

UKHCDO

UNITED KINGDOM HAEMOPHILIA CENTRES DOCTORS' ORGANISATION



Bleeding Disorder Statistics for April 2011 to March 2012

A report from the National Haemophilia Database

In Register – The total number of registered patients with all types of bleeding disorder as of 31st March 2012 and the number treated between April 2011 & March 2012

Coagulation Defect	Number of Patients		Percent Treated
	In Register	Treated	
Haemophilia A	5,467	2,991	54.71%
Haemophilia B	1,156	631	54.58%
Females with VIII deficiency	1,154	65	5.63%
Females with IX deficiency	351	40	11.40%
Haemophilia B Leyden	12	1	8.33%
Haemophilia B Leyden Carrier	2	1	50.00%
von Willebrand disease	9,377	1,104	11.77%
F.V deficiency	140	11	7.86%
F.VII deficiency	756	50	6.61%
F.X deficiency	189	32	16.93%
F.XI Deficiency	2,079	56	2.69%
F.XIII Deficiency	60	50	83.33%
Fibrinogen Deficiency	175	18	10.29%
Prothrombin Deficiency	11	4	36.36%
Dysfibrinogenaemia	175	17	9.71%
Hypofibrinogenaemia	3	0	0.00%
Combined II+VII+IX+X Deficiency	4	0	0.00%
Combined V+VIII Deficiency	23	4	17.39%
Other combined diagnoses	233	25	10.73%
Acquired Haemophilia A	344	76	22.09%
Acquired Haemophilia B	1	0	0.00%
Acquired von Willebrands	65	19	29.23%
Acquired Prothrombin Deficiency	1	1	100.00%
Acquired F.XIII Deficiency	1	0	0.00%
Acquired F.V deficiency	3	1	33.33%
Acquired Deficiency (other)	5	2	40.00%
Glanzmann's Thrombasthenia	111	38	34.23%
Bernard Soulier	62	6	9.68%
Other platelet defects	1,402	85	6.06%
Haemophilia A with Liver Transplant	9	1	11.11%
Haemophilia B with Liver Transplant	5	0	0.00%
von Willebrand with Liver Transplant	1	0	0.00%
Miscellaneous	156	18	11.54%
Unclassified	124	7	5.65%
Pseudo von Willebrand's disease	1	0	0.00%
Probable von Willebrand's disease	91	14	15.38%
Total	23,749	5,368	22.60%

New Registrations
– Number of
patients newly
registered at UK
Haemophilia
Centres between
April 2011 &
March 2012
showing their
coagulation defect
and gender

Coagulation Defect	Male	Female	Grand Total
Haemophilia A	154	-	154
Haemophilia B	34	-	34
F.IX Leyden	1	0	1
Females with VIII deficiency	-	59	59
Females with IX deficiency	-	8	8
von Willebrand disease	175	309	484
Probable von Willebrand's disease	13	24	37
F.V deficiency	6	3	9
F.VII deficiency	44	49	93
F.X deficiency	4	6	10
F.XI Deficiency	88	109	197
F.XIII Deficiency	2	1	3
Fibrinogen Deficiency	0	5	5
Prothrombin Deficiency	1	0	1
Dysfibrinogenaemia	8	6	14
Hypofibrinogenaemia	2	1	3
Acquired Haemophilia A	33	33	66
Acquired von Willebrands	5	4	9
Acquired F.V deficiency	2	1	3
Acquired Deficiency (other)	2	0	2
Glanzmann's Thrombasthenia	0	2	2
Bernard Soulier	1	3	4
Other platelet defects	25	85	110
Combined diagnoses	9	13	22
Miscellaneous	8	19	27
Unclassified	4	12	16
Total	621	752	1,373

New Registrations
of Haemophilia A
& B between April
2011 & March
2012, by age at
the end of
September 2011
and disease
severity

Coagulation Defect	Age (years)	Number of Patients (factor level iu/dl)			
		≤1	>1 & <5	≥5	Total
Haemophilia A	0 : 9	32	8	35	75
	10 : 19	3	1	12	16
	20 : 29	7	4	9	20
	30 : 39	2	0	7	9
	40 : 49	2	0	7	9
	50 : 59	0	1	5	6
	60 : 69	0	0	10	10
	70 : +	0	0	9	9
	Total	46	14	94	154
Haemophilia B	0 : 9	11	3	6	20
	10 : 19	0	0	3	3
	20 : 29	0	1	2	3
	30 : 39	0	0	2	2
	40 : 49	0	0	1	1
	50 : 59	0	0	1	1
	60 : 69	0	0	3	3
	70 : +	0	0	2	2
	Total	11	4	20	35

In Register – The number of patients with selected rarer bleeding disorders currently registered and the number treated between April 2011 & March 2012, by disease severity

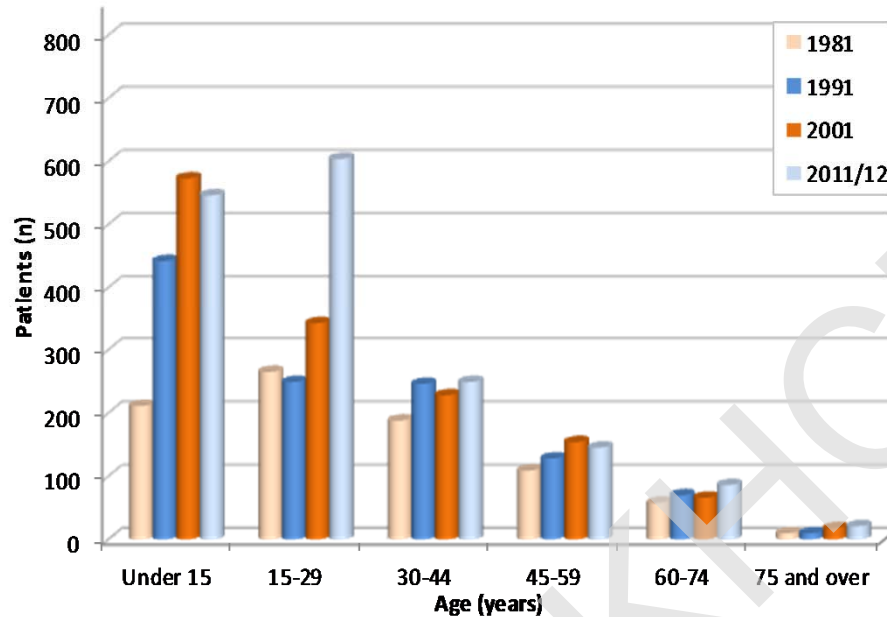
Coagulation Defect	Number of Patients (factor level iu/dl)					
	<5		≥5		Total	
	In Reg	Treated	In Reg	Treated	In Reg	Treated
F.V deficiency	42	10	98	1	140	11
F.VII deficiency	104	27	652	23	756	50
Haemophilia B Leyden	0	0	12	1	12	1
Haemophilia B Leyden Carrier	0	0	2	1	2	1
F.X deficiency	36	23	153	9	189	32
F.XI Deficiency	187	12	1892	44	2079	56
Total	369	72	2,809	79	3,178	151

Coagulation Defect	<2		≥2		Total	
	In Reg	Treated	In Reg	Treated	In Reg	Treated
F.XIII Deficiency	28	25	32	25	60	50
Total	28	25	32	25	60	50

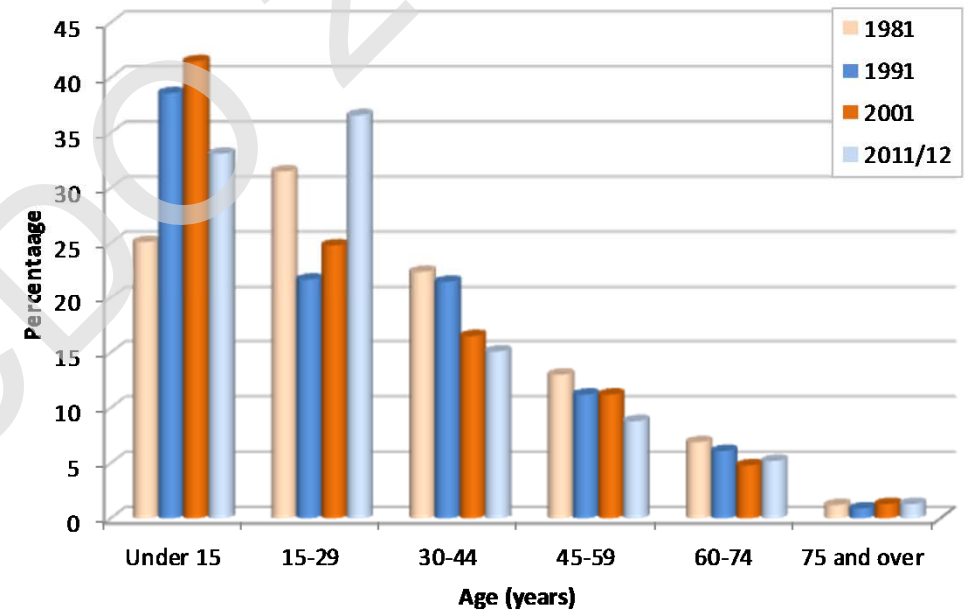
In Register – The total number of Haemophilia A, B and von Willebrand's disease patients currently registered, by severity, age group and gender

Coagulation Defect	Males										Total Males
	<18 years (factor level iu/dl)					≥18 years (factor level iu/dl)					
	≤ 1	>1 & <5	≥ 5	N/K	Sub Total	≤ 1	>1 & <5	≥ 5	N/K	Sub Total	
Haemophilia A	653	137	644	0	1434	1252	389	2388	0	4029	5463
Haemophilia B	124	60	101	0	285	292	175	412	3	882	1167
von Willebrand disease	23	19	706	227	975	39	48	2224	151	2462	3437
Coagulation Defect	Females										Total Females
	<18 years (factor level iu/dl)					≥18 years (factor level iu/dl)					
	≤ 1	>1 & <5	≥ 5	N/K	Sub Total	≤ 1	>1 & <5	≥ 5	N/K	Sub Total	
Haemophilia A	0	1	0	0	1	0	0	0	0	0	1
Haemophilia B	0	0	0	0	0	0	1	0	0	1	1
Female with VIII deficiency	4	3	77	42	126	33	6	883	105	1027	1153
Female with IX deficiency	1	1	43	15	60	7	6	251	28	292	352
von Willebrand disease	10	25	602	233	870	48	68	4449	493	5058	5928

Trend in number and proportion of *Severe* Haemophilia A patients (HIV negative), by age group, in register 1981 – 2011/12

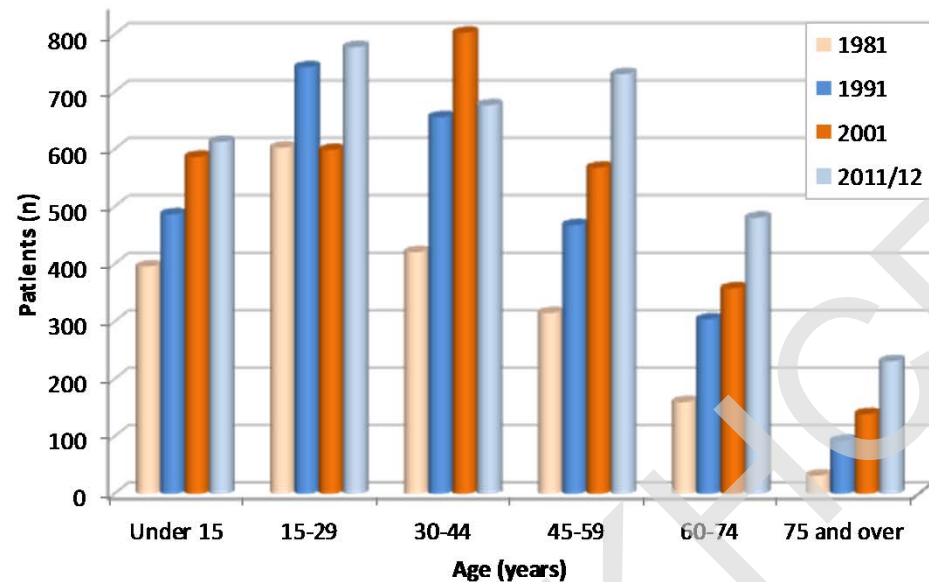


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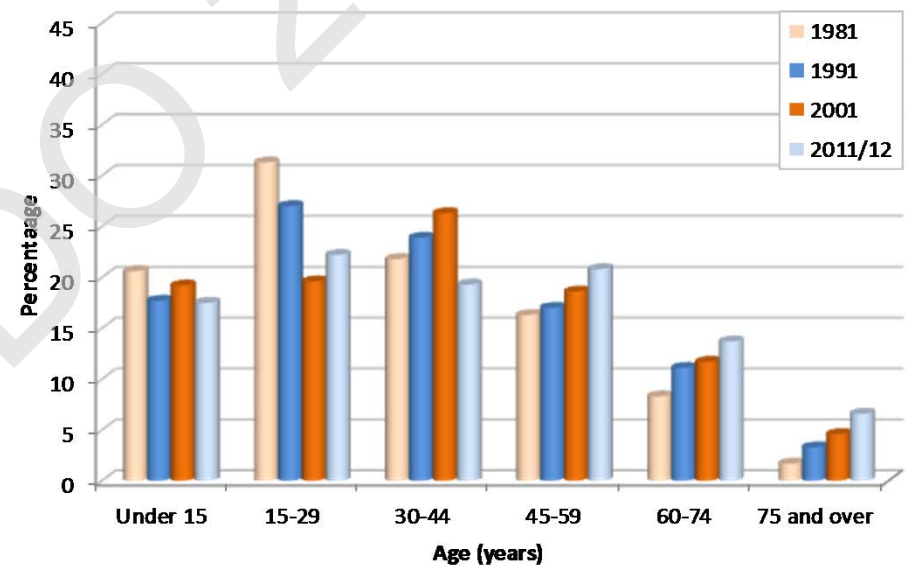


Proportion

Trend in number and proportion of *Non-Severe* Haemophilia A patients (HIV negative), by age group, in register 1981 - 2011/12

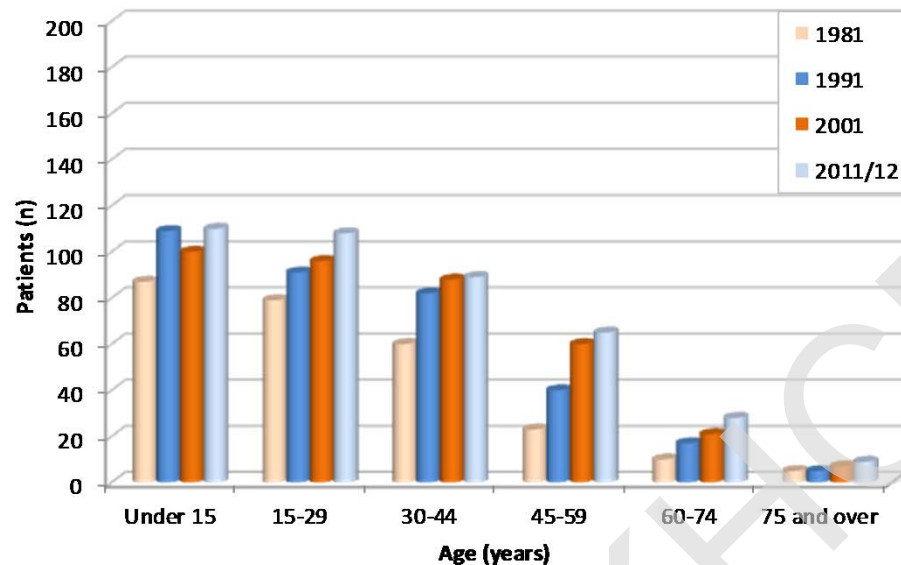


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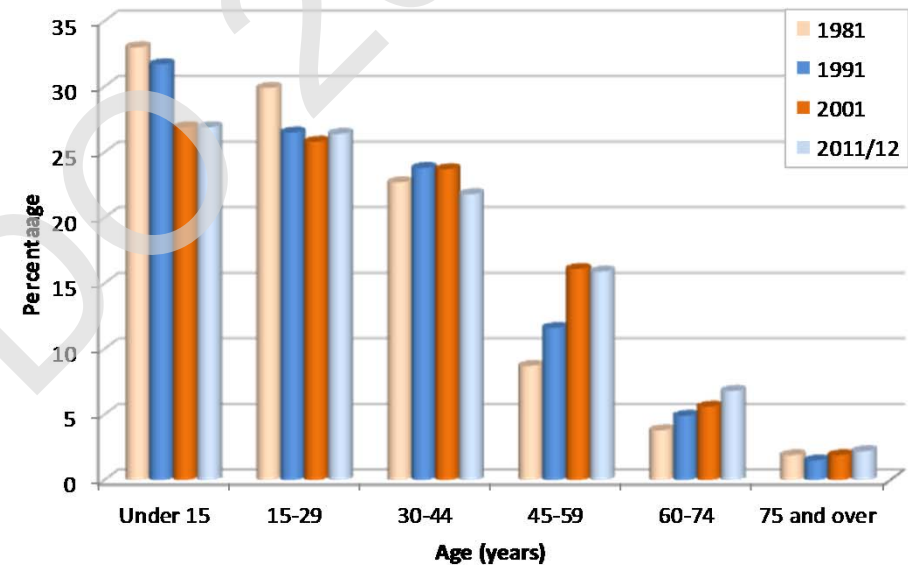


Proportion

Trend in number and proportion of *Severe* Haemophilia B patients (HIV negative), by age group, in register 1981 – 2011/12

