

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 136 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.

Data for the [HTC Population Profile](#) component of the Community Counts project are collected as a de-identified data set, meaning that the person's identity cannot be connected with the information because personal identifiers, such as name, address, and birthdate, have been removed. This 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 December 31, 2016, 136 individual HTCs have contributed data over time. One hundred and twenty-one 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 12/31/2016

		2012	2013	2014	2015	2016	Unique patients ¹	Multi-year patients ²
		#	#	#	#	#	#	#
	# of HTC's contributing data	125	130**	132	134	132***		
	# of patients	25340	26688	29868	30785	25173	62842	34766
Age (years)	<2	804	859	1041	1103	848	2282	423
	2-10	5695	5751	6154	6274	5070	11245	6748
	11-19	7035	7360	8077	8267	7021	16927	10114
	20-44	6982	7205	8253	8554	6951	18056	10341
	45-64	3545	3941	4511	4632	3632	9893	4946
	65+	1279	1572	1832	1955	1651	4439	2194
Sex†	Male	16854	17351	19194	19721	16124	36067	22703
	Female	8486	9337	10674	11064	9049	26775	12063
Ethnicity	Hispanic, Latino/a, or Spanish origin	3713	3767	4340	4490	3817	8649	5158
	Not Hispanic, Latino/a, or Spanish origin	21422	22668	25150	25687	21000	53294	29317
	Unknown	205	253	378	608	356	899	291
Race	American Indian/Alaska Native	179	170	189	235	207	419	245
	Asian	703	747	886	964	770	1704	1044
	Black or African American	2904	3060	3553	3648	2959	7222	4053
	Native Hawaiian or other Pacific Islander	115	94	106	126	89	216	136
	White	21252	22265	24410	24806	20216	51432	28526
	More than one of these	83	144	205	300	262	512	339
	Unknown	104	208	519	706	670	1337	423
Insurance status	Insured	23999	25564	28695	29730	24288	60567	33545
	Uninsured	921	899	956	855	724	1785	997
	Unknown	420	225	217	200	161	490	224
Diagnosis	Blood coagulation disorder without specific diagnosis	186	308	285	345	219	995	222
	Ehlers-Danlos syndrome	45	44	57	49	41	154	48
	Factor I, hereditary	56	76	73	85	65	181	93
	Factor II, hereditary	18	14	18	17	19	43	22
	Factor V, hereditary	98	109	119	111	84	326	100
	Factor VII, hereditary	459	473	497	551	461	1308	604
	Factor VIII, hereditary	9413	9285	10253	10361	8729	16162	12407
	Factor IX, hereditary	2831	2810	3176	3134	2659	5099	3820
	Factor X, hereditary	68	59	68	70	65	152	76
	Factor XI, hereditary	272	250	310	336	259	824	329
	Factor XIII, hereditary	71	84	99	101	89	167	107
	Factors V & VIII, combined	*	*	*	*	*	15	*
	Alpha-2 antiplasmin deficiency	*	*	*	*	*	6	*
	Platelet function disorder	1497	1614	1849	1942	1680	4553	2372
	PAI-1 deficiency	106	83	52	60	75	233	74
	Thrombocytopenia, hereditary	133	113	109	147	93	398	110
	Venous thromboembolism (VTE)	3519	4865	5974	6374	4683	16092	5482
	Von Willebrand disease, type 1	5163	5081	5268	5316	4503	12674	6913
	Von Willebrand disease, type 1C	10	15	23	34	17	45	31
	Von Willebrand disease, type 2A	327	333	342	382	329	724	468
	Von Willebrand disease, type 2B	196	192	213	220	177	428	275
	Von Willebrand disease, type 2M	150	170	205	207	196	352	266
	Von Willebrand disease, type 2N	34	45	53	53	55	114	72
Von Willebrand disease, type 2, type unknown	83	114	160	188	147	357	209	
Von Willebrand disease, type 3	230	231	248	260	205	375	297	
Von Willebrand disease, unknown	321	281	367	387	277	939	306	
Von Willebrand disease, type other	43	30	40	45	40	126	47	
History of HCV infection	Yes	3016	2883	3169	3202	2578	4828	3942
	No	14564	14096	15682	16535	14021	31370	20070
	Unknown	4241	4844	5043	4674	3891	10552	5272
	Not Applicable†	3519	4865	5974	6374	4683	16092	5482
History of HIV infection	Yes	932	881	964	957	745	1423	1173
	No	16344	15725	17535	18560	15634	34318	22493
	Unknown	4545	5217	5395	4894	4111	11009	5618
	Not Applicable†	3519	4865	5974	6374	4683	16092	5482

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 twenty-two 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.

