes**	6	(4)	5	(12)	6	(2)	*		17	(1)	8	(6)	25	(3)	9	(6)	*		0	(0)
	No	99	(61)	31	(76)	208	(70)	12	(86)	807	(69)	103	(74)	542	(73)	118	(77)	*		120	(56)
	Unknown	58	(36)	5	(12)	82	(28)	*		343	(29)	28	(20)	178	(24)	26	(17)	*		93	(44)

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