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.

National Center on Birth Defects and Developmental Disabilities
Division of Blood 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 September 30, 2016, 136 individual HTCs have contributed data over time. One hundred and eighteen 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 9/30/2016

		2012	2013	2014	2015	2016	Unique patients[1]	Multi-year patients[2]
		#	#	#	#	#	#	#
	# of HTCs contributing data	125	129**	132	134	128		
	# of patients	25301	26671	29838	30554	17743	60354	33483
Age (years)	**<2**	804	859	1039	1091	565	2104	420
	2–10	5689	5746	6149	6213	3630	10910	6581
	11–19	7027	7359	8068	8183	4932	16262	9697
	20–44	6967	7201	8246	8507	4884	17364	9923
	45–64	3538	3936	4507	4618	2555	9482	4763
	65+	1276	1570	1829	1942	1177	4232	2099
Sex[†]	**Male**	16832	17342	19178	19580	11510	34914	21987
	Female	8469	9329	10660	10974	6233	25440	11496
Ethnicity	**Hispanic, Latino/a, or Spanish origin**	3709	3764	4334	4433	2623	8267	4922
	Not Hispanic, Latino/a, or Spanish origin	21387	22654	25126	25516	14861	51248	28281
	Unknown	205	253	378	605	259	839	280
Race	**American Indian/Alaska Native**	179	170	189	233	149	398	232
	Asian	698	747	885	957	542	1632	1010
	Black or African American	2900	3059	3549	3635	2198	6947	3935
	Native Hawaiian or other Pacific Islander	115	94	106	123	48	205	127
	White	21222	22249	24385	24613	14151	49503	27463
	More than one of these	83	144	205	300	204	489	328
	Unknown	104	208	519	693	451	1180	388
Insurance status	**Insured**	23982	25547	28666	29509	17161	58194	32321
	Uninsured	921	899	955	849	463	1706	949
	Unknown	398	225	217	196	119	454	213
Diagnosis	**Blood coagulation disorder without specific diagnosis**	186	306	283	337	128	932	201
	Ehlers-Danlos syndrome	45	44	57	49	24	141	46
	Factor I, hereditary	56	76	73	82	50	173	89
	Factor II, hereditary	18	14	18	17	14	42	22
	Factor V, hereditary	97	108	119	111	57	307	96
	Factor VII, hereditary	458	473	496	543	296	1232	574
	Factor VIII, hereditary	9399	9284	10247	10274	6372	15785	12098
	Factor IX, hereditary	2828	2807	3171	3114	1838	4965	3708
	Factor X, hereditary	68	59	68	68	47	148	73
	Factor XI, hereditary	269	250	311	334	179	787	314
	Factor XIII, hereditary	71	84	99	102	65	158	104
	Factors V & VIII, combined	*	*	*	*	*	15	*
	Alpha-2 antiplasmin deficiency	*	*	*	*	*	6	*
	Platelet function disorder	1495	1613	1847	1932	1226	4384	2257
	PAI-1 deficiency	106	83	52	60	57	224	70
	Thrombocytopenia, hereditary	133	113	108	146	47	364	105
	Venous thromboembolism (VTE)	3519	4858	5970	6357	3218	15186	5223
	Von Willebrand disease, type 1	5153	5079	5260	5256	3117	12188	6599
	Von Willebrand disease, type 1C	10	15	23	34	15	47	33
	Von Willebrand disease, type 2A	323	333	342	380	224	694	449
	Von Willebrand disease, type 2B	195	192	212	219	122	417	266
	Von Willebrand disease, type 2M	150	170	204	207	161	340	257
	Von Willebrand disease, type 2N	34	45	53	53	34	106	64
	Von Willebrand disease, type 2, type unknown	83	114	160	186	101	342	198
	Von Willebrand disease, type 3	230	231	248	256	149	366	291
	Von Willebrand disease, unknown	321	281	367	382	171	888	288
	Von Willebrand disease, type other	43	30	40	45	27	117	43
History of HCV infection	**Yes**	43	2880	3164	3180	1858	4744	3836
	No	14547	14091	15664	16358	9923	30218	19290
	Unknown	4221	4842	5040	4659	2744	10206	5134
	Not Applicable[‡]	3519	4858	5970	6357	3218	15186	5223
History of HIV infection	**Yes**	932	879	961	955	549	1403	1154
	No	16325	15720	17515	18368	11047	33091	21642
	Unknown	4525	5214	5392	4874	2929	10674	5464
	Not Applicable[‡]	3519	4858	5970	6357	3218	15186	5223

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 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 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 9/30/2016