***One HTC contributed data only through 9/30/2016. A new HTC began contributing data during the 2016 calendar year.

HTC Population Profile Patient Characteristics, Factor VIII and Factor IX, data reported from 1/1/2012 through 12/31/2016

		Factor VIII (n=15689)								Factor IX (n=4929)							
		Mild		Moderate		Severe		Severity Unknown		Mild		Moderate		Severe		Severity Unknown	
		#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)
# of patients		5407	(100)	2785	(100)	7755	(100)	215	(100)	1755	(100)	1902	(100)	1385	(100)	57	(100)
Age (years)	<2	114	(2)	101	(4)	237	(3)	14	(7)	52	(3)	51	(3)	55	(4)	5	(9)
	2–10	932	(17)	561	(20)	1647	(21)	31	(14)	319	(18)	377	(20)	266	(19)	11	(19)
	11–19	1252	(23)	628	(23)	1755	(23)	22	(10)	387	(22)	467	(25)	267	(19)	10	(18)
	20–44	1719	(32)	969	(35)	3169	(41)	102	(47)	558	(32)	578	(30)	553	(40)	20	(35)
	45–64	931	(17)	384	(14)	807	(10)	29	(13)	292	(17)	299	(16)	191	(14)	11	(19)
	65+	459	(8)	142	(5)	140	(2)	17	(8)	147	(8)	130	(7)	53	(4)	0	(0)
Sex†	Male	4289	(79)	2743	(98)	7722	(100)	128	(60)	1256	(72)	1885	(99)	*		41	(72)
	Female	1118	(21)	42	(2)	33	(0)	87	(40)	499	(28)	17	(1)	*		16	(28)
Ethnicity	Hispanic, Latino/a, or Spanish origin	986	(18)	545	(20)	1300	(17)	49	(23)	128	(7)	125	(7)	243	(18)	8	(14)
	Not Hispanic, Latino/a, or Spanish origin	4369	(81)	2224	(80)	6420	(83)	159	(74)	1564	(89)	1767	(93)	1135	(82)	48	(84)
	Unknown	52	(1)	16	(1)	35	(0)	7	(3)	63	(4)	10	(1)	7	(1)	1	(2)
Race	American Indian/Alaska Native	98	(2)	30	(1)	61	(1)	5	(2)	*		20	(1)	12	(1)	1	(2)
	Asian	132	(2)	98	(4)	374	(5)	10	(5)	26	(1)	22	(1)	67	(5)	1	(2)
	Black or African American	325	(6)	381	(14)	1198	(15)	22	(10)	151	(9)	72	(4)	206	(15)	3	(5)
	Native Hawaiian or other Pacific Islander	7	(0)	12	(0)	45	(1)	2	(1)	*		14	(1)	10	(1)	0	(0)
	White	4684	(87)	2179	(78)	5896	(76)	164	(76)	1528	(87)	1756	(92)	1059	(76)	51	(89)
	More than one of these	53	(1)	32	(1)	97	(1)	1	(0)	*		5	(0)	15	(1)	1	(2)
	Unknown	108	(2)	53	(2)	84	(1)	11	(5)	39	(2)	13	(1)	16	(1)	0	(0)
Insurance status	Insured	5193	(96)	2696	(97)	7512	(97)	191	(89)	1492	(85)	1514	(80)	1345	(97)	46	(81)
	Uninsured	168	(3)	79	(3)	194	(3)	15	(7)	204	(12)	378	(20)	35	(3)	8	(14)
	Unknown	46	(1)	10	(0)	49	(1)	9	(4)	59	(3)	10	(1)	5	(0)	3	(5)
History of HCV infection	Yes	714	(13)	617	(22)	2072	(27)	24	(11)	166	(9)	330	(17)	459	(33)	6	(11)
	No	3891	(72)	1930	(69)	5022	(65)	121	(56)	1222	(70)	1259	(66)	800	(58)	29	(51)
	Unknown	802	(15)	238	(9)	661	(9)	70	(33)	367	(21)	313	(16)	126	(9)	22	(39)
History of HIV infection	Yes	103	(2)	176	(6)	861	(11)	7	(4)	18	(1)	42	(2)	119	(9)	0	(0)
	No	4275	(82)	2287	(83)	6055	(79)	123	(63)	1293	(76)	1474	(79)	1100	(81)	35	(61)
	Unknown	835	(16)	278	(10)	721	(9)	64	(33)	380	(22)	342	(18)	140	(10)	22	(39)

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HTC Population Profile Patient Characteristics, von Willebrand Disease (VWD), data reported from 1/1/2012 through 12/31/2016