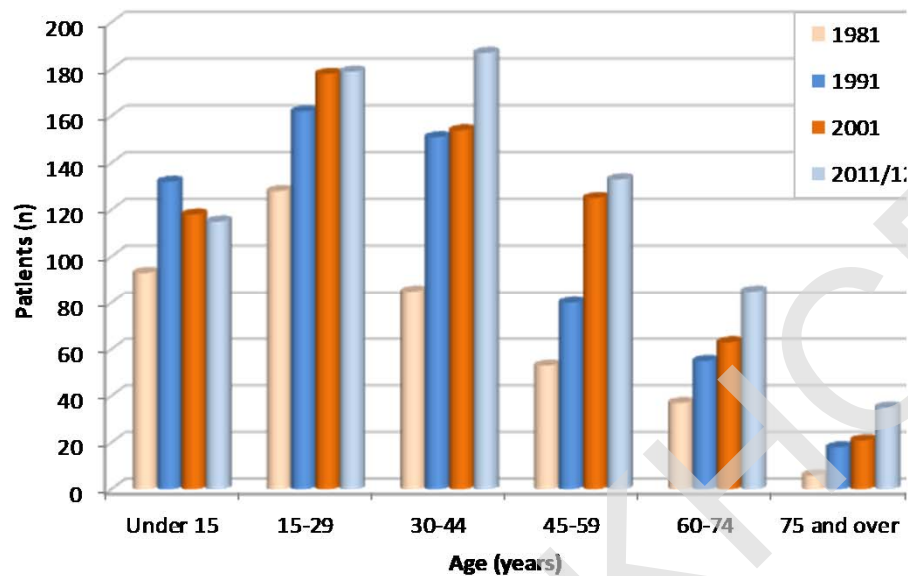


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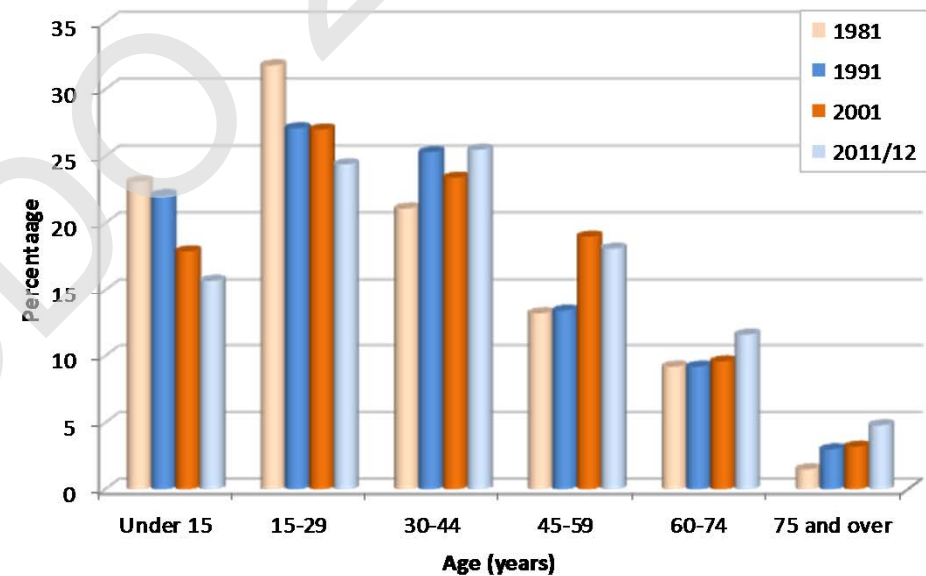


Proportion

Trend in number and proportion of *Non-Severe* Haemophilia B patients (HIV negative), by age group, in register 1981 – 2011/12

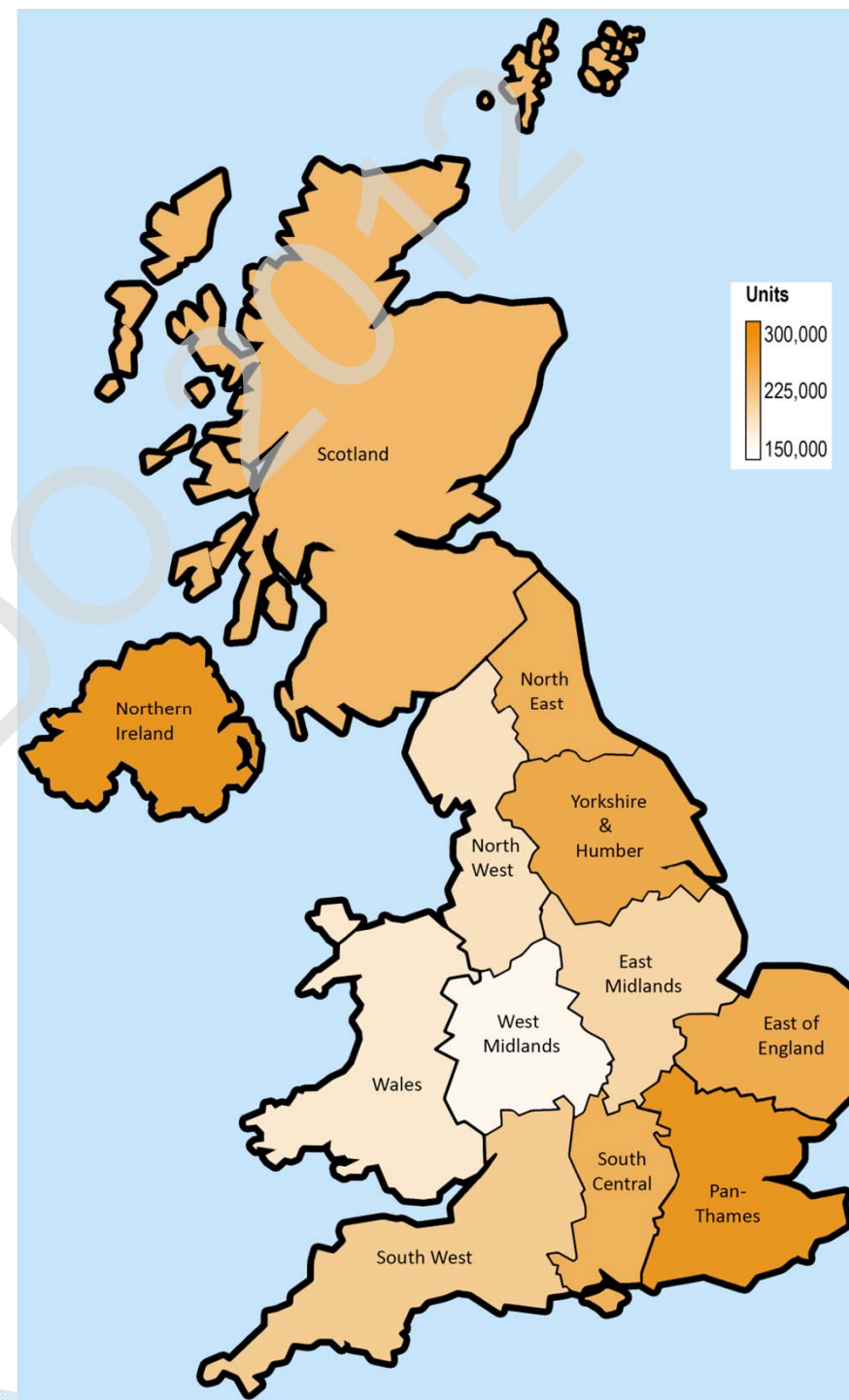


Number



Proportion

Factor VIII Usage (inc.
inhibitor) divided by
number of Severe
Haemophilia A
patients by
commissioning
region



Total Number of Severe Haemophilia A patients by commissioning region



FVIII Units – usage
per capita of general
population by
commissioning
region



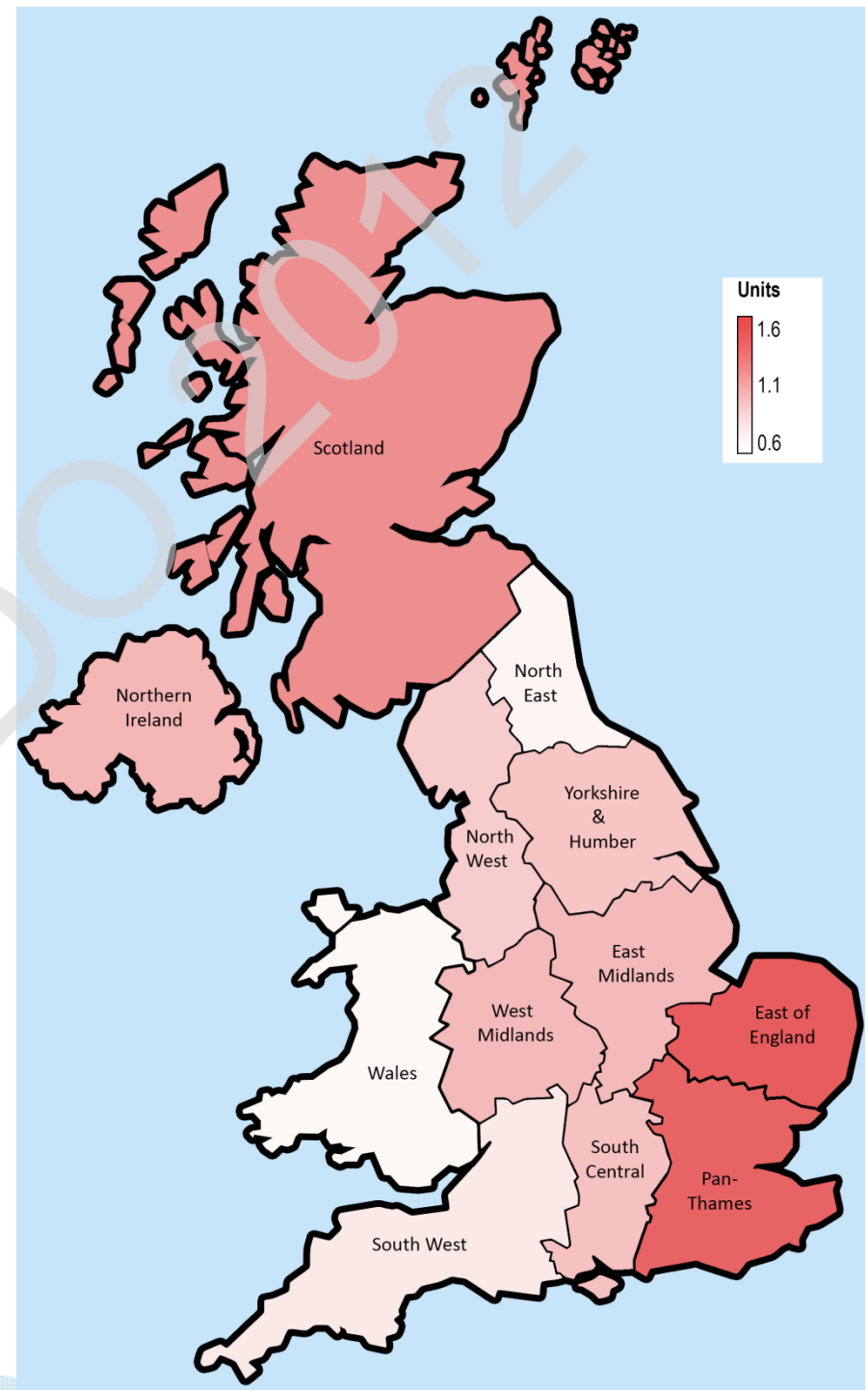
Factor IX Usage (inc.
inhibitor) divided by
number of Severe
Haemophilia B
patients by
commissioning
region



Total Number of Severe Haemophilia B patients by commissioning region



FIX Units – usage per capita of general population by commissioning region



Factor VIII usage by commissioning region for Severe Haemophilia A patients only (inc. inhibitor but excluding non-severe haemophilia)

Commissioning Group / Region	General Population *	Severe Haemophilia A Patients treated (n)	Total FVIII Units Used For Severe Haemophilia A Only	Mean Usage Severe Haemophilia A	FVIII Units Used For Severe Haemophilia A Per Capita
South Central Specialised Commissioning Group	4,137,700	155	35,304,692	227,772	8.53
Pan-Thames Haemophilia Consortium	15,658,300	460	129,151,155	280,763	8.25
Yorkshire and Humber Specialised Commissioning Group	5,301,300	169	43,680,716	258,466	8.24
East Midlands Specialised Commissioning Group	4,481,400	127	25,503,505	200,815	5.69
South West Specialised Commissioning Group	5,273,700	134	28,879,230	215,517	5.48
North East Specialised Commissioning Group	2,606,600	52	12,851,222	247,139	4.93
East of England Specialised Commissioning Group	2,371,600	42	10,716,000	255,143	4.52
North West Specialised Commissioning Group	6,935,700	154	28,851,082	187,345	4.16
West Midlands Specialised Commissioning Group	5,455,200	136	21,855,314	160,701	4.01
England	52,221,500	1,429	336,792,916	235,684	6.45
Northern Ireland	1,799,392	62	17,765,750	286,544	9.87
Scotland	5,222,100	151	35,362,123	234,186	6.77
Wales	3,006,400	74	13,045,238	176,287	4.34
United Kingdom	62,249,392	1,716	402,966,027	234,829	6.47

* Source: ONS, Mid-year population estimates, 2010 – resident population based on the ONS National Population Census 200

Factor IX usage by commissioning region for Severe Haemophilia B patients only (inc. inhibitor but excluding non-severe haemophilia)

Commissioning Group / Region	General Population *	Severe Haemophilia B Patients treated (n)	Total FIX Units Used For Severe Haemophilia B Only	Mean Usage Severe Haemophilia B	FIX Units Used For Severe Haemophilia B Per Capita
East of England Specialised Commissioning Group	2,371,600	17	3,600,500	211,794	1.52
Pan-Thames Haemophilia Consortium	15,658,300	110	23,053,908	209,581	1.47
East Midlands Specialised Commissioning Group	4,481,400	24	4,431,089	184,629	0.99
West Midlands Specialised Commissioning Group	5,455,200	31	5,383,590	173,664	0.99
South Central Specialised Commissioning Group	4,137,700	25	3,888,988	155,560	0.94
Yorkshire and Humber Specialised Commissioning Group	5,301,300	29	4,922,478	169,741	0.93
North West Specialised Commissioning Group	6,935,700	31	6,108,293	197,042	0.88
South West Specialised Commissioning Group	5,273,700	19	3,771,824	198,517	0.72
North East Specialised Commissioning Group	2,606,600	10	1,724,450	172,445	0.66
England	52,221,500	296	56,885,120	192,179	1.09
Scotland	5,222,100	36	6,674,556	185,404	1.28
Northern Ireland	1,799,392	8	1,824,110	228,014	1.01
Wales	3,006,400	12	1,947,189	162,266	0.65
United Kingdom	62,249,392	352	67,330,975	191,281	1.08

* Source: ONS, Mid-year population estimates, 2010 – resident population based on the ONS National Population Census 200

Distance of patient's home from haemophilia centre

Measure	Distance (miles)
Minimum	0.12
First quartile	3.67
Median	8.68
Third quartile	19.2
Maximum	299.7

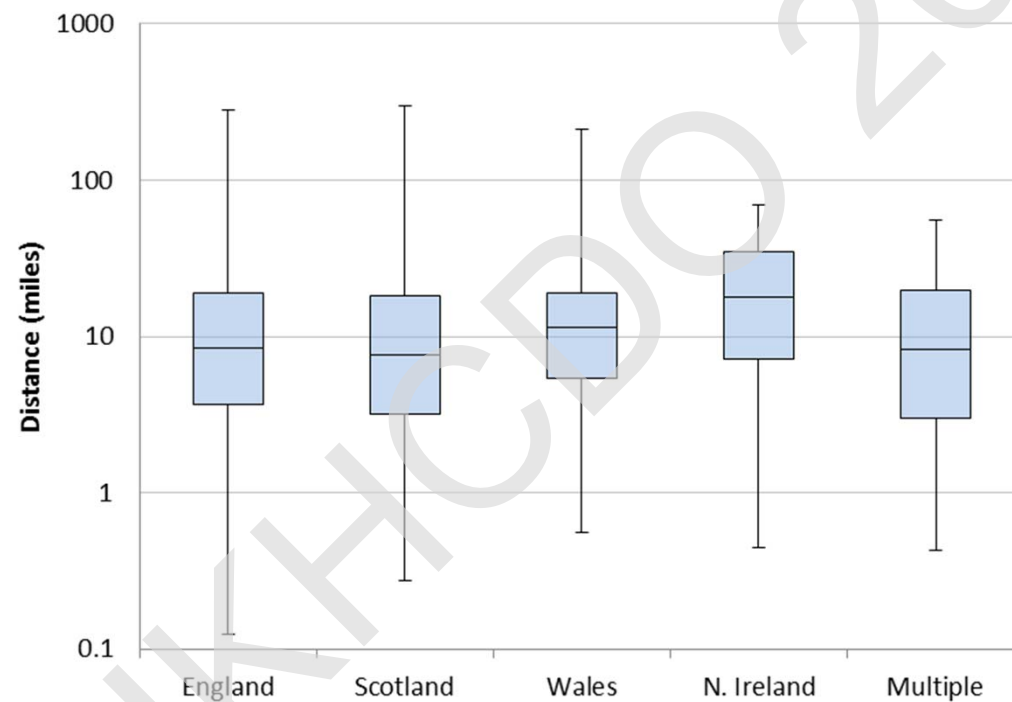
Distance of patient's home from haemophilia centre

Patients registered at nearest centre

Group	Patients registered at nearest centre (n)	Total	% of total
Adults	2492	3659	68
Children	890	1463	61
Total	3382	5122	66

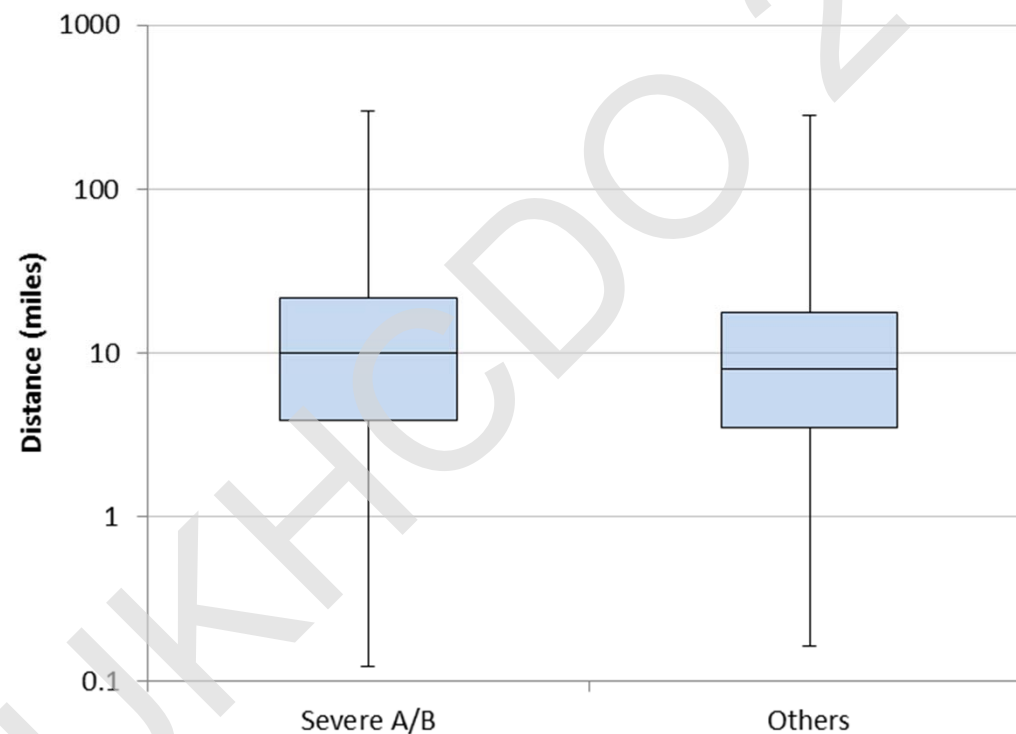
Distance of patient's home from haemophilia centre