		Factor VIII (n=15785***)								Factor IX (n=4965***)							
		Mild		Moderate		Severe		Severity Unknown		Mild		Moderate		Severe		Severity Unknown	
		#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)
	# of patients	5213	(100)	2741	(100)	7637	(100)	194	(100)	1691	(100)	1858	(100)	1359	(100)	57	(100)
Age (years)	<2	99	(2)	97	(4)	201	(3)	12	(6)	50	(3)	50	(3)	51	(4)	4	(7)
	2–10	896	(17)	556	(20)	1649	(22)	29	(15)	305	(18)	378	(20)	262	(19)	12	(21)
	11–19	1219	(23)	626	(23)	1737	(23)	22	(11)	375	(22)	453	(24)	257	(19)	11	(19)
	20–44	1661	(32)	944	(34)	3124	(41)	90	(46)	533	(32)	560	(30)	550	(40)	19	(33)
	45–64	896	(17)	377	(14)	789	(10)	25	(13)	285	(17)	297	(16)	187	(14)	11	(19)
	65+	442	(8)	141	(5)	137	(2)	16	(8)	143	(8)	120	(6)	52	(4)	0	(0)
Sex[†]	Male	4169	(80)	2700	(99)	7604	(100)	114	(59)	1227	(73)	1843	(99)	**		40	(70)
	Female	1044	(20)	41	(1)	33	(0)	80	(41)	464	(27)	15	(1)	**		17	(30)
Ethnicity	Hispanic, Latino/a, or Spanish origin	942	(18)	536	(20)	1265	(17)	46	(24)	123	(7)	124	(7)	234	(17)	7	(12)
	Not Hispanic, Latino/a, or Spanish origin	4222	(81)	2194	(80)	6336	(83)	143	(74)	1505	(89)	1724	(93)	1118	(82)	48	(84)
	Unknown	49	(1)	11	(0)	36	(0)	5	(3)	63	(4)	10	(1)	7	(1)	2	(4)
Race	American Indian/Alaska Native	94	(2)	29	(1)	55	(1)	4	(2)	*		20	(1)	14	(1)	1	(2)
	Asian	124	(2)	100	(4)	367	(5)	9	(5)	26	(2)	21	(1)	65	(5)	0	(0)
	Black or African American	315	(6)	376	(14)	1187	(16)	22	(11)	150	(9)	70	(4)	202	(15)	3	(5)
	Native Hawaiian or other Pacific Islander	6	(0)	13	(0)	42	(1)	2	(1)	*		13	(1)	10	(1)	0	(0)
	White	4533	(87)	2145	(78)	5814	(76)	149	(77)	1467	(87)	1718	(92)	1039	(76)	51	(89)
	More than one of these	49	(1)	32	(1)	94	(1)	1	(1)	*		5	(0)	15	(1)	1	(2)
	Unknown	92	(2)	46	(2)	78	(1)	7	(4)	37	(2)	11	(1)	14	(1)	1	(2)
Insurance status	Insured	5005	(96)	2649	(97)	7394	(97)	172	(89)	1451	(86)	1501	(81)	1324	(97)	47	(82)
	Uninsured	170	(3)	83	(3)	197	(3)	15	(8)	184	(11)	347	(19)	28	(2)	7	(12)
	Unknown	38	(1)	9	(0)	46	(1)	7	(4)	56	(3)	10	(1)	7	(1)	3	(5)
History of HCV infection	Yes	704	(14)	606	(22)	2049	(27)	21	(11)	164	(10)	320	(17)	453	(33)	6	(11)
	No	3752	(72)	1897	(69)	4943	(65)	110	(57)	1170	(69)	1237	(67)	783	(58)	29	(51)
	Unknown	757	(15)	238	(9)	645	(8)	63	(32)	357	(21)	301	(16)	123	(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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**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. Greater than 99% of these patients are male.

***Total corrected from reports posted prior to 4/4/2017.

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HTC Population Profile Patient Characteristics, von Willebrand Disease (VWD), data reported from 1/1/2012 through 9/30/2016