		VWD (n=15323)							
		Type 1		Type 2		Type 3		Type other and Type unknown	
		#	(%)	#	(%)	#	(%)	#	(%)
	# of patients	12719	(100)	1975	(100)	375	(100)	1065	(100)
Age (years)	<2	12719	(100)	1975	(100)	375	(100)	1065	(100)
	2–10	2796	(23)	435	(23)	70	(19)	244	(24)
	11–19	4978	(41)	536	(28)	71	(19)	324	(32)
	20–44	3006	(25)	503	(26)	131	(36)	232	(23)
	45–64	1016	(8)	258	(14)	72	(20)	113	(11)
	65+	331	(3)	146	(8)	*		71	(7)
Sex†	Male	4269	(35)	818	(43)	184	(50)	337	(34)
	Female	7966	(65)	1081	(57)	182	(50)	668	(66)
Ethnicity	Hispanic, Latino/a, or Spanish origin	2016	(16)	240	(12)	33	(9)	173	(16)
	Not Hispanic, Latino/a, or Spanish origin	10561	(83)	1672	(85)	339	(90)	848	(80)
	Unknown	142	(1)	63	(3)	(3)	(1)	44	(4)
Race	American Indian/Alaska Native	77	(1)	13	(1)	*		7	(1)
	Asian	292	(2)	56	(3)	19	(5)	28	(3)
	Black or African American	892	(7)	161	(8)	26	(7)	93	(9)
	Native Hawaiian or other Pacific Islander	57	(0)	9	(0)	*		2	(0)
	White	11020	(87)	1662	(84)	318	(85)	877	(82)
	More than one of these	97	(1)	14	(1)	*		8	(1)
	Unknown	284	(2)	60	(3)	4	(1)	50	(5)
Insurance status	Insured	12404	(98)	1810	(92)	362	(97)	1034	(97)
	Uninsured	211	(2)	115	(6)	6	(2)	15	(1)
	Unknown	104	(1)	50	(3)	7	(2)	16	(2)
History of HCV infection	Yes	109	(1)	86	(4)	87	(23)	13	(1)
	No	8694	(68)	1390	(70)	259	(69)	708	(66)
	Unknown	3916	(31)	499	(25)	29	(8)	344	(32)
History of HIV infection	Yes	34	(0)	8	(0)	7	(2)	2	(0)
	No	8621	(68)	1456	(74)	331	(88)	717	(67)
	Unknown	4064	(32)	511	(26)	37	(10)	346	(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 12/31/2016

		FI		FII		FV		Factors V & VIII, combined		FVII		FX		FXI		FXIII		Alpha-2 Antiplasmin Deficiency		PAI-1 Deficiency	
		#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)
# of patients		181	(100)	43	(100)	326	(100)	15	(100)	1308	(100)	152	(100)	824	(100)	167	(100)	6	(100)	224	(100)
Age (years)	<2	7	(4)	*		9	(3)	*		23	(2)	*		26	(3)	9	(5)	*		7	(3)
	2–10	48	(27)	9	(21)	43	(13)	*		414	(32)	32	(21)	138	(17)	34	(20)	*		53	(24)
	11–19	49	(27)	19	(44)	104	(32)	*		504	(39)	50	(33)	238	(29)	34	(20)	*		100	(45)
	20–44	53	(29)	9	(21)	115	(35)	6	(40)	250	(19)	40	(26)	201	(24)	68	(41)	*		40	(18)
	45–64	17	(9)	*		37	(11)	*		84	(6)	20	(13)	122	(15)	16	(10)	*		15	(7)
	65+	7	(4)	*		18	(6)	*		33	(3)	*		99	(12)	6	(4)	*		9	(4)
Sex†	Male	76	(42)	21	(49)	126	(39)	8	(53)	654	(50)	66	(43)	392	(48)	88	(53)	*		84	(38)
	Female	105	(58)	22	(51)	200	(61)	7	(47)	654	(50)	86	(57)	432	(52)	79	(47)	*		140	(63)
Ethnicity	Hispanic, Latino/a, or Spanish origin	21	(12)	13	(30)	53	(16)	0	(0)	289	(22)	38	(25)	104	(13)	27	(16)	*		36	(16)
	Not Hispanic, Latino/a, or Spanish origin	156	(86)	30	(70)	266	(82)	15	(100)	992	(76)	112	(74)	715	(87)	140	(84)	*		185	(83)
	Unknown	4	(2)	0	(0)	7	(2)	0	(0)	27	(2)	2	(1)	5	(1)	0	(0)	*		3	(1)
Race	American Indian/Alaska Native	*		*		*		0	(0)	8	(1)	*		*		*		0	(0)	0	(0)
	Asian	*		*		8	(2)	*		37	(3)	12	(8)	33	(4)	19	(11)	*		*	
	Black or African American	8	(4)	*		14	(4)	*		255	(19)	21	(14)	41	(5)	18	(11)	0	(0)	23	(10)
	Native Hawaiian or other Pacific Islander	0	(0)	0	(0)	0	(0)	0	(0)	*		0	(0)	0	(0)	*		0	(0)	*	
	White	152	(84)	37	(86)	290	(89)	11	(73)	932	(71)	111	(73)	732	(89)	122	(73)	*		185	(83)
	More than one of these	*		*		*		0	(0)	*		*		*		*		0	(0)	*	
	Unknown	11	(6)	1	(2)	*		*		58	(4)	*		*		*		0	(0)	6	(3)
Insurance status	Insured	175	(97)	41	(95)	319	(98)	14	(93)	1280	(98)	151	(99)	811	(98)	164	(98)	6	(100)	205	(92)
	Uninsured	*		*		*		*		18	(1)	*		6	(1)	*		0	(0)	11	(5)
	Unknown	*		*		*		*		10	(1)	*		7	(1)	*		0	(0)	8	(4)

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