

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.

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 factor 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 twelve items collected are 1) year of birth, 2) sex, 3) ethnicity, 4) race, 5) 3-digit zip code of residence, 6) insurance status, 7) primary bleeding disorder diagnosis, 8) baseline factor activity, 9) von Willebrand factor activity (vWF:RCof), 10) von Willebrand factor antigen level (vWF:Ag), 11) hepatitis C (HCV) infection status, and 12) human immunodeficiency virus (HIV) infection status. 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 March 31, 2016, 135 individual HTCs have contributed data over time. One hundred and eight 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 3/31/2016

	2012	2013	2014	2015	2016	Unique patients ¹	Multi-year patients ²	
	#	#	#	#	#	#	#	
	# of HTC's contributing data	125	129**	132	134	115		
	# of patients	25286	26617	29698	29200	5004	56879	30852
Age (years)	<2	802	857	1037	1034	153	1929	374
	2-10	5685	5738	6122	5870	1074	10437	6221
	11-19	7024	7352	8037	7762	1320	15334	8937
	20-44	6967	7189	8211	8179	1380	16333	9047
	45-64	3535	3919	4482	4473	738	8933	4403
	65+	1273	1562	1809	1882	339	3913	1870
Sex [†]	Male	16823	17313	19095	18667	3233	33163	20533
	Female	8463	9304	10603	10533	1771	23716	10319
Ethnicity	Hispanic, Latino/a, or Spanish origin	3705	3759	4307	4016	716	7674	4490
	Not Hispanic, Latino/a, or Spanish origin	21376	22605	25013	24601	4180	48388	26061
	Unknown	205	253	378	583	108	817	301
Race	American Indian/Alaska Native	178	168	187	221	51	361	213
	Asian	698	747	879	871	135	1510	919
	Black or African American	2895	3048	3533	3540	667	6571	3656
	Native Hawaiian or other Pacific Islander	115	94	105	110	10	192	120
	White	21213	22208	24271	23532	3957	46825	25343
	More than one of these	83	144	205	297	83	453	303
	Unknown	104	208	518	629	101	967	298
Insurance status	Insured	23967	25493	28531	28189	4784	54757	29727
	Uninsured	921	899	953	826	163	1669	909
	Unknown	398	225	214	185	57	453	216
Diagnosis	Blood coagulation disorder without specific diagnosis	185	304	280	233	29	787	167
	Ehlers-Danlos syndrome	45	44	57	48	5	130	44
	Factor I, hereditary	56	76	73	79	13	159	85
	Factor II, hereditary	18	14	18	16	*	39	17
	Factor V, hereditary	97	107	114	105	11	288	83
	Factor VII, hereditary	458	472	491	500	59	1136	505
	Factor VIII, hereditary	9397	9276	10205	9762	1842	15223	11467
	Factor IX, hereditary	2828	2805	3161	2995	553	4787	3482
	Factor X, hereditary	68	59	68	65	10	136	63
	Factor XI, hereditary	267	248	306	308	41	733	267
	Factor XIII, hereditary	71	84	99	97	19	148	98
	Factors V & VIII, combined	*	*	*	*	*	14	*
	Alpha-2 antiplasmin deficiency	*	*	*	*	*	5	*
	Platelet function disorder	1493	1609	1836	1858	289	4063	1995
	PAI-1 deficiency	106	82	51	57	20	204	63
	Thrombocytopenia, hereditary	133	113	107	135	14	340	97
	Venous thromboembolism (VTE)	3513	4835	5940	6254	1001	14050	4738
	Von Willebrand disease, type 1	5152	5071	5242	5007	793	11474	5955
	Von Willebrand disease, type 1C	10	15	23	34	6	48	30
	Von Willebrand disease, type 2A	323	333	340	348	63	648	401
	Von Willebrand disease, type 2B	195	192	212	202	45	391	239
	Von Willebrand disease, type 2M	150	170	204	201	46	333	236
	Von Willebrand disease, type 2N	34	44	51	49	9	98	54
Von Willebrand disease, type 2, type unknown	83	114	159	175	35	326	183	
Von Willebrand disease, type 3	229	230	245	247	42	355	269	
Von Willebrand disease, unknown	321	281	367	373	50	854	264	
Von Willebrand disease, type other	43	30	39	42	7	110	35	
History of HCV infection	Yes	3012	2880	3152	3052	538	4623	3654
	No	14589	14130	15634	15400	2661	28515	17724
	Unknown	4172	4772	4972	4494	804	9691	4736
	Not Applicable [‡]	3513	4835	5940	6254	1001	14050	4738
History of HIV infection	Yes	931	880	961	911	160	1370	1113
	No	16367	15757	17475	17328	2983	31325	19976
	Unknown	4475	5145	5322	4707	860	10134	5025
	Not Applicable [‡]	3513	4835	5940	6254	1001	14050	4738