Comparison of countries



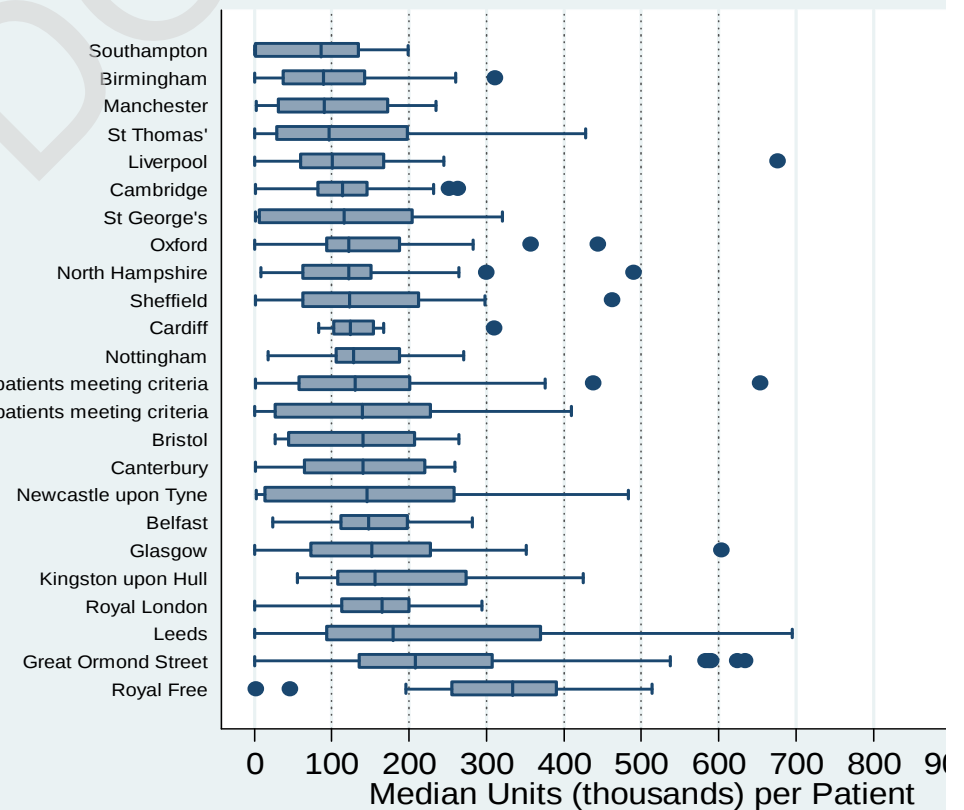
Distance of patient's home from haemophilia centre

Severe Haemophilia A and B Vs. other bleeding disorders



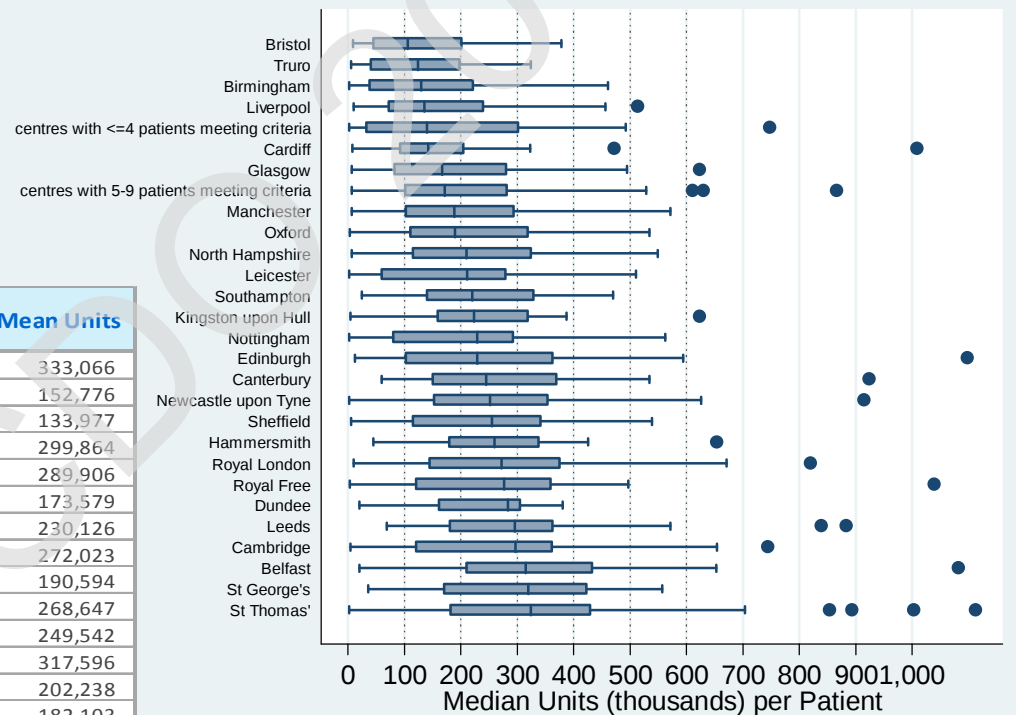
FVIII usage in Severe Haemophilia A patients with no current inhibitor by centre, aged less than 18 years, ranked by median usage

Haemophilia Centre	Patients treated	Total Units	Median Units	Mean Units
Belfast	26	3,877,750	147,500	149,144
Birmingham	39	3,873,500	89,000	99,321
Bristol	15	2,086,000	140,500	139,067
Cambridge	21	2,630,250	114,000	125,250
Canterbury	12	1,625,750	141,000	135,479
Cardiff	11	1,564,250	124,500	142,205
Glasgow	32	5,090,500	151,500	159,078
Great Ormond Street	80	18,848,560	208,500	235,607
Kingston upon Hull	11	2,068,500	156,000	188,045
Leeds	30	6,919,250	179,625	230,642
Liverpool	20	2,677,750	101,125	133,888
Manchester	20	2,054,510	90,375	102,726
Newcastle upon Tyne	20	3,366,500	146,000	168,325
North Hampshire	18	2,547,750	122,000	141,542
Nottingham	13	1,810,250	128,500	139,250
Oxford	39	5,520,250	122,000	141,545
Royal Free	21	6,518,150	334,000	310,388
Royal London	15	2,499,500	165,000	166,633
Sheffield	30	4,458,000	123,500	148,600
Southampton	13	1,085,750	86,000	83,519
St George's	14	1,643,000	116,000	117,357
St Thomas'	29	3,880,750	96,750	133,819
Centres with <=4 patients meeting criteria	24	3,603,238	139,119	150,135
Centres with 5-9 patients meeting criteria	70	10,148,472	130,037	144,978

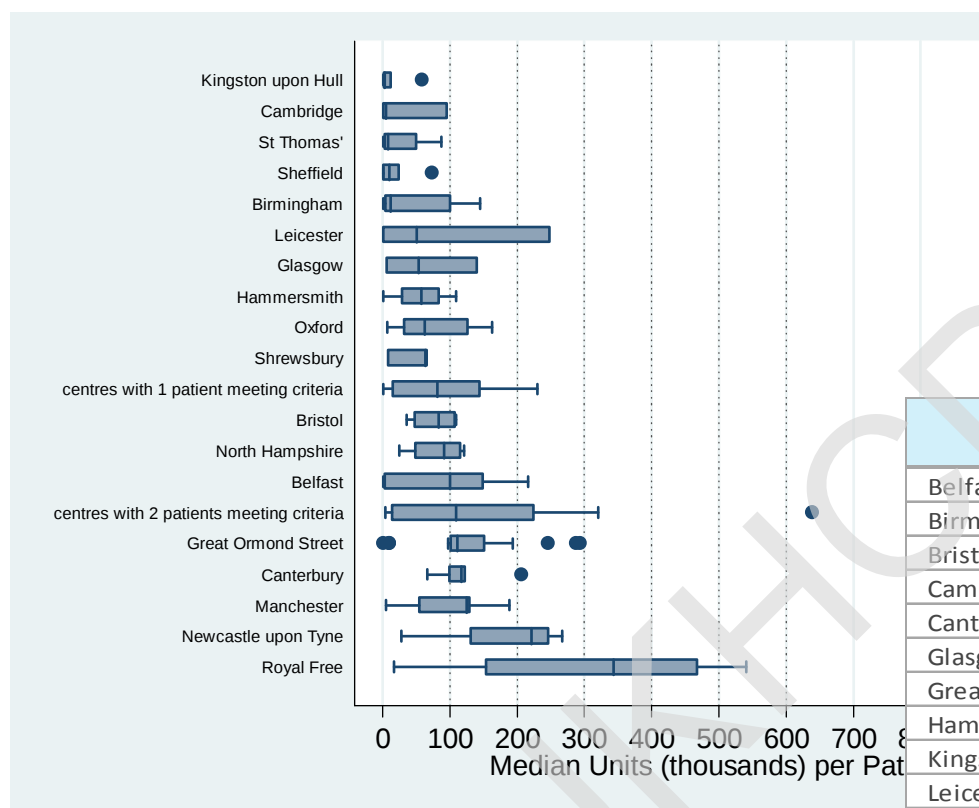


FVIII usage in Severe Haemophilia A patients with no current inhibitor by centre, aged 18 years or more, ranked by median usage

Haemophilia Centre	Patients treated	Total Units	Median Units	Mean Units
Belfast	38	12,656,500	315,500	333,066
Birmingham	68	10,388,750	129,500	152,776
Bristol	22	2,947,500	105,500	133,977
Cambridge	22	6,597,000	296,750	299,864
Canterbury	16	4,638,500	244,500	289,906
Cardiff	35	6,075,250	142,500	173,579
Dundee	12	2,761,506	282,960	230,126
Edinburgh	29	7,888,660	229,000	272,023
Glasgow	45	8,576,750	167,000	190,594
Hammersmith	17	4,567,000	260,000	268,647
Kingston upon Hull	12	2,994,500	223,000	249,542
Leeds	26	8,257,500	295,500	317,596
Leicester	20	4,044,750	210,500	202,238
Liverpool	29	5,281,000	135,000	182,103
Manchester	82	15,713,822	188,000	191,632
Newcastle upon Tyne	41	10,659,000	252,000	259,976
North Hampshire	47	10,504,000	210,000	223,489
Nottingham	24	4,780,000	228,500	199,167
Oxford	89	18,832,500	189,000	211,601
Royal Free	97	24,627,368	276,000	253,890
Royal London	38	10,790,000	272,000	283,947
Sheffield	41	10,049,221	255,000	245,103
Southampton	13	3,067,500	220,000	235,962
St George's	27	7,990,250	319,000	295,935
St Thomas'	98	32,702,500	324,500	333,699
Truro	10	1,295,500	123,750	129,550
Centres with <=4 patients meeting criteria	31	6,135,564	140,000	197,921
Centres with 5-9 patients meeting criteria	95	19,997,996	171,000	210,505

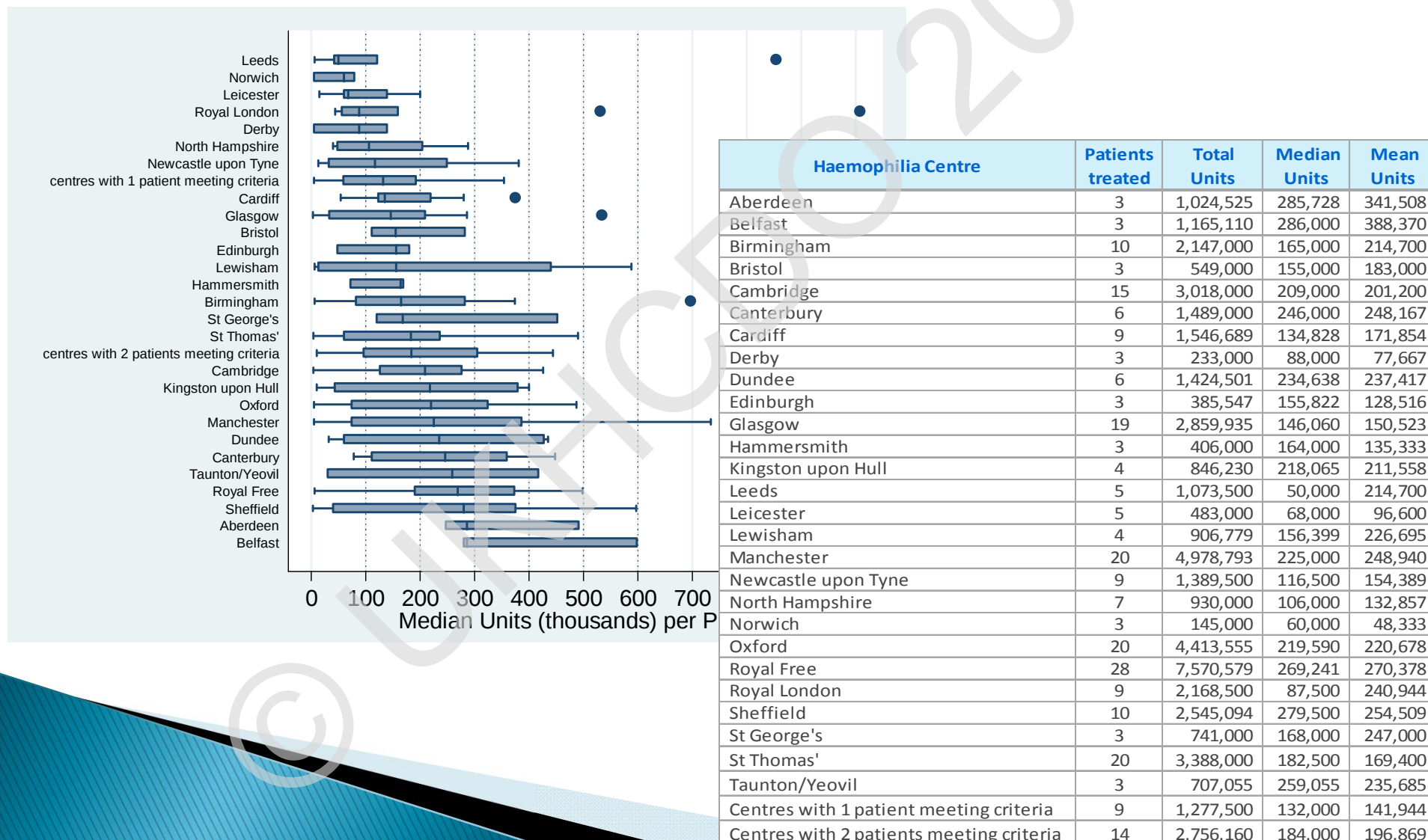


FIX usage in Severe Haemophilia B patients with no current inhibitor by centre, aged less than 18 years

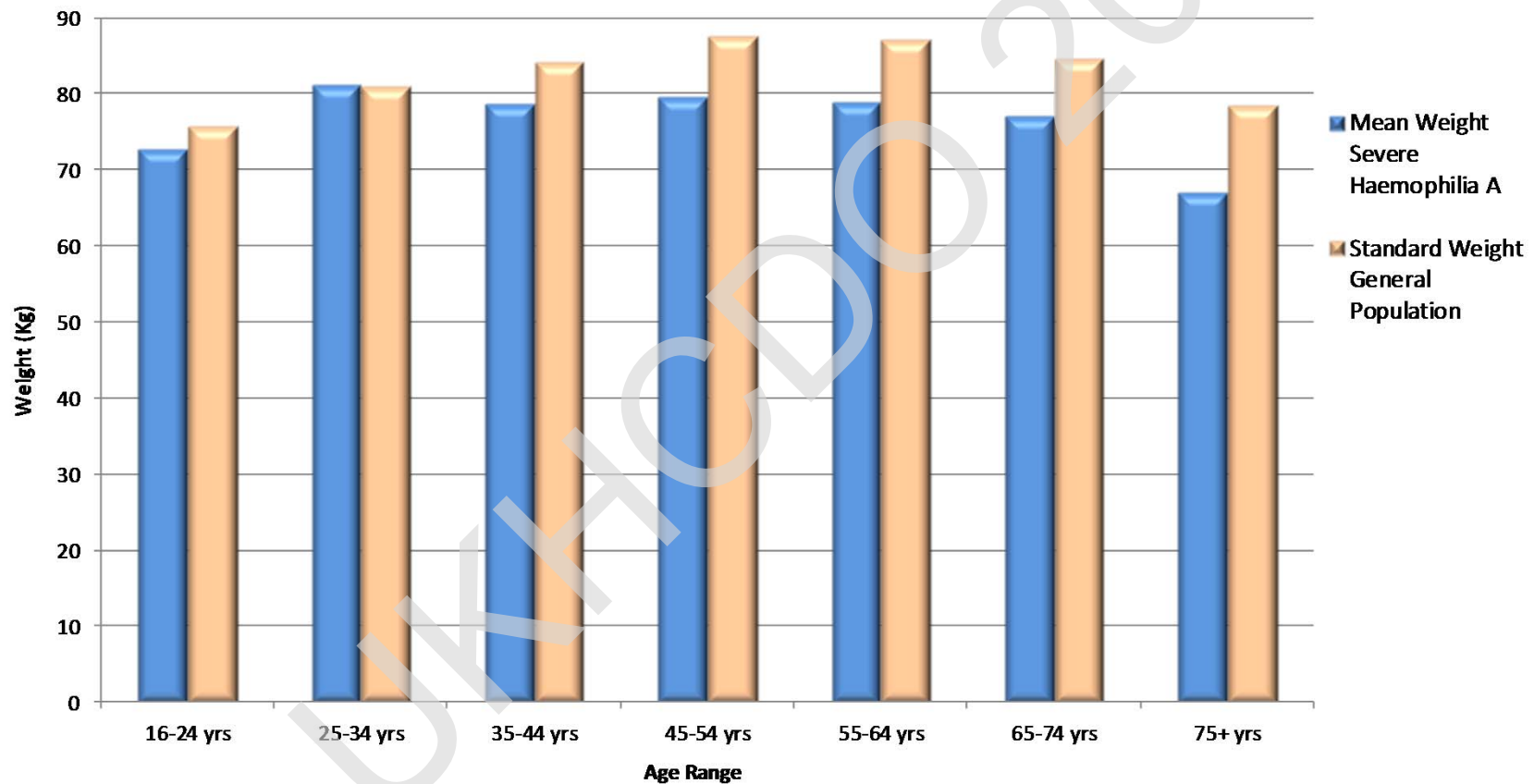


Haemophilia Centre	Patients treated	Total Units	Median Units	Mean Units
Belfast	5	470,000	100,000	94,000
Birmingham	8	380,750	11,875	47,594
Bristol	4	312,000	83,500	78,000
Cambridge	3	101,500	4,500	33,833
Canterbury	5	611,000	117,000	122,200
Glasgow	3	200,250	53,500	66,750
Great Ormond Street	22	2,848,009	111,375	129,455
Hammersmith	4	225,000	57,750	56,250
Kingston upon Hull	5	76,126	2,500	15,225
Leicester	3	301,000	51,000	100,333
Manchester	9	918,500	125,000	102,056
Newcastle upon Tyne	5	894,000	221,000	178,800
North Hampshire	4	328,500	91,500	82,125
Oxford	8	612,500	62,750	76,563
Royal Free	4	1,244,235	343,214	311,059
Sheffield	5	109,500	10,000	21,900
Shrewsbury	3	138,000	63,500	46,000
St Thomas'	5	148,750	7,500	29,750
Centres with 1 patient meeting criteria	12	1,050,737	80,875	87,561
Centres with 2 patients meeting criteria	14	2,187,580	108,750	156,256