		VWD (n=15505***)							
		Type 1		Type 2		Type 3		Type other and Type unknown	
		#	(%)	#	(%)	#	(%)	#	(%)
	# of patients	12235	(100)	1899	(100)	366	(100)	1005	(100)
Age (years)	<2	108	(1)	21	(1)	*		21	(2)
	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	1934	(16)	235	(12)	32	(9)	160	(16)
	Not Hispanic, Latino/a, or Spanish origin	10172	(83)	1601	(84)	333	(91)	804	(80)
	Unknown	129	(1)	63	(3)	1	(0)	41	(4)
Race	American Indian/Alaska Native	73	(1)	13	(1)	*		5	(0)
	Asian	278	(2)	55	(3)	19	(5)	23	(2)
	Black or African American	860	(7)	157	(8)	24	(7)	91	(9)
	Native Hawaiian or other Pacific Islander	53	(0)	9	(0)	*		1	(0)
	White	10627	(87)	1597	(84)	313	(86)	837	(83)
	More than one of these	94	(1)	14	(1)	*		7	(1)
	Unknown	250	(2)	54	(3)	2	(1)	41	(4)
Insurance status	Insured	11940	(98)	1740	(92)	354	(97)	971	(97)
	Uninsured	199	(2)	109	(6)	8	(2)	17	(2)
	Unknown	96	(1)	50	(3)	4	(1)	17	(2)
History of HCV infection	Yes	105	(1)	80	(4)	85	(23)	12	(1)
	No	8370	(68)	1340	(71)	252	(69)	673	(67)
	Unknown	3760	(31)	479	(25)	29	(8)	320	(32)
History of HIV infection	Yes	29	(0)	8	(0)	8	(2)	2	(0)
	No	8295	(68)	1396	(74)	322	(88)	679	(68)
	Unknown	3911	(32)	495	(26)	36	(10)	324	(32)

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***Total corrected from reports posted prior to 4/4/2017.

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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 9/30/2016

		FI		FII		FV		Factors V & VIII, combined		FVII		FX		FXI		FXIII		Alpha-2 Antiplasmin Deficiency		PAI-1 Deficiency	
		#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)	#	(%)
	# of patients	173	(100)	42	(100)	307	(100)	15	(100)	1232	(100)	148	(100)	787	(100)	158	(100)	6	(100)	224	(100)
Age (years)	**<2**	6	(3)	*		7	(2)	*		17	(1)	*		25	(3)	7	(4)	*		7	(3)
	2–10	45	(26)	9	(21)	42	(14)	*		391	(32)	31	(21)	131	(17)	31	(20)	*		53	(24)
	11–19	48	(28)	18	(43)	95	(31)	*		476	(39)	46	(31)	227	(29)	33	(21)	*		100	(45)
	20–44	51	(29)	9	(21)	110	(36)	6	(40)	239	(19)	40	(27)	191	(24)	65	(41)	*		40	(18)
	45–64	16	(9)	*		36	(12)	*		77	(6)	20	(14)	116	(15)	16	(10)	*		15	(7)
	65+	7	(4)	*		17	(6)	*		32	(3)	*		97	(12)	6	(4)	*		9	(4)
Sex†	**Male**	73	(42)	21	(50)	123	(40)	8	(53)	614	(50)	63	(43)	375	(48)	84	(53)	*		84	(38)
	Female	100	(58)	21	(50)	184	(60)	7	(47)	618	(50)	85	(57)	412	(52)	74	(47)	*		140	(63)
Ethnicity	**Hispanic, Latino/a, or Spanish origin**	20	(12)	13	(31)	51	(17)	0	(0)	272	(22)	37	(25)	95	(12)	25	(16)	*		36	(16)
	Not Hispanic, Latino/a, or Spanish origin	149	(86)	29	(69)	250	(81)	15	(100)	939	(76)	109	(74)	687	(87)	133	(84)	*		185	(83)
	Unknown	4	(2)	0	(0)	6	(2)	0	(0)	21	(2)	2	(1)	5	(1)	0	(0)	*		3	(1)
Race	**American Indian/Alaska Native**	*		*		0	(0)	0	(0)	8	(1)	0	(0)	*		*		0	(0)	0	(0)
	Asian	*		*		5	(2)	*		34	(3)	12	(8)	32	(4)	17	(11)	*		*	
	Black or African American	7	(4)	*		14	(5)	*		243	(20)	21	(14)	40	(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	146	(84)	36	(86)	278	(91)	11	(73)	883	(72)	107	(72)	699	(89)	117	(74)	*		185	(83)
	More than one of these	*		*		*		0	(0)	*		*		*		*		0	(0)	*	
	Unknown	11	(6)	1	(2)	*		*		50	(4)	*		*		*		0	(0)	6	(3)
Insurance status	**Insured**	167	(97)	40	(95)	301	(98)	14	(93)	1206	(98)	147	(99)	777	(99)	155	(98)	6	(100)	205	(92)
	Uninsured	*		*		*		*		17	(1)	*		7	(1)	*		0	(0)	11	(5)
	Unknown	*		*		*		*		9	(1)	*		3	(0)	*		0	(0)	8	(4)
History of HCV infection	**Yes**	6	(3)	5	(12)	6	(2)	*		18	(1)	8	(5)	24	(3)	9	(6)	*		0	(0)
	No	111	(64)	32	(76)	213	(69)	11	(73)	856	(69)	111	(75)	574	(73)	123	(78)	*		123	(55)
	Unknown	56	(32)	5	(12)	88	(29)	*		358	(29)	29	(20)	189	(24)	26	(16)	*		101	(45)

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