¹"Unique patients" is the total number of individual patients reported by the HTC's 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 HTC's 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.

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

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

HTC Population Profile Patient Characteristics, Factor VIII and Factor IX, data reported from 1/1/2012 through 3/31/2016

		Factor VIII (n=15223)				Factor IX (n=4787)											
		Mild		Moderate		Severe		Severity Unknown		Mild		Moderate		Severe		Severity Unknown	
		#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)
	# of patients	4977	(100)	2684	(100)	7394	(100)	168	(100)	1611	(100)	1802	(100)	1319	(100)	55	(100)
Age (years)	<2	101	(2)	93	(3)	201	(3)	10	(6)	46	(3)	45	(2)	53	(4)	7	(13)
	2-10	879	(18)	568	(21)	1593	(22)	25	(15)	300	(19)	380	(21)	263	(20)	11	(20)
	11-19	1162	(23)	632	(24)	1697	(23)	24	(14)	351	(22)	425	(24)	247	(19)	11	(20)
	20-44	1569	(32)	899	(33)	3001	(41)	78	(46)	504	(31)	554	(31)	525	(40)	15	(27)
	45-64	851	(17)	359	(13)	770	(10)	22	(13)	279	(17)	286	(16)	184	(14)	10	(18)
	65+	415	(8)	133	(5)	132	(2)	9	(5)	131	(8)	112	(6)	47	(4)	1	(2)
Sex ¹	Male	4017	(81)	2641	(98)	7364	(100)	96	(57)	1181	(73)	1788	(99)	**		40	(73)
	Female	960	(19)	43	(2)	30	(0)	72	(43)	430	(27)	14	(1)	**		15	(27)
Ethnicity	Hispanic, Latino/a, or Spanish origin	915	(18)	540	(20)	1181	(16)	42	(25)	120	(7)	115	(6)	230	(17)	8	(15)
	Not Hispanic, Latino/a, or Spanish origin	4016	(81)	2135	(80)	6186	(84)	124	(74)	1425	(88)	1676	(93)	1084	(82)	45	(82)
	Unknown	46	(1)	9	(0)	27	(0)	2	(1)	66	(4)	11	(1)	5	(0)	2	(4)
Race	American Indian/Alaska Native	87	(2)	26	(1)	53	(1)	5	(3)	*		19	(1)	12	(1)	1	(2)
	Asian	111	(2)	97	(4)	341	(5)	9	(5)	26	(2)	19	(1)	64	(5)	0	(0)
	Black or African American	296	(6)	359	(13)	1172	(16)	18	(11)	147	(9)	70	(4)	194	(15)	3	(5)
	Native Hawaiian or other Pacific Islander	5	(0)	13	(0)	41	(1)	2	(1)	*		12	(1)	10	(1)	0	(0)
	White	4352	(87)	2114	(79)	5643	(76)	128	(76)	1394	(87)	1665	(92)	1015	(77)	48	(87)
	More than one of these	47	(1)	33	(1)	86	(1)	1	(1)	*		6	(0)	14	(1)	1	(2)
	Unknown	79	(2)	42	(2)	58	(1)	5	(3)	34	(2)	11	(1)	10	(1)	2	(4)
Insurance status	Insured	4783	(96)	2588	(96)	7149	(97)	145	(86)	1380	(86)	1455	(81)	1281	(97)	43	(78)
	Uninsured	156	(3)	88	(3)	204	(3)	16	(10)	176	(11)	337	(19)	30	(2)	9	(16)
	Unknown	38	(1)	8	(0)	41	(1)	7	(4)	55	(3)	10	(1)	8	(1)	3	(5)
History of HCV infection	Yes	679	(14)	578	(22)	2020	(27)	18	(11)	161	(10)	312	(17)	449	(34)	6	(11)
	No	3582	(72)	1900	(71)	4782	(65)	97	(58)	1111	(69)	1199	(67)	752	(57)	28	(51)
	Unknown	716	(14)	206	(8)	592	(8)	53	(32)	339	(21)	291	(16)	118	(9)	21	(38)
History of HIV infection	Yes	100	(2)	165	(6)	849	(11)	8	(5)	17	(1)	42	(2)	118	(9)	0	(0)
	No	4090	(82)	2286	(85)	5882	(80)	105	(63)	1231	(76)	1428	(79)	1069	(81)	34	(62)
	Unknown	787	(16)	233	(9)	663	(9)	55	(33)	363	(23)	332	(18)	132	(10)	21	(38)