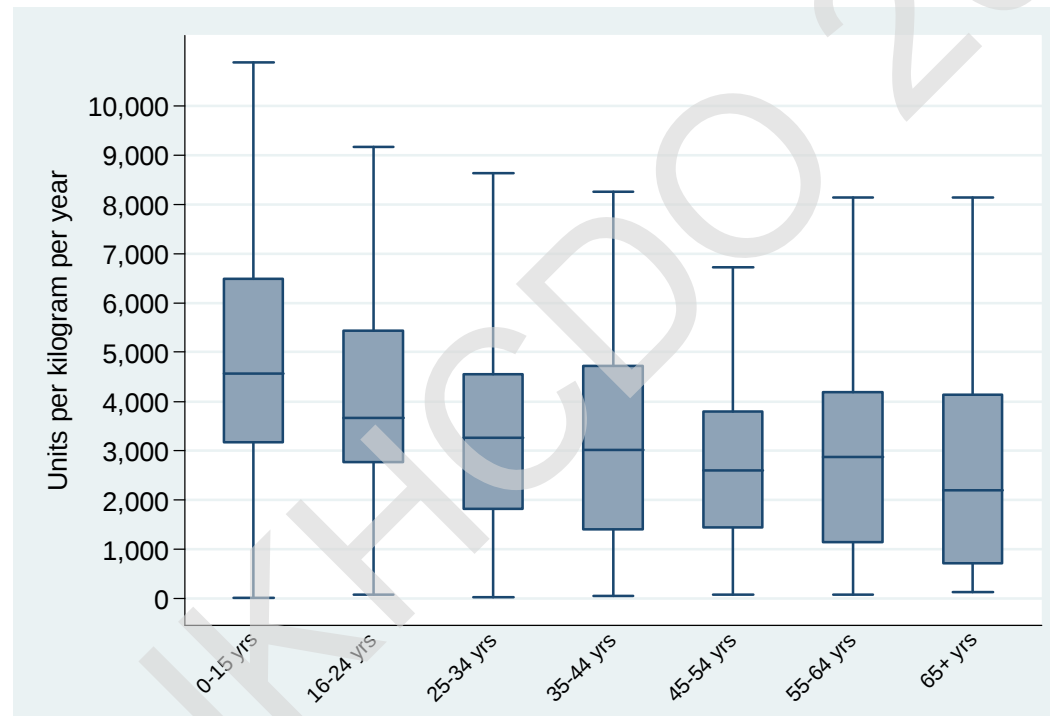
FIX usage in Severe Haemophilia B patients with no current inhibitor by centre, aged 18 years or more



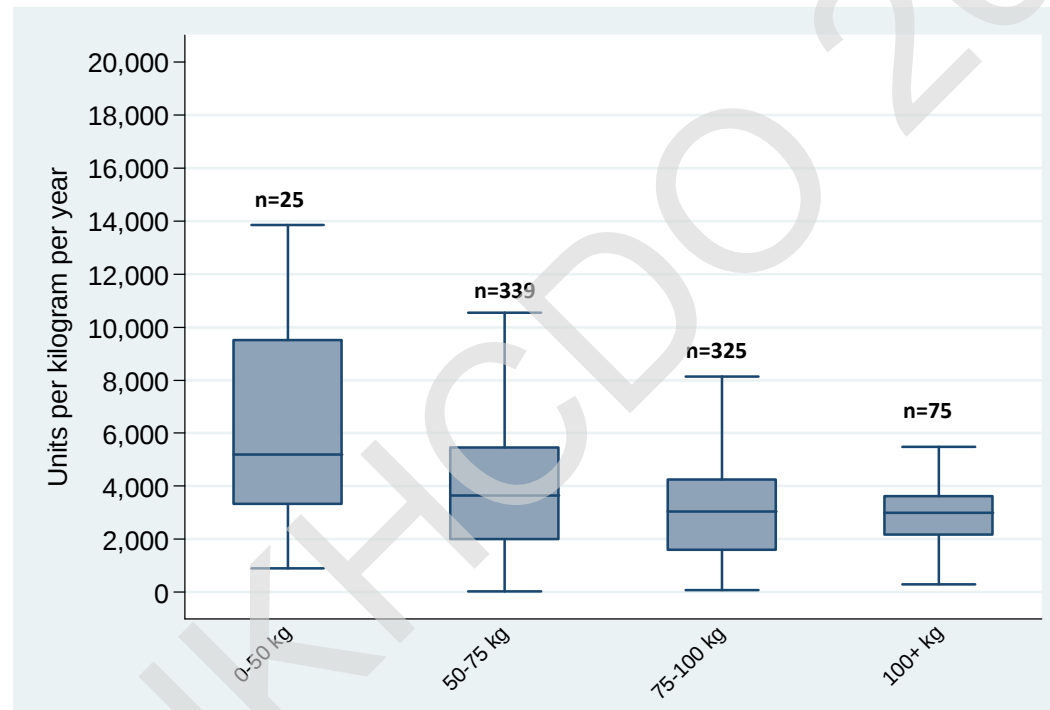
Mean weight of Severe Haemophilia A males compared to the general population, broken down by decades of life



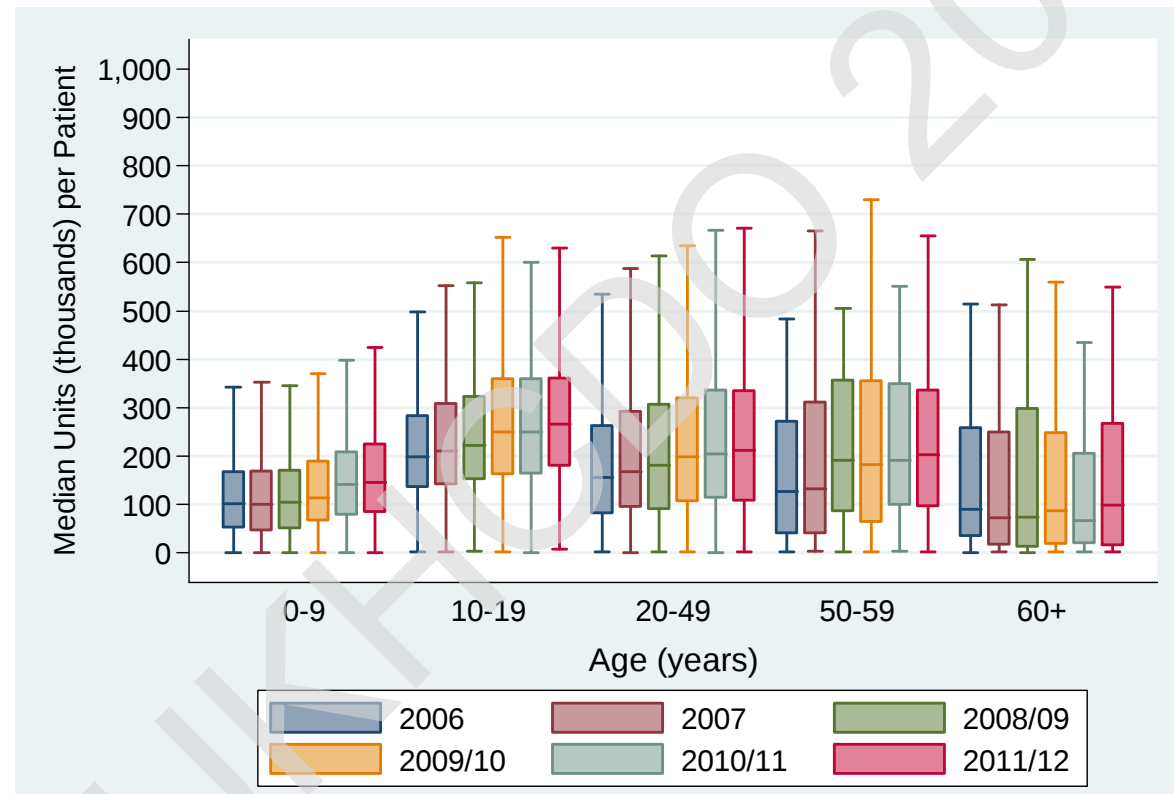
Median factor VIII units used per kilogram body weight per year in Severe Haemophilia A patients, 2011/12, broken down by decades of life



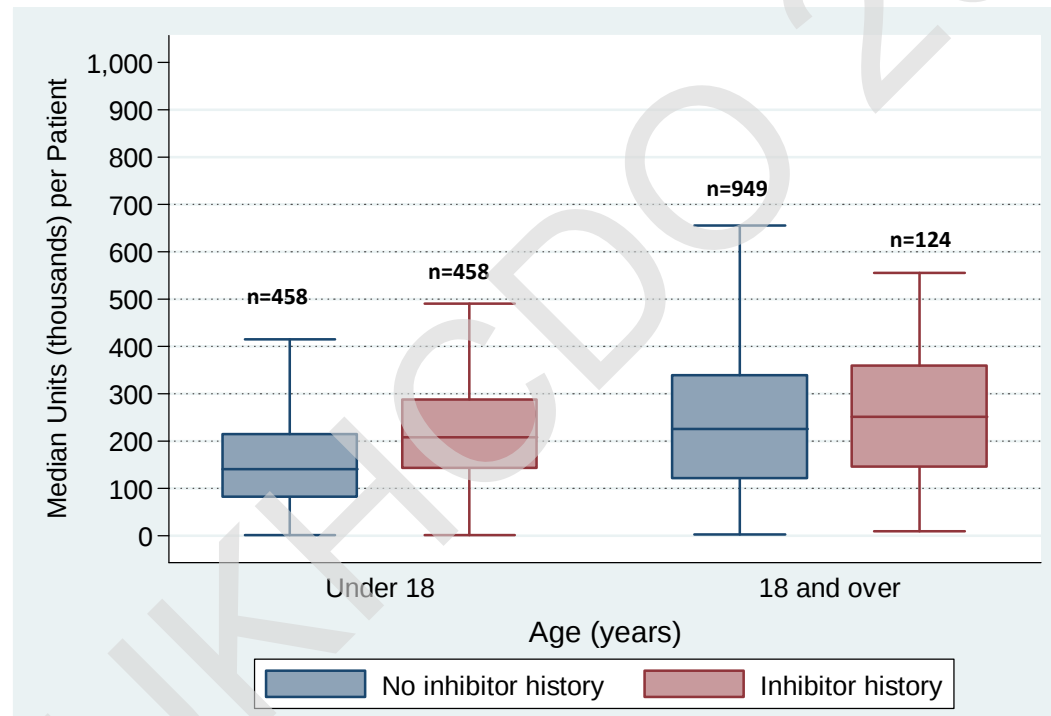
Median factor VIII units used per kilogram body weight per year in Severe Haemophilia A patients aged 16 and over, 2011/12



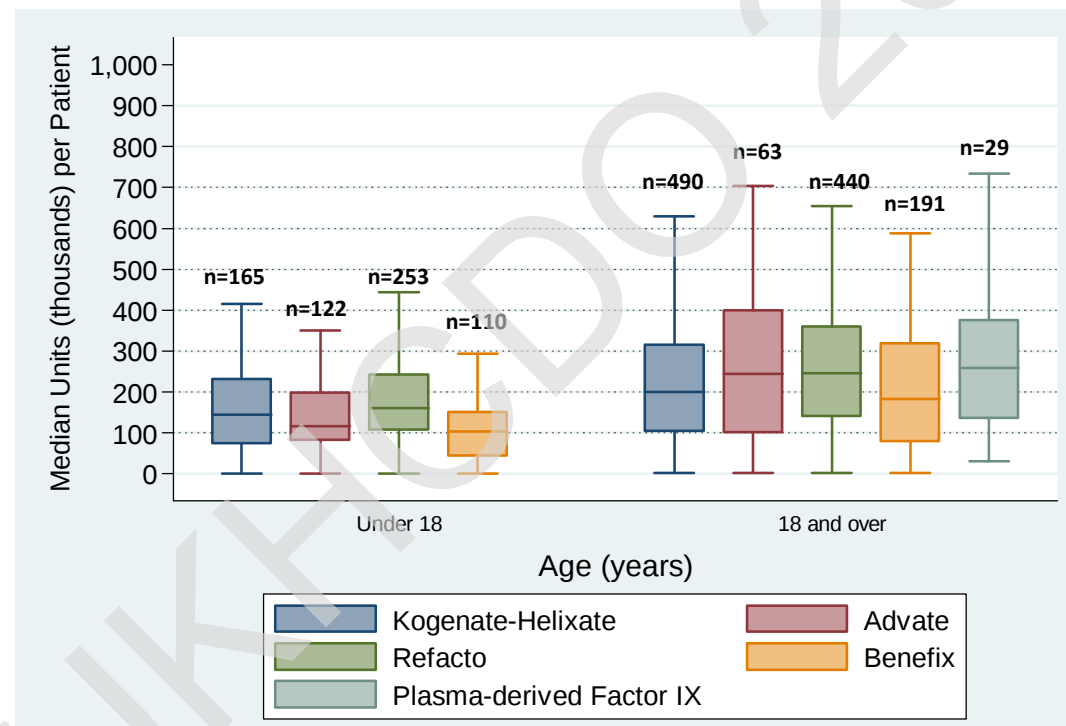
Median and interquartile range usage of factor VIII: UK patients with severe Haemophilia A lacking inhibitors broken down by age, 2006–2011



Severe Haemophilia A patients with no current inhibitor between April 2011 & March 2012: median usage by inhibitor history



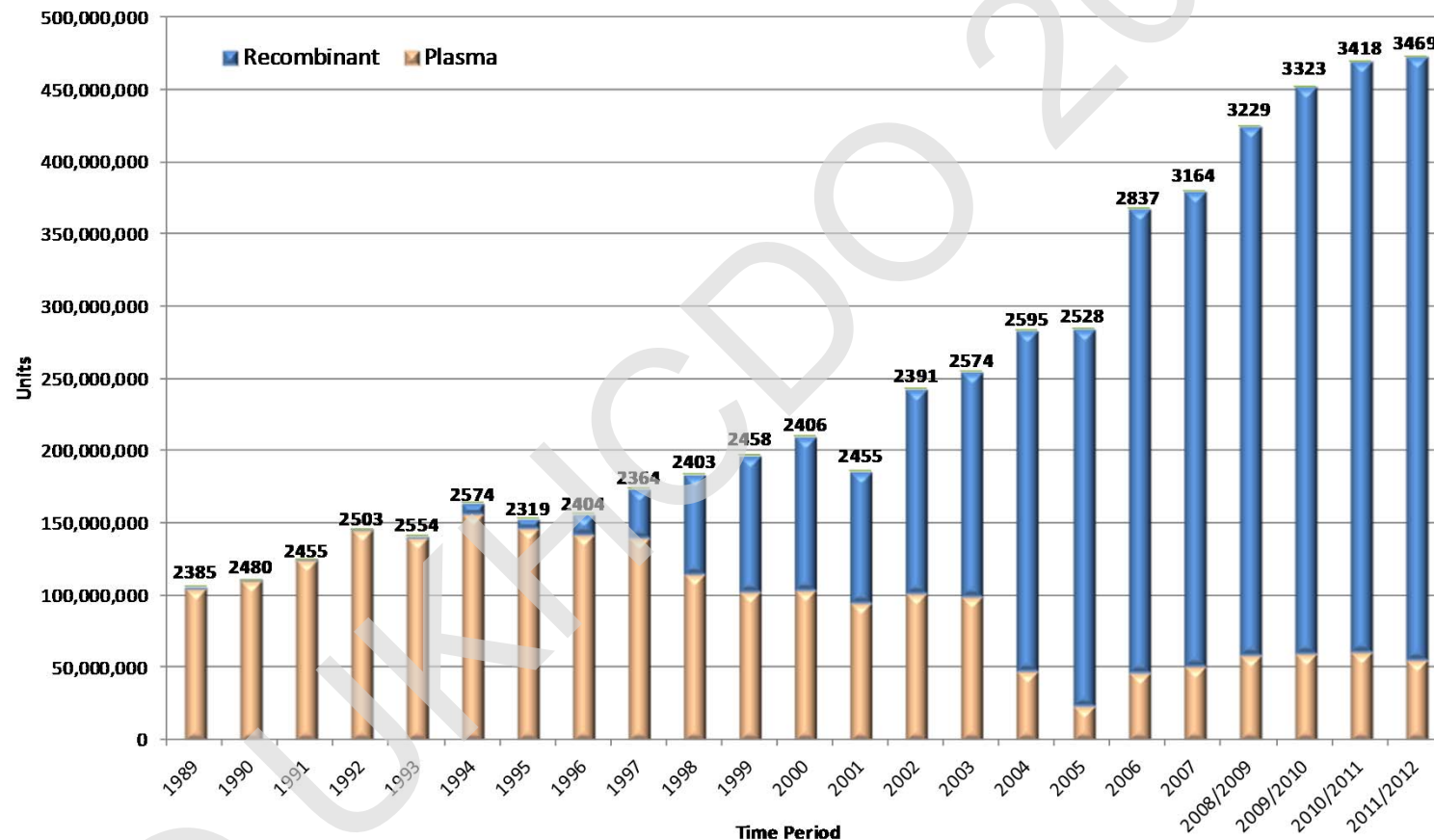
Severe Haemophilia A & B patients with no current inhibitor using only one product between April 2011 & March 2012: median usage



Factor VIII units used by UK Haemophilia Centres

Coagulation Defect	Patients Treated	Plasma FVIII	Recombinant FVIII	Total FVIII
Haemophilia A	2,783	38,801,379	417,042,135	455,843,514
Haemophilia A with Liver Transplant	1	-	10,280	10,280
Acquired Haemophilia A	32	8,500	736,122	744,622
Females with VIII deficiency	32	8,500	736,122	744,622
von Willebrand disease	592	15,599,290	22,000	15,621,290
Probable von Willebrands disease	4	9,000	-	9,000
Acquired von Willebrands	16	327,500	-	327,500
Combined V+VIII Deficiency	3	-	6,500	6,500
Other Combined Defects	12	219,000	1,144,000	1,363,000
Miscellaneous	9	158,500	-	158,500
F.XI Deficiency	1	-	3,000	3,000
Platelet defects (misc)	1	60,000	-	60,000
Haemophilia B	1	1,000	-	1,000
Total	3,487	55,192,669	419,700,159	474,892,828

Factor VIII units by UK Haemophilia Centres 1989–2012 (by calendar year between 1989 and 2007 and by financial year from April 2008 onwards)

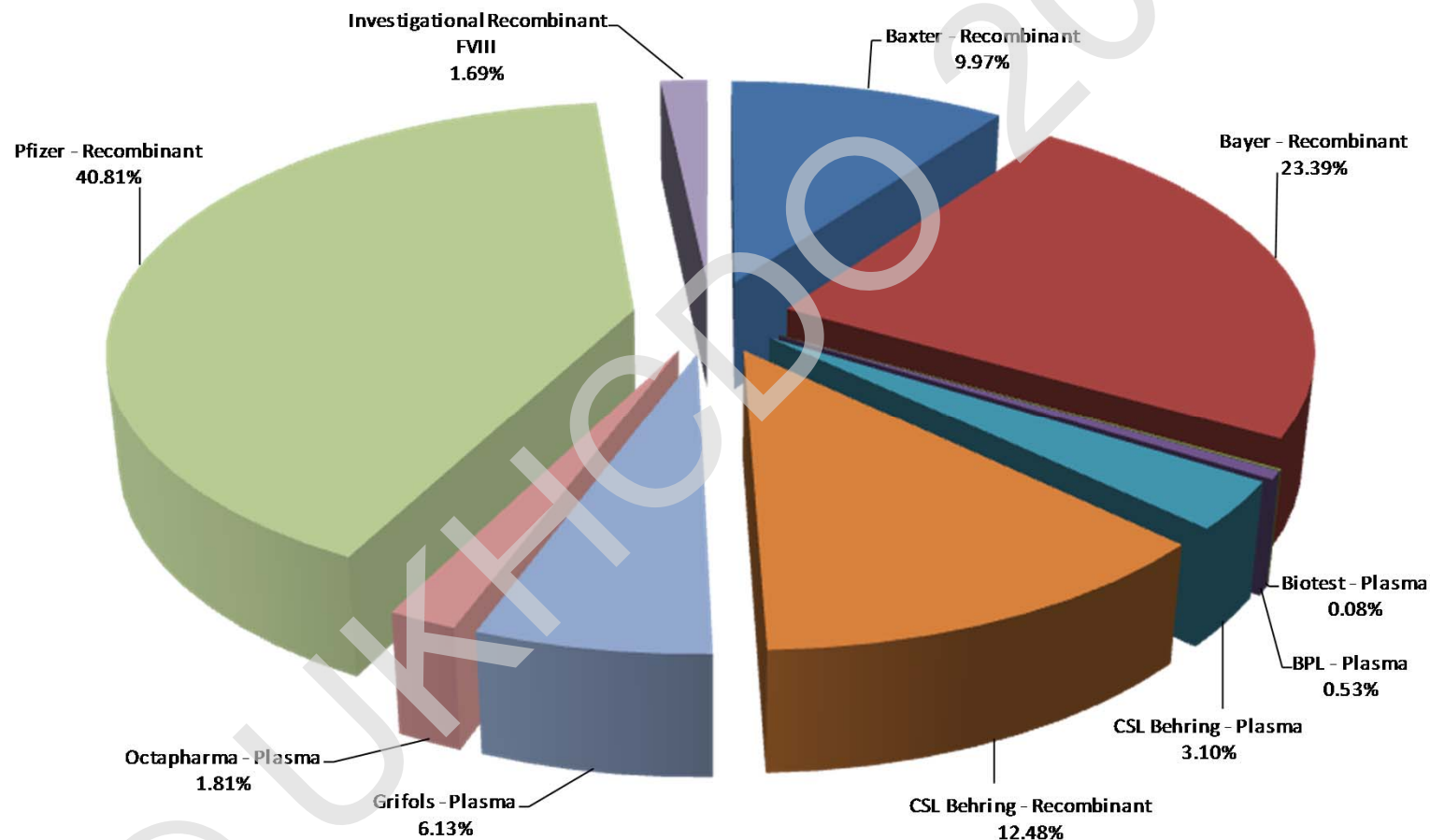


Numbers above the bars indicate number of patients with any diagnosis treated with factor VIII concentrate during the course of the year

Products used to treat Haemophilia A (including inhibitors)

Manufacturer	Product	Total Units
Baxter	Advate	47,015,652
	FEIBA	22,328,342
Bayer	Kogenate	110,638,002
Biotest	Haemoctin	380,000
BPL	FVIII 8Y	1,395,009
	Optivate	707,870
CSL Behring	Haemate P	366,000
	Helixate Nexgen	58,410,500
Grifols	Alphanate	82,000
	Fanhdi	27,285,000
Novo Nordisk	NovoSeven (mg)	22,075
Octapharma	Octanate	8,585,500
	Octaplex	1,500
Pfizer	BeneFIX	1,000
	ReFacto AF	193,036,124
	Investigational Factor VII	132
	Investigational Factor VIII	6,827,267

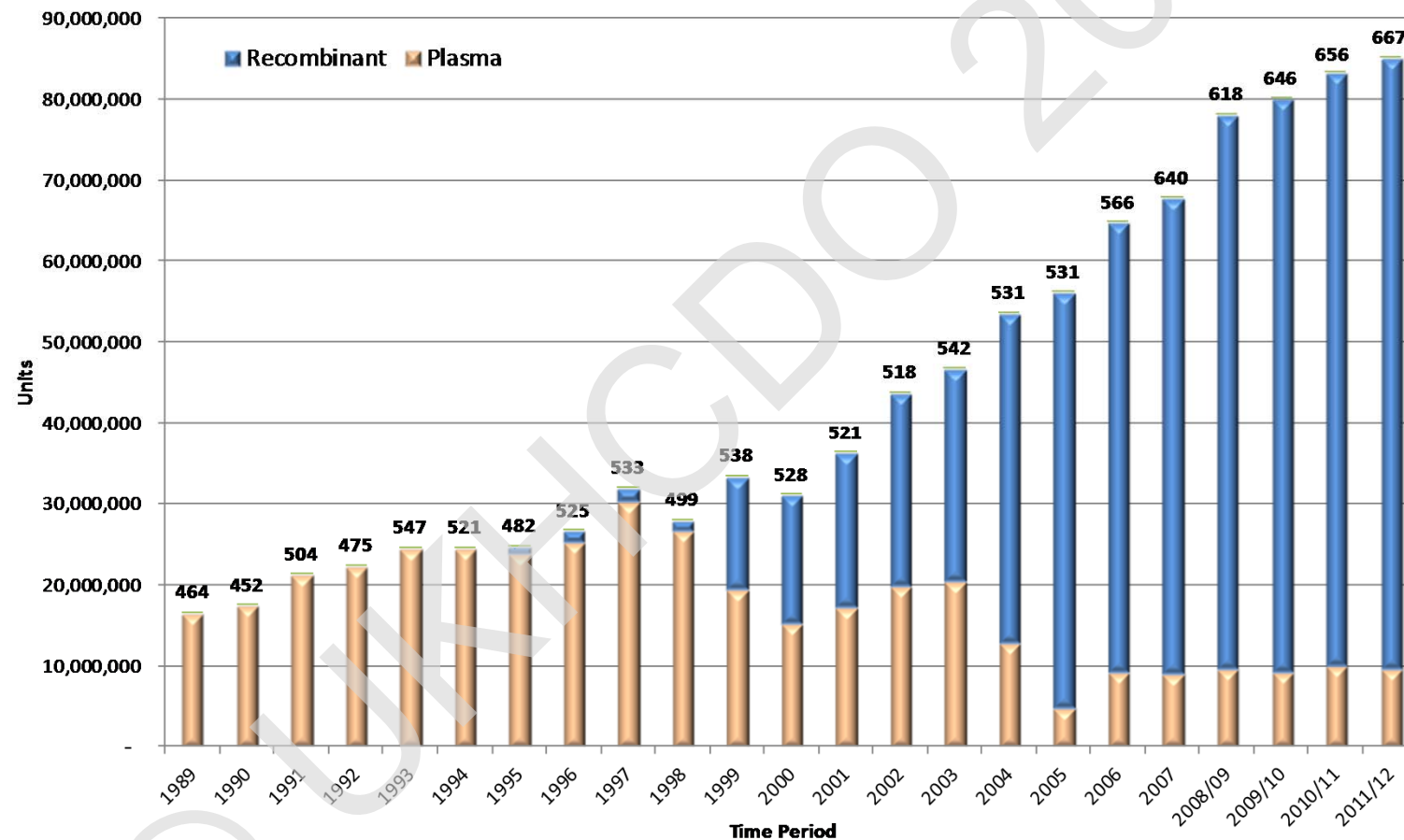
Market Share of factor VIII concentrates known to have been used by UK Haemophilia Centres



Factor IX units used by UK Haemophilia Centres

Coagulation Defect	Patients Treated	Plasma FIX	Recombinant FIX	Total FIX Units
Haemophilia A	1	-	1,000	1,000
Haemophilia B	623	9,615,350	74,489,699	84,105,049
Females with IX deficiency	39	4,000	682,741	686,741
FIX Leyden	1	-	1,000	1,000
FIX Leyden Carrier	1	-	3,000	3,000
Combined von Willebrands, FIX deficiency	1	-	2,000	2,000
Combined Haemophilia A, Haemophilia B	1	-	152,010	152,010
Total	667	9,619,350	75,331,450	84,950,800

Factor FIX units by UK Haemophilia Centres 1989–2012 (by calendar year between 1989 and 2007 and by financial year from April 2008 onwards)

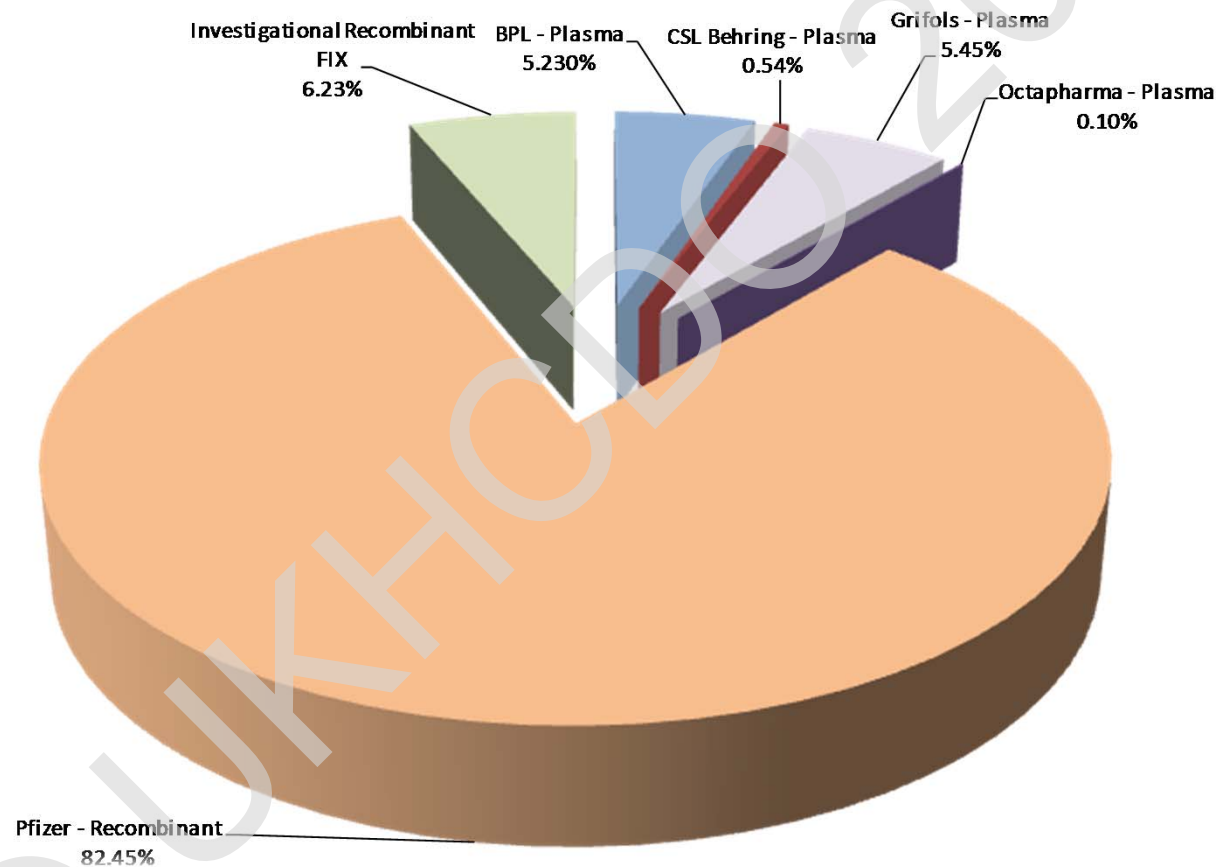


Numbers above the bars indicate number of patients with any diagnosis treated with factor VIII concentrate during the course of the year

Products used to treat Haemophilia B (including inhibitors)

Manufacturer	Product	Total Units
Baxter	FEIBA	1,355,000
BPL	Replenine	4,442,540
CSL Behring	Haemate P	1,000
	Mononine	460,000
Grifols	Alphanine	4,628,810
Novo Nordisk	NovoSeven (mg)	5,115
Octapharma	Nanotiv	84,000
Pfizer	BeneFIX	69,227,970
Anonymised	Investigational Factor VII	46
	Investigational Factor IX	4,839,356

Market Share of factor IX concentrates known to have been used by UK Haemophilia Centres



Concentrates used to treat von Willebrand's Disease

Manufacturer	Product	Total Units
Baxter	Advate	1,000
	FEIBA	155,000
Bayer	Kogenate	13,000
BPL	FVIII 8Y	155,320
	Optivate	18,500
CSL Behring	Haemate P	13,811,050
Grifols	Alphanate	1,559,420
	Fanhdia	55,000
	Wilfactin	464,190
Novo Nordisk	NovoSeven (mg)	524
Octapharma	Wilate	3,485,400
Pfizer	ReFacto AF	8,000

Inhibitors by disease severity

Coagulation Defect	Number of Patients ever known to have an inhibitor by disease severity								
	≤ 1 iu/dl			>1 and <5 iu/dl			≥ 5 iu/dl		
	In Reg *	Inhib. Pts	%	In Reg *	Inhib. Pts	%	In Reg *	Inhib. Pts	%
Haemophilia A	1906	395	20.72%	529	35	6.62%	3032	59	1.95%
Haemophilia B	416	16	3.85%	236	0	0.00%	513	0	0.00%
von Willebrand disease	120	5	4.17%	160	2	1.25%	7991	6	0.08%

Coagulation Defect	Patients with a current inhibitor between April 2011 and March 2012 by disease severity								
	≤ 1 iu/dl			>1 and <5 iu/dl			≥ 5 iu/dl		
	In Reg *	Inhib. Pts	%	In Reg *	Inhib. Pts	%	In Reg *	Inhib. Pts	%
Haemophilia A	1906	142	7.45%	529	10	1.89%	3032	20	0.66%
Haemophilia B	416	11	2.64%	236	0	0.00%	513	0	0.00%
von Willebrand disease	120	4	3.33%	160	2	1.25%	7991	3	0.04%

Von Willebrand's Sub-Types

vW Sub-types currently in register	Patients (n)
1	2,560
2 (unspecified sub-type)	115
2A	213
2B	80
2M	115
Normandy (2N)	53
3	80
Other	12
Type Reported	3,228
Type not reported	6,149

[illegible]

Acquired defects: Concentrates used by number of patients

Manufacturer	Product	Acquired Haemophilia A		Acquired von Willebrands		Acquired Prothrombin Deficiency		Acquired FV deficiency		Acquired Other	
		Pts (n)	Units (n)	Pts (n)	Units (n)	Pts (n)	Units (n)	Pts (n)	Units (n)	Pts (n)	Units (n)
Baxter	Advate	1	27,000	-	-	-	-	-	-	-	-
	FEIBA	64	5,426,265	-	-	-	-	1	76,000	-	-
CSL Behring	Beriplex	-	-	-	-	1	1,750	-	-	-	-
	Haemate P	-	-	15	321,500	-	-	-	-	-	-
Grifols	Alphanate	-	-	1	6,000	-	-	-	-	-	-
	Fanhdi	1	160,000	-	-	-	-	-	-	-	-
Novo Nordisk	NovoSeven (mg)	20	1,932	-	-	-	-	1	5	1	400
Octapharma	Octaplex	-	-	-	-	1	7,000	-	-	1	5,000
	Wilate	-	-	2	10,350	-	-	-	-	-	-
Pfizer	ReFacto AF	7	614,532	-	-	-	-	-	-	-	-
Anonymised	Investigational FVIII	1	90,092	-	-	-	-	-	-	-	-

Adverse events

Adverse Event	Number of Events
Inhibitors	17
Thromboses	4
Allergic reactions	2
Blurred vision *	1*
Hyponatraemia *	1*
Total	25

* Adverse reactions to Desmopressin

Causes of Death



Causes of death in patients with Haemophilia A, Haemophilia B, Females with FVIII & Females with FIX deficiency

Cause of Death	Severity (factor level iu/dl)				Total
	≤1	>1 and <5	≥5	Unkown	
Acute myeloid leukaemia	0	0	1	0	1
ARDS	2	0	1	0	3
Bowel perforation	1	0	0	0	1
Carcinoma	2	4	11	1	18
Cardiomyopathy	0	0	1	0	1
Cerebral haemorrhage	5	1	1	0	7
COAD	0	0	1	0	1
Hepatocellular Carcinoma	0	0	1	0	1
Infection (Bacterial)	1	1	10	0	12
Ischaemic Heart Disease	1	1	7	0	9
Liver Failure	2	0	2	0	4
Renal Failure	0	1	2	0	3
Stroke	1	0	1	0	2
Venous Thromboembolism	1	0	0	0	1
Unknown	1	0	4	0	5
Total	16	8	39	1	64