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HTC Population Profile Patient Characteristics, von Willebrand Disease (VWD), data reported from 1/1/2012 through 3/31/2016

		VWD (n=14637)							
		Type 1		Type 2		Type 3		Type other and Type unknown	
		#	(%)	#	(%)	#	(%)	#	(%)
	# of patients	11522	(100)	1796	(100)	355	(100)	964	(100)
Age (years)	<2	98	(1)	26	(1)	*		22	(2)
	2–10	2660	(23)	426	(24)	62	(17)	242	(25)
	11–19	4704	(41)	506	(28)	73	(21)	316	(33)
	20–44	2798	(24)	473	(26)	129	(36)	213	(22)
	45–64	954	(8)	231	(13)	69	(19)	103	(11)
	65+	308	(3)	134	(7)	*		68	(7)
Sex ¹	Male	4030	(35)	776	(43)	178	(50)	327	(34)
	Female	7492	(65)	1020	(57)	177	(50)	637	(66)
Ethnicity	Hispanic, Latino/a, or Spanish origin	1785	(15)	221	(12)	29	(8)	152	(16)
	Not Hispanic, Latino/a, or Spanish origin	9612	(83)	1470	(82)	325	(92)	776	(80)
	Unknown	125	(1)	105	(6)	1	(0)	36	(4)
Race	American Indian/Alaska Native	67	(1)	11	(1)	*		3	(0)
	Asian	267	(2)	54	(3)	17	(5)	21	(2)
	Black or African American	825	(7)	151	(8)	24	(7)	87	(9)
	Native Hawaiian or other Pacific Islander	51	(0)	8	(0)	*		0	(0)
	White	10017	(87)	1496	(83)	307	(86)	807	(84)
	More than one of these	88	(1)	14	(1)	*		7	(1)
	Unknown	207	(2)	62	(3)	0	(0)	39	(4)
Insurance status	Insured	11226	(97)	1636	(91)	343	(97)	929	(96)
	Uninsured	206	(2)	97	(5)	8	(2)	19	(2)
	Unknown	90	(1)	63	(4)	4	(1)	16	(2)
History of HCV infection	Yes	101	(1)	76	(4)	85	(24)	11	(1)
	No	7893	(69)	1267	(71)	237	(67)	647	(67)
	Unknown	3528	(31)	453	(25)	33	(9)	306	(32)
History of HIV infection	Yes	25	(0)	8	(0)	7	(2)	2	(0)
	No	7828	(68)	1314	(73)	311	(88)	654	(68)
	Unknown	3669	(32)	474	(26)	37	(10)	308	(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 3/31/2016