Causes of death in other coagulation defects

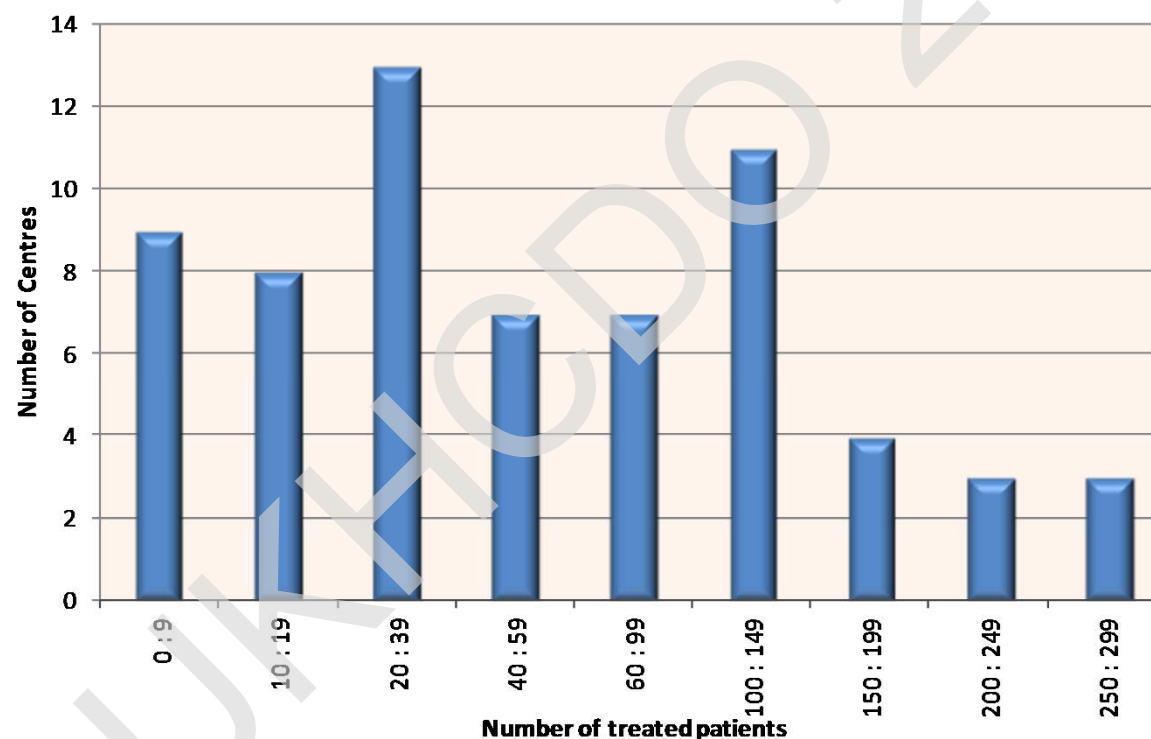
Coagulation Defect	Cause of Death	Total
Acquired F.V deficiency	COAD	1
	Infection (Bacterial)	1
Acquired Haemophilia A	Infection (Bacterial)	13
	Unknown	7
	Carcinoma	5
	Ischaemic Heart Disease	5
	Haemorrhage (Misc)	3
	COAD	2
	Renal Failure	2
	ARDS	1
	Cerebral haemorrhage	1
	Diabetic Coma	1
	Dissecting Aortic Aneurysm	1
	Lymphoproliferative Malignancy	1
	Peripheral vascular disease	1
	Ruptured Aorta (Peripheral vascular disease)	1
Acquired von Willebrands	Infection (Bacterial)	1
	Lymphoproliferative malignancy	1
Combined V+VIII Deficiency	Ischaemic Heart Disease	1
Dysfibrinogenaemia	Infection (Bacterial)	2
	Carcinoma	1
F.VII deficiency	Haemorrhage (misc)	2
	Infection (Bacterial)	1
	Liver Failure	1
	Lymphoproliferative Malignancy	1
	Unknown	1
F.XI Deficiency	Infection (Bacterial)	7
	Haemorrhage (Misc)	3
	Carcinoma	2
	Cerebral haemorrhage	2
	Ischaemic Heart Disease	2
	Lymphoproliferative malignancy	1

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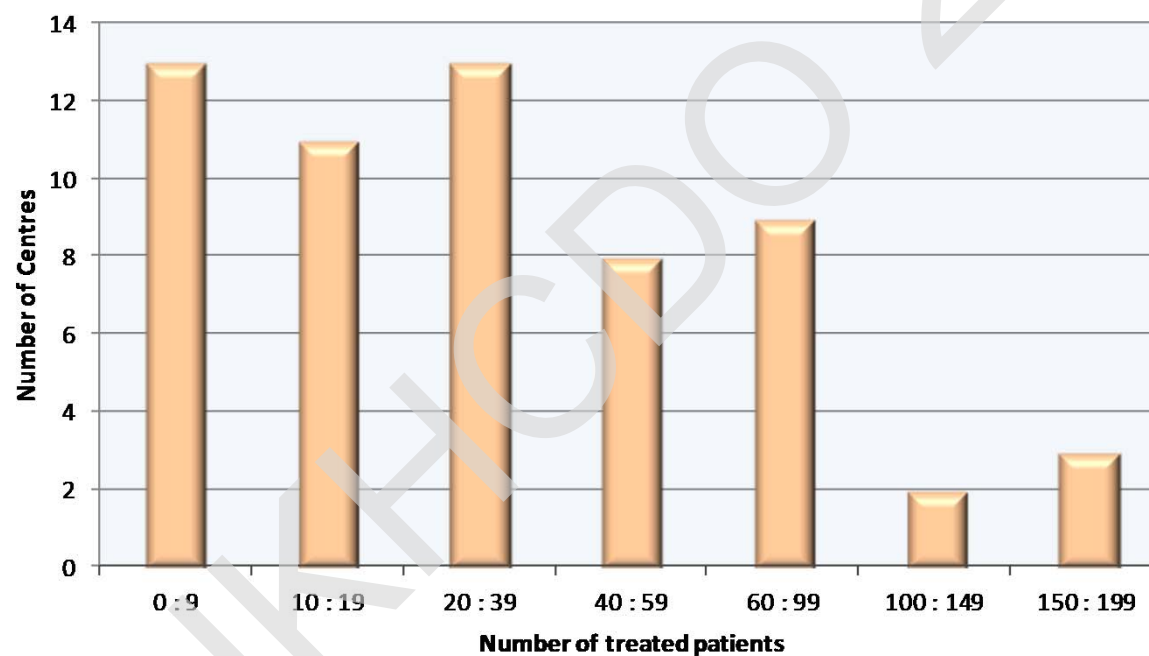
Causes of death in other coagulation defects (cont'd)

Coagulation Defect	Cause of Death	Total
Fibrinogen Deficiency	Carcinoma	1
Haemophilia A with Liver Transplant	Carcinoma	1
	Unknown	1
Miscellaneous	COAD	1
	Ischaemic Heart Disease	1
	Renal Failure	1
Multiple Diagnoses	Liver Failure	1
Platelet defects (misc)	Infection (Bacterial)	4
	Acute myeloid leukaemia	1
Severe Platelet Disorders - Other	COAD	1
	Ischaemic Heart Disease	1
Unclassified	Ischaemic Heart Disease	1
von Willebrand disease	Carcinoma	8
	Infection (Bacterial)	7
	Haemorrhage (Misc)	3
	Ischaemic Heart Disease	3
	Cerebral haemorrhage	2
	Lymphoproliferative malignancy	2
	Renal Failure	2
	Unknown	2
	Acute myeloid leukaemia	1
	ARDS	1
	COAD	1
	Intestinal Obstruction	1
	Mixed drug toxicity	1
	Stroke (Unknown)	1
	Suicide	1
	Undiagnosed metabolic disorder	1
	Venous Thromboembolism	1
Total		128

Total number of patients with Haemophilia A, Haemophilia B or von Willebrand's Disease treated by UK Haemophilia Centres



Total number of severely affected patients with Haemophilia A, Haemophilia B or von Willebrand's Disease treated by UK Haemophilia Centres



Hepatitis C Look-back Progress report



Hepatitis C Eligible Patients

Hepatitis C Look-back forms	n	%
Number of eligible patients *	27,187	
No. of patients Alive	22,607	83%
No. of patients Deceased	4,580	17%

Hepatitis C Look-back reports received

Of those patients for whom a report has been submitted	n	% of submitted	% of eligible
Number of Reports Submitted	8,396		
No. of patients Alive	7,389	88%	27%
No. of patients Deceased	1,007	12%	4%

Exposure to blood components or clotting factor concentrate and HCV status

Treatment	Ab Neg	Ab Pos, Ag Neg	Ab Pos Ag Pos	Not known	Ab pos Ag N/K	Total
None	23	0	2	3,205	1	3,231
Not known	434	126	157	2,888	13	3,618
Blood Components	226	9	29	90	2	356
Clotting Factor Concentrate or both	273	211	427	220	45	1,176
Total	956	346	615	6,403	61	8,381

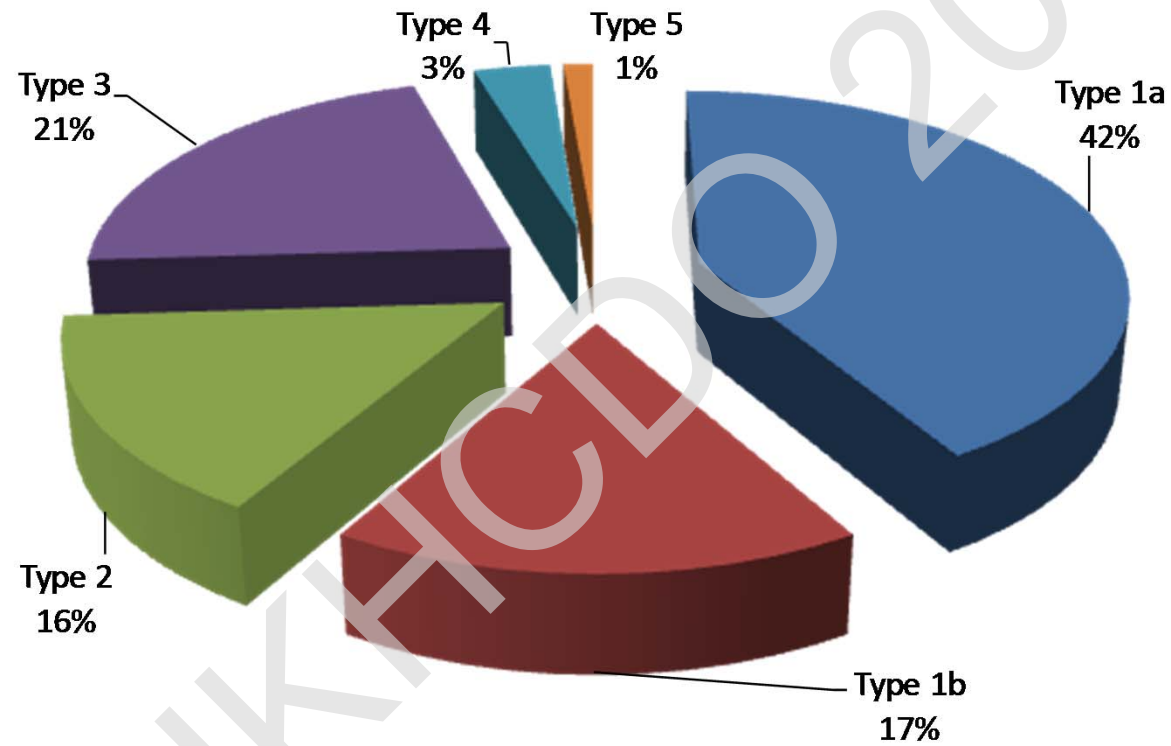
Diagnostic breakdown for patients reported to be HCV Antibody positive

Diagnosis	Severe	Moderate	Mild	Total
Haemophilia A	327	102	261	690
Haemophilia B	83	35	59	177
Females with VIII deficiency	0	0	13	13
Females with IX deficiency	0	1	9	10
von Willebrand disease	9	7	76	92
F.VII deficiency	1	0	2	3
F.X deficiency	3	0	0	3
F.XI Deficiency	0	0	2	2
Fibrinogen Deficiency	1	0	0	1
Combined von Willebrands + IX deficiency	0	0	1	1
Acquired Haemophilia A	2	0	0	2
Glanzmanns Thrombasthenia	0	0	0	0
Other platelet defects	0	0	1	1
Haemophilia A with Liver Transplant	1	0	3	4
Unclassified	0	0	3	3
Temporary coagulation defect, now normal	0	0	1	1
Total	427	145	431	1,003

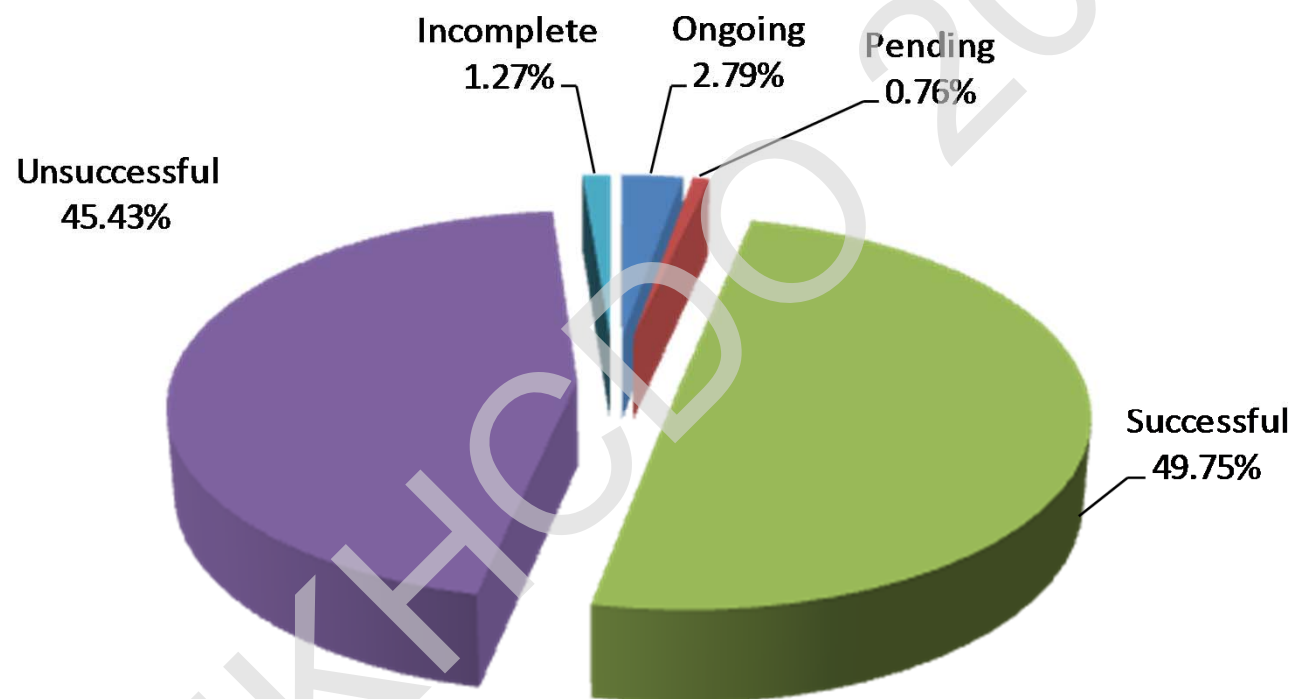
Number of patients alive with severe liver disease

Disease	Number of patients
Cirrhosis	58
Hepatocellular Carcinoma	5
Liver Failure	8
Liver Transplant	10

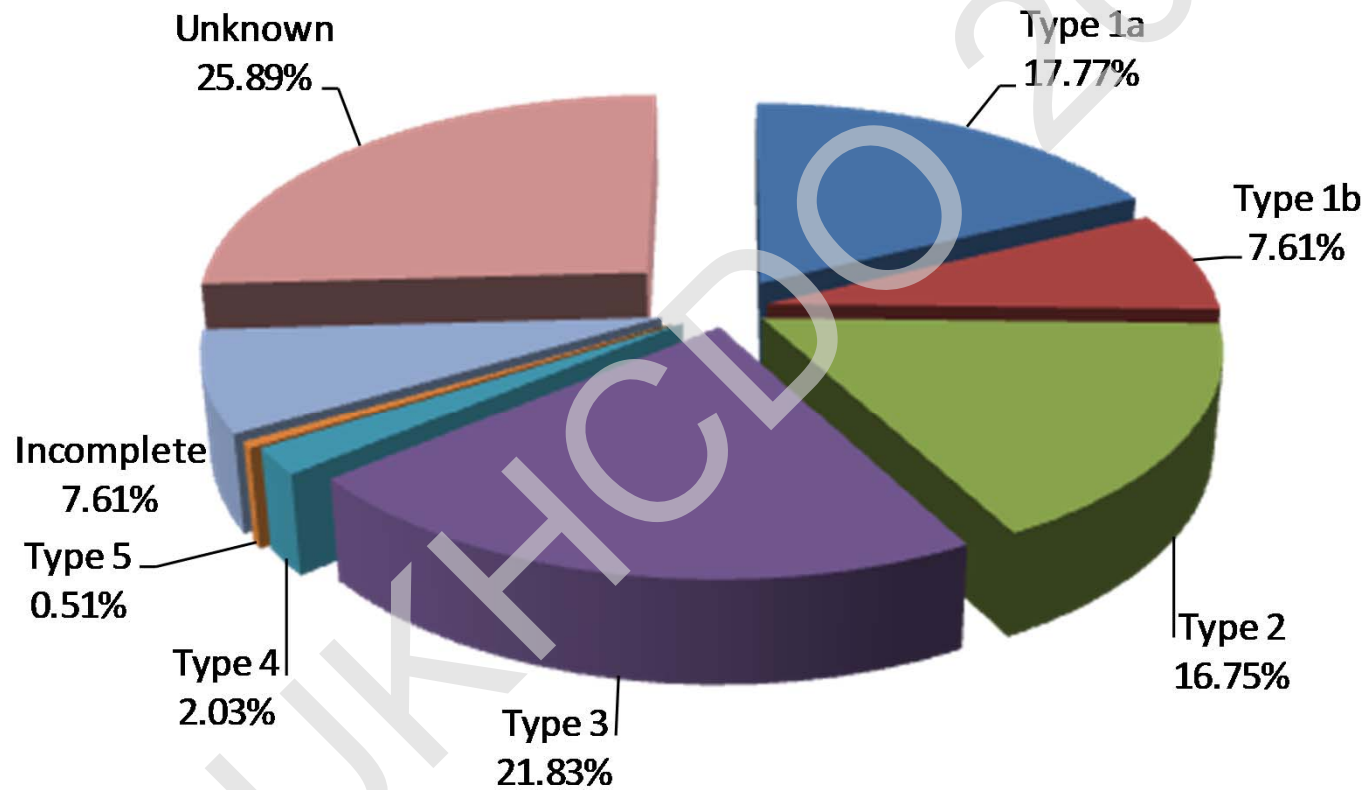
Genotypes



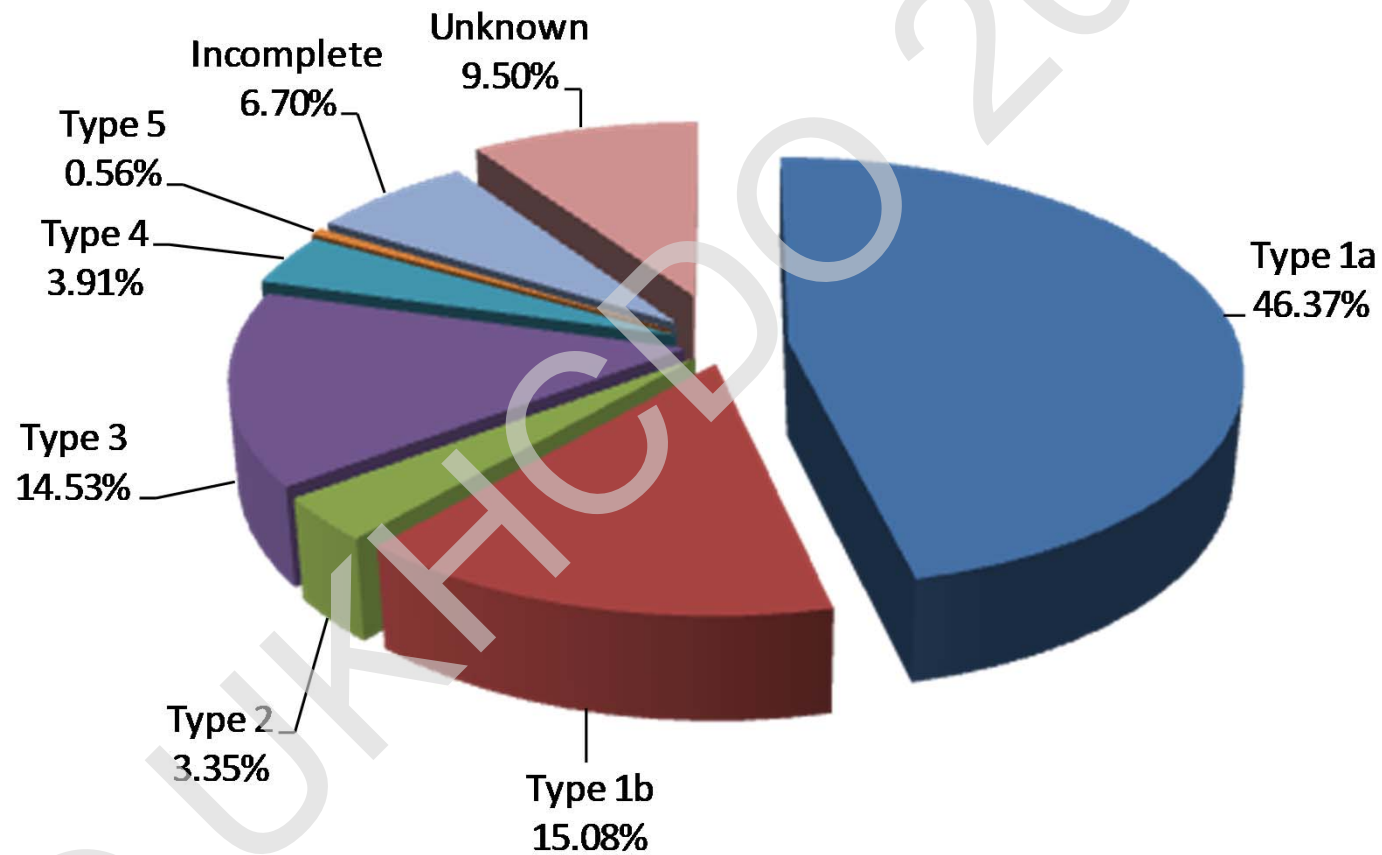
Treatment Outcomes



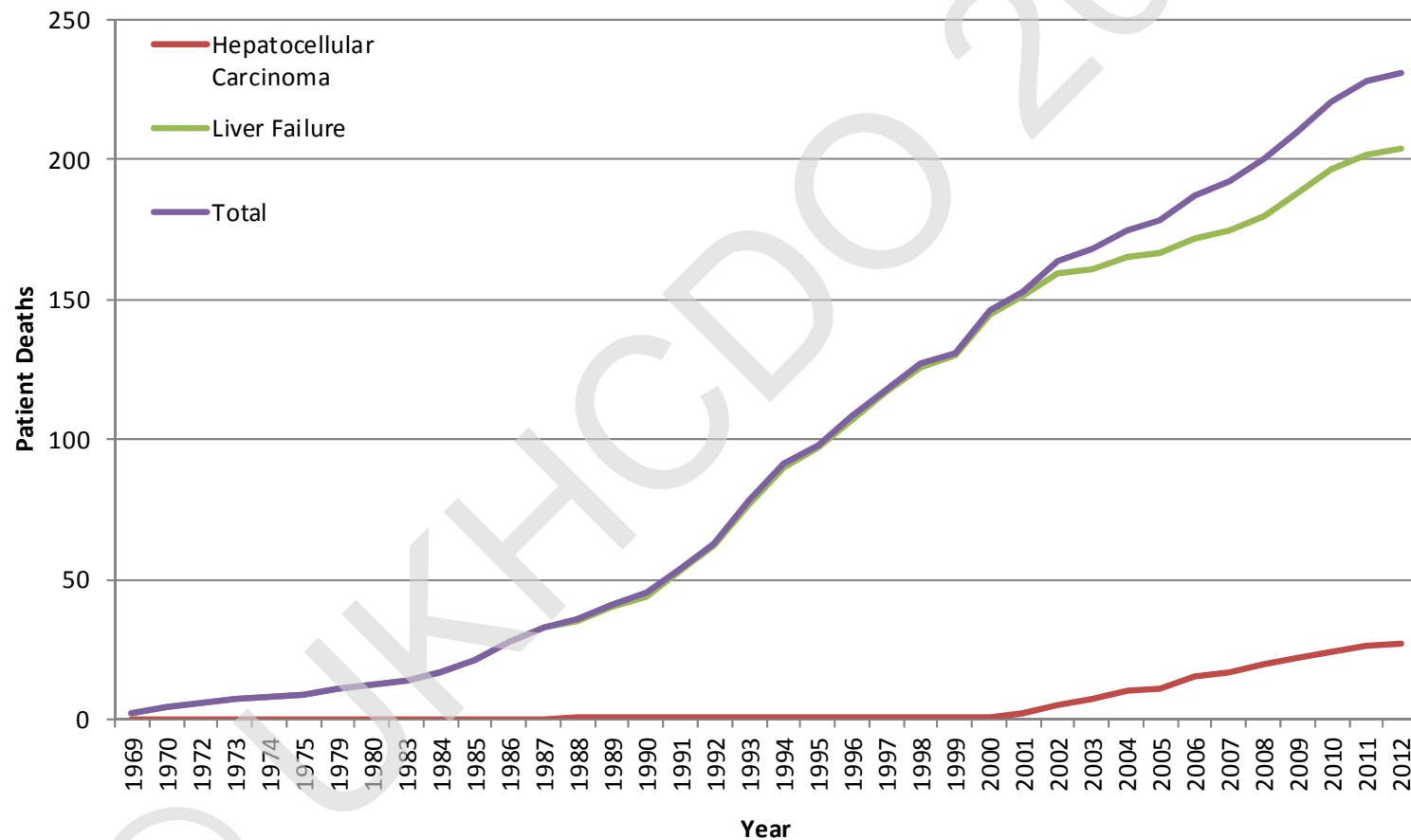
Genotypes of patients whose treatment was successful



Genotypes of patients whose treatment was unsuccessful



Cumulative incidence chart of deaths from hepatocellular carcinoma or liver failure in UK patients with bleeding disorders 1969–2012



Hepatitis C Look-back – Centre Returns

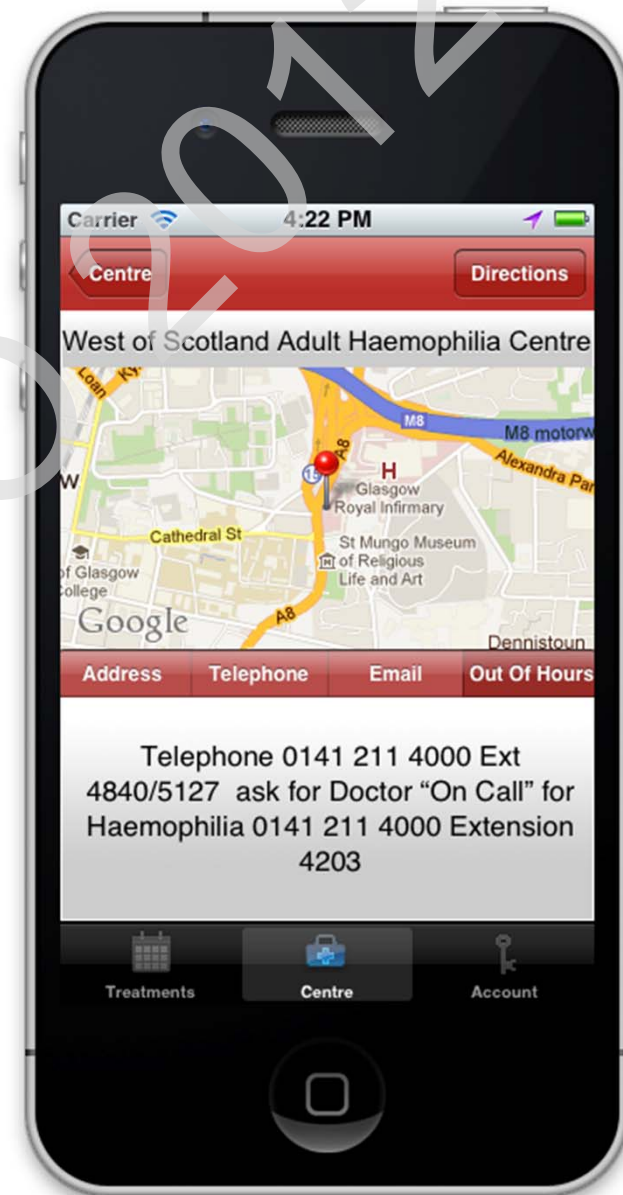
Completed Return	Partial Return	No Return
Barnstaple	Bangor	Aberdeen
Bristol (Infirmary & Children's)	Belfast - Adult's	Ashford & St. Peters
Canterbury	Birmingham (Queen Elizabeth)	Belfast - Children's
Glasgow (R.H.S.C.)	Birmingham Children's	Camberley (Frimley Park)
Lincoln	Bournemouth / Poole	Carshalton
Norwich	Bradford	Colchester
Nottingham	Brighton	Dorchester
Sheffield (Children's)	Cambridge	Eastbourne
Southampton	Cardiff	Gillingham, Kent (Medway)
Staffordshire (Stoke on Trent)	Chichester	Harrow (Northwick Park Hosp.)
Truro	Coventry	Inverness
Worcester	Derby	James Paget
	Dundee	Kettering
	Edinburgh	Lancaster
	Exeter	Liverpool Children's
	Glasgow (R.I.)	Manchester Children's
	Great Ormond Street	Middlesbrough
	Hammersmith Hospital, London	Milton Keynes
	Ipswich	Newport
	Kingston upon Hull (Hull)	Northampton
	Leeds	Peterborough
	Leicester	Plymouth
	Lewisham	St Thomas' and Guy's Hospital
	Liverpool (R. I.)	Thornton Heath
	Luton	U.C.H. and Middlesex Hospitals
	Manchester (Adults)	Whitehaven
	Newcastle upon Tyne	Wolverhampton
	North Hampshire (Basingstoke)	
	Oxford	
	Portsmouth	
	Royal Free	
	Salisbury	
	Sheffield (Royal Hallamshire)	
	Shrewsbury	
	St George's Hospital, London	
	St. Leonard's on Sea	
	Swansea	
	Taunton / Yeovil	
	The Royal London Hospital	
	Torquay	
	York	

Haemtrack Report



Haemtrack iPhone App

- Over 180 patients
- Does not require a wireless or mobile data connection
- Built-in Haemophilia Centre locator
- Remaining mobile platforms starting with the development of an application for Google Android very shortly



Haemtrack Home Delivery Interface

- Evaluated with the help of the 'Factor Direct' delivery company
- Records the deliveries that have been made to a patient, including product, units, batch and expiry date
- Eliminates the possibility of transcription errors
- Stock audit immediately available to centre staff

HAEMTRACK HOME THERAPY SUPPORT SERVICE

Home Admin

Welcome [Logout](#)

My Guide
You are logged in as Haemtrack Stock Admin
From here you can record a new delivery to a patient or view details of a previously recorded delivery.

Recent Batches

Batch	Size	Expires
LE01L035AJ	1000	01-Sep-2013
A1234	1000	01-Jan-2013
A9876	1000	01-Jan-2013
BEN872	500	01-Jan-2013

Support
If you notice an error with previous deliveries please contact the NHD team.
Tel : 0161 277 7991
Email : nhd.support@nhs.net

Add New Delivery JOHN BLOGGS (1 Jan 2005)

* Delivery Date : 06, September, 2012

* Delivery Time : Please use 24 hour clock

* Enter Details Of Each Batch Delivered :

* Product:	* Batch No:	* Vials:	* Vial Size:	Units	* Expires
Please Select			X	= 0 IU	

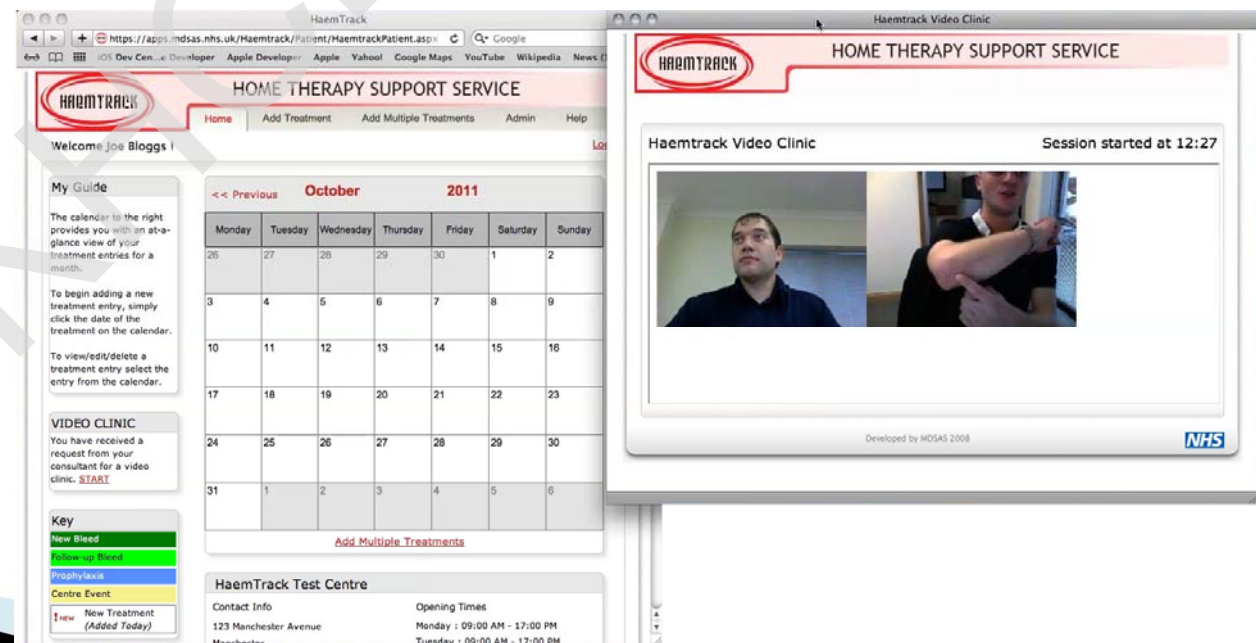
[Add another batch \(+\)](#) Total Units = 0 IU

[Show Stock for JOHN BLOGGS \(1 Jan 2005\)](#)

Developed by MDSAS

Haemtrack Video Consultation Module

- Improved patient / clinician contact
- Simple webcam utilises similar technology to Skype
- Allows the booking of a video consultation slot
- The consultation is initiated by the clinician from within Haemtrack
- Currently seeking funding to complete development