	# of patients	FI	FII	FV	Factors V & VIII, combined	FVII	FX	FXI	FXIII	Alpha-2 Antiplasmin Deficiency	PAI-1 Deficiency
		# (%)	# (%)	# (%)	# (%)	# (%)	# (%)	# (%)	# (%)	# (%)	# (%)
	# of patients	159 (100)	39 (100)	288 (100)	14 (100)	1136 (100)	136 (100)	733 (100)	148 (100)	5 (100)	204 (100)
Age (years)	<2	6 (4)	*	6 (2)	*	19 (2)	*	25 (3)	6 (4)	*	5 (2)
	2-10	46 (29)	11 (28)	42 (15)	*	372 (33)	31 (23)	125 (17)	27 (18)	*	54 (26)
	11-19	44 (28)	14 (36)	87 (30)	*	439 (39)	42 (31)	217 (30)	31 (21)	*	90 (44)
	20-44	44 (28)	9 (23)	103 (36)	6 (43)	211 (19)	36 (26)	175 (24)	63 (43)	*	35 (17)
	45-64	14 (9)	*	36 (13)	*	67 (6)	19 (14)	108 (15)	16 (11)	*	14 (7)
	65+	5 (3)	*	14 (5)	*	28 (2)	*	83 (11)	5 (3)	*	6 (3)
Sex†	Male	69 (43)	19 (49)	117 (41)	7 (50)	558 (49)	58 (43)	349 (48)	76 (51)	*	74 (36)
	Female	90 (57)	20 (51)	171 (59)	7 (50)	578 (51)	78 (57)	384 (52)	72 (49)	*	130 (64)
Ethnicity	Hispanic, Latino/a, or Spanish origin	21 (13)	13 (33)	47 (16)	0 (0)	249 (22)	36 (26)	84 (11)	25 (17)	*	32 (16)
	Not Hispanic, Latino/a, or Spanish origin	137 (86)	26 (67)	236 (82)	14 (100)	871 (77)	98 (72)	645 (88)	123 (83)	*	167 (82)
	Unknown	1 (1)	0 (0)	5 (2)	0 (0)	16 (1)	2 (1)	4 (1)	0 (0)	*	5 (2)
Race	American Indian/Alaska Native	*	*	0 (0)	0 (0)	8 (1)	0 (0)	0 (0)	*	0 (0)	0 (0)
	Asian	*	*	5 (2)	*	27 (2)	10 (7)	31 (4)	15 (10)	*	*
	Black or African American	7 (4)	*	12 (4)	*	226 (20)	20 (15)	39 (5)	18 (12)	0 (0)	18 (9)
	Native Hawaiian or other Pacific Islander	0 (0)	0 (0)	0 (0)	0 (0)	*	0 (0)	0 (0)	*	0 (0)	*
	White	134 (84)	33 (85)	264 (92)	10 (71)	825 (73)	98 (72)	652 (89)	109 (74)	*	171 (84)
	More than one of these	*	*	*	0 (0)	*	*	*	*	0 (0)	*
	Unknown	9 (6)	1 (3)	*	*	39 (3)	*	*	*	0 (0)	5 (2)
Insurance status	Insured	153 (96)	37 (95)	282 (98)	13 (93)	1112 (98)	135 (99)	724 (99)	146 (99)	5 (100)	183 (90)
	Uninsured	5 (3)	*	*	*	14 (1)	*	6 (1)	*	0 (0)	11 (5)
	Unknown	1 (1)	*	*	*	10 (1)	*	3 (0)	*	0 (0)	10 (5)
History of HCV infection	Yes	6 (4)	*	5 (2)	*	17 (1)	8 (6)	24 (3)	9 (6)	*	0 (0)
	No	96 (60)	30 (77)	203 (70)	12 (86)	792 (70)	100 (74)	533 (73)	115 (78)	*	123 (60)
	Unknown	57 (36)	*	80 (28)	*	327 (29)	28 (21)	176 (24)	24 (16)	*	81 (40)

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