PLEASE RETURN THIS FORM TO YOUR HAEMOPHILIA CENTRE WHEN COMPLETE

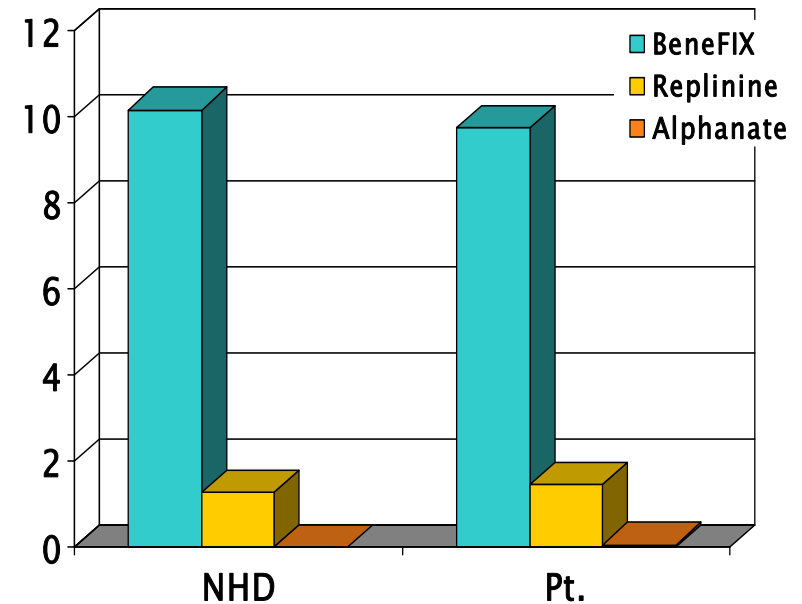
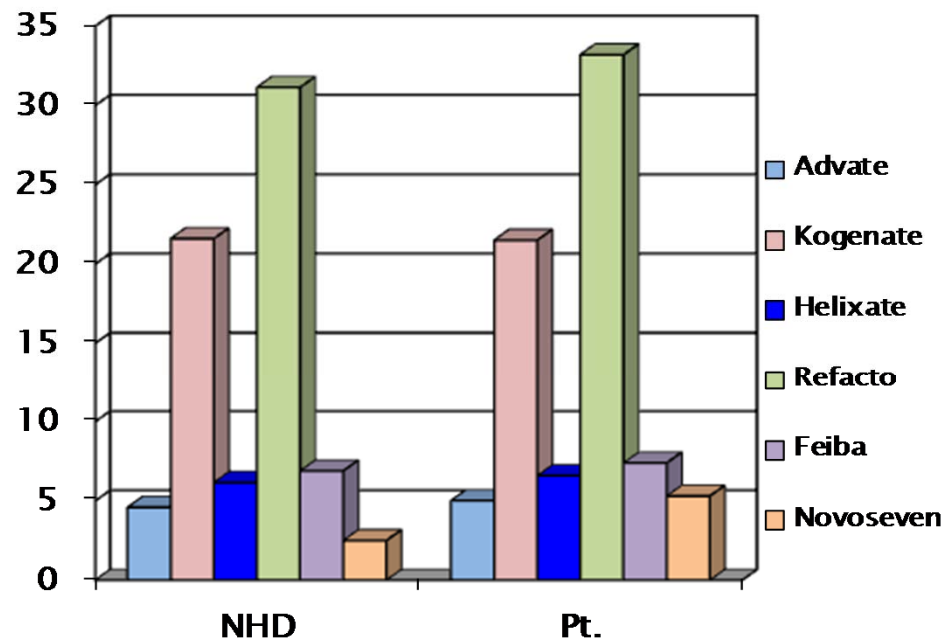
- www.haemtrack.nhs.uk

www.haemtrack.nhs.uk

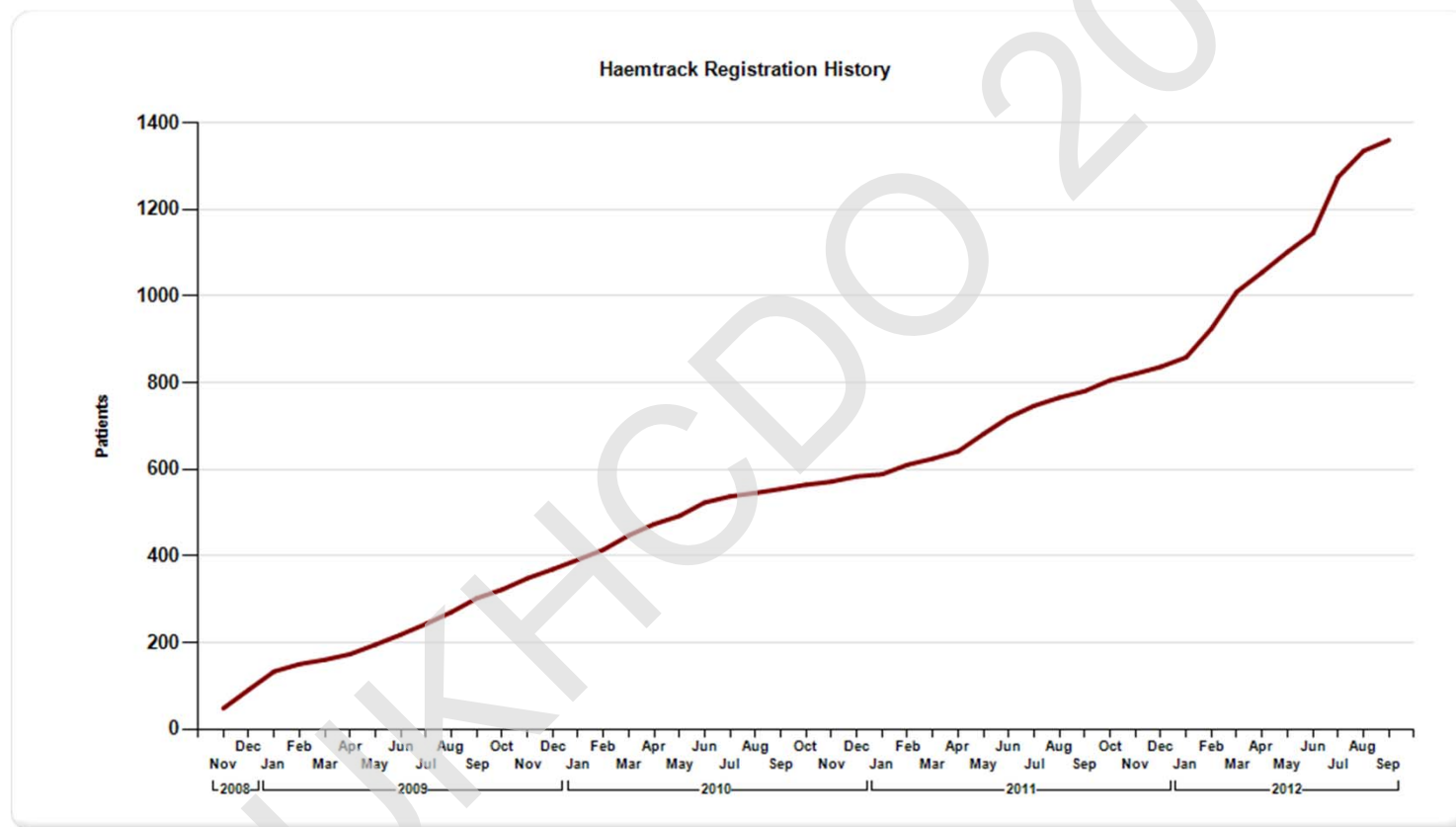
Product usage – comparison between HAEMTRACK and NHD

Treatment Period: 1 st October 2011 - 31 st March 2012		NHD reported issued	Haemtrack reported used	% Match
Haemophilia A	Advate	4,592,750	5,008,450	109.05%
	BPL 8Y	483,029	189,360	39.20%
	Fanhdi	378,000	450,000	119.05%
	FEIBA	6,894,000	7,394,000	107.25%
	Helixate NexGen	6,159,500	6,588,000	106.96%
	Kogenate	21,598,002	21,496,604	99.53%
	Nanotiv	0	2,000	-
	NovoSeven	2,508	5,281	210.57%
	Octanate	293,000	259,000	88.40%
	Refacto AF	31,147,920	33,212,354	106.63%
Haemophilia B	Alphanine	0	44,926	-
	Benefix	10,171,284	9,754,483	95.90%
	Replenine	1,266,050	1,448,320	114.40%
von Willebrands	Alphanate	254,000	300,024	118.12%
	Haemate-P	188,000	504,000	268.09%
	Wiloctin	915,300	971,100	106.10%
Factor VII Deficiency	FVII (Baxter)	46,800	60,440	129.15%
	NovoSeven	110	112	101.82%
Factor X Deficiency	Octaplex	32,500	45,000	138.46%

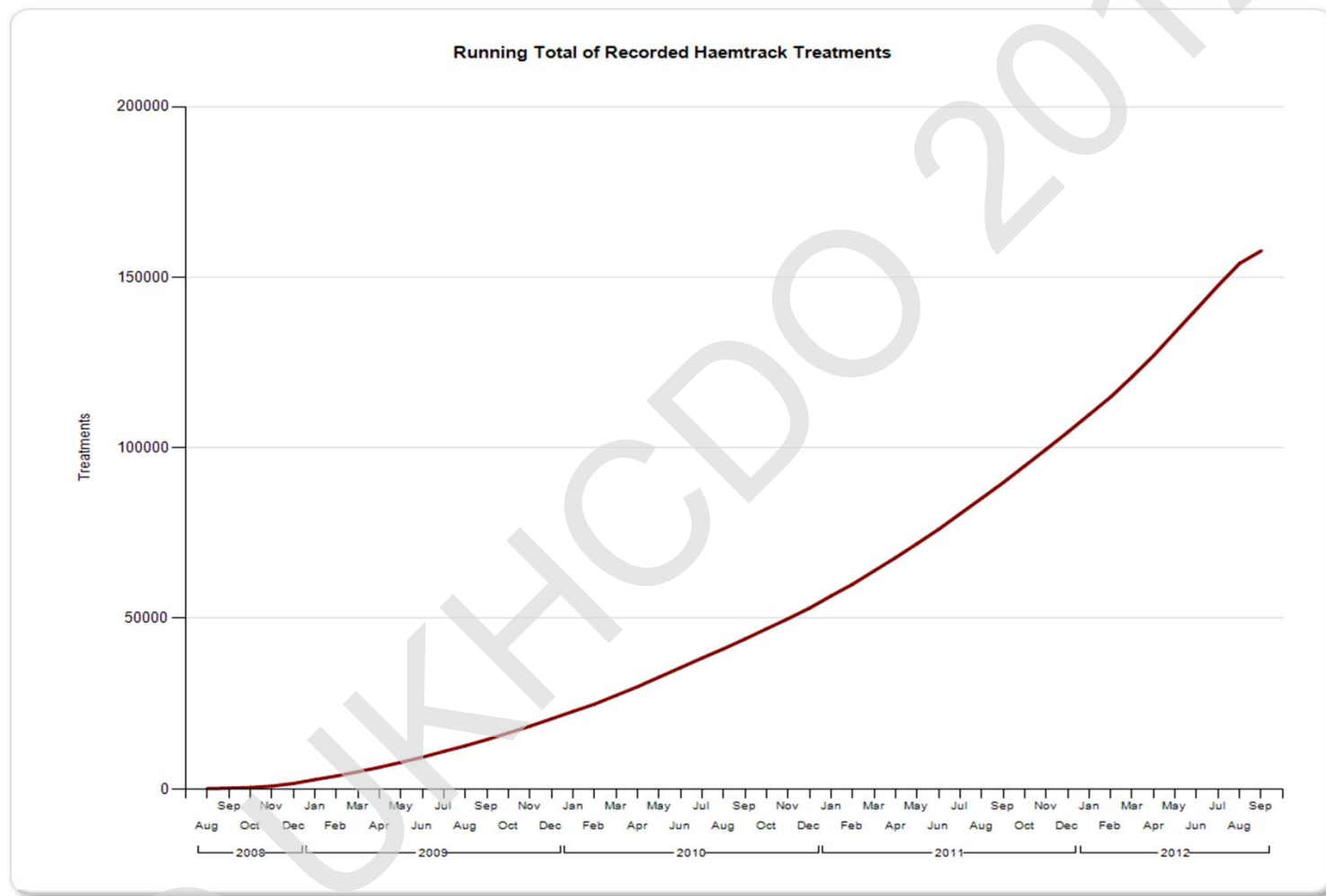
Product usage – comparison between HAEMTRACK and NHD (Million iu)



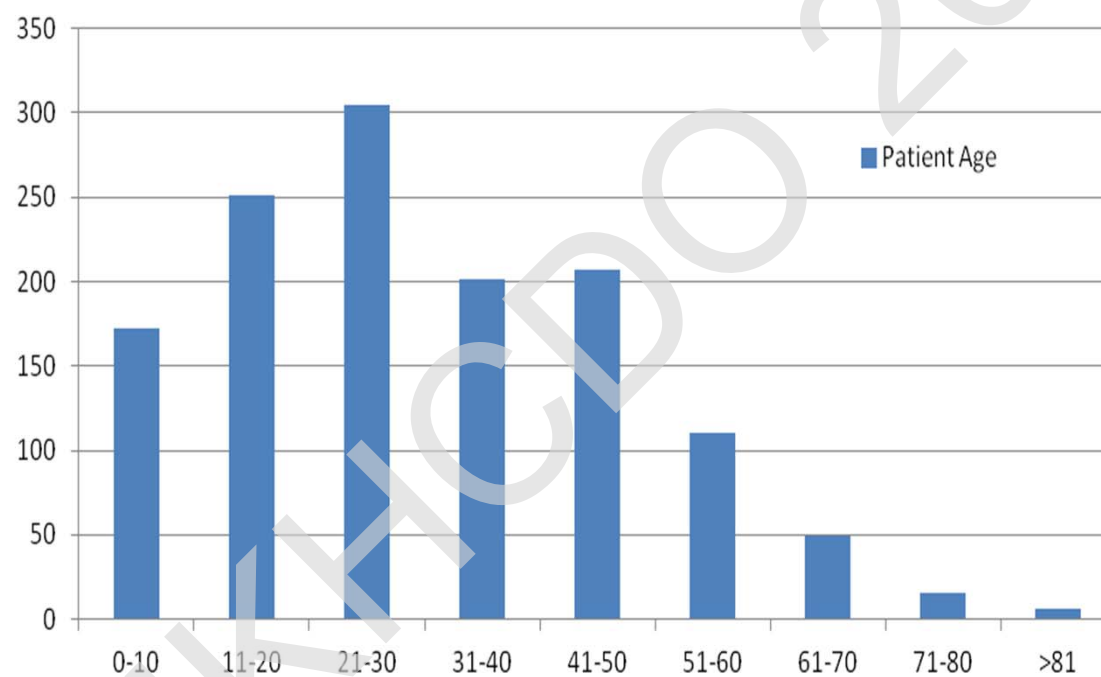
Patient Registrations



Patient Treatments Recorded



Haemtrack Users – Age Breakdown



Diagnosis

Coagulation Defect	Patients (n)	% of Total
Haemophilia A	1,011	79.17%
Haemophilia B	203	15.90%
von Willebrands	52	4.07%
Factor VII Deficiency	5	0.39%
Factor X Deficiency	4	0.31%
Congenital TTP	2	0.16%
Total	1,277	

Coagulation Defect Severity

Coagulation Defect	% of Patients		
	Severe	Moderate	Mild
Haemophilia A	87.37%	9.77%	2.86%
Haemophilia B	83.70%	13.33%	2.96%

Registered Centres

Centre Name	Patients Registered (n)
Oxford Haemophilia Centre	149
Guy's & St Thomas' Haemophilia Reference Centre	129
Barts Health NHS Trust	94
Newcastle	86
Manchester Royal Infirmary	81
Cambridge Comprehensive Haemophilia Centre	78
Sheffield (Adults)	72
Royal Free Haemophilia Centre and Thrombosis unit	56
Bristol Haemophilia Centre	49
St Georges Healthcare NHS Trust	43
Nottingham Haemophilia Centre	40
Basingstoke Haemophilia Comprehensive Care Centre	35
Kent Haemophilia Centre	34
Leicester Royal Infirmary Haemophilia Centre	34
Glasgow Royal Infirmary	26
Dundee Haemophilia Centre	23
West Midlands Adult Comprehensive Care Centre	23
Arthur Bloom Centre - Cardiff	22
Truro Haemophilia Centre	21
Bradford Haemophilia Centre	20
Hammersmith Hospital, Imperial College ACHT	20
Hull Royal Infirmary	18
Southampton Haemophilia Care Centre	17
Royal Hospital for Sick Children, Glasgow	17
United Lincolnshire Hospitals NHS Trust	17
Royal Manchester Children's Hospital	11
Edinburgh Haemophilia & Thrombosis Centre	9
Swansea Haemophilia Centre	8
Torbay Hospital	6
St James' Hospital	6
The Roald Dahl Centre	4
Shrewsbury and Telford NHS Trust	4
North Staffordshire	4
Lewisham	4
Great Ormond Street Hospital	4
Aberdeen	2
York Teaching Hospital NHS Foundation Trust	2
Inverness Haemophilia Centre	1
Taunton	1
Total	1270

Treatment Regime – recorded by centre staff

Treatment Regime	% of Patients *
Prophylaxis	70.78%
On Demand	28.88%
Immune Tolerance	0.33%

Treatment type – recorded by the patient

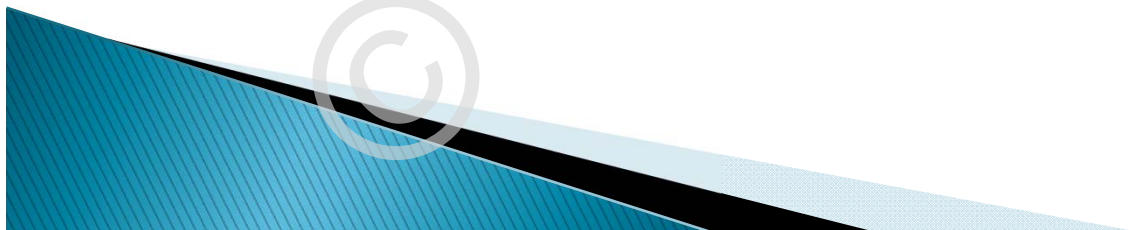
Treatment Type	Treatments Entered (n)	% of Total
Routine Prophylaxis	118,869	79.90%
New Bleed	11,150	7.49%
FollowUp Bleed	9,570	6.43%
Prescribed Treatment	3,749	2.52%
Activity	1,996	1.34%
Immune Tolerance	1,237	0.83%
Other	1,121	0.75%
Surgery	867	0.58%
Physiotherapy	220	0.15%
Total	148,779	

Bleed Position

Bleed Position	Bleeds (n)	% of Total
Elbow – Left	1,089	10.34%
Ankle – Left	1,064	10.10%
Ankle – Right	1,039	9.86%
Elbow – Right	964	9.15%
Knee – Left	820	7.78%
Knee – Right	775	7.36%
Not listed	316	3.00%
Back	266	2.52%
Shoulder – Left	251	2.38%
Shoulder – Right	221	2.10%
Other Tissue	217	2.06%
Thigh – Right	217	2.06%
Head	209	1.98%
Thigh – Left	208	1.97%
Hand – Right	180	1.71%
Foot – Right	172	1.63%
Lower Arm – Left	172	1.63%
Lower Arm – Right	171	1.62%
Wrist – Left	170	1.61%
Nose Bleed	168	1.59%
Wrist – Right	163	1.55%
Upper Arm – Left	158	1.50%
Foot – Left	151	1.43%
Hand – Left	145	1.38%
Toe - Right Foot	139	1.32%
Calf – Right	135	1.28%
Upper Arm – Right	132	1.25%
Hip – Right	128	1.21%
Hip – Left	126	1.20%
Finger - Right Hand	119	1.13%
Calf – Left	113	1.07%
Lower Leg – Left	86	0.82%
Lower Leg – Right	85	0.81%
Finger - Left Hand	84	0.80%
Toe - Left Foot	84	0.80%
Total	10,537	

Bleed location

Bleed Location	Bleeds (n)	% of Total
Joint	7,303	63.29%
Muscle / Soft Tissue	3,083	26.72%
Mouth	282	2.44%
Other	871	7.55%
Total	11,539	



Bleed Cause

Bleed Cause	Bleeds (n)	% of Total
Spontaneous	5,818	52.11%
Trauma / Activity	5,291	47.39%
Surgery / Dental	55	0.49%
Total	11,164	

Bleed Location by Cause

Cause of bleed	Joint		Muscle / Soft Tissue		Mouth		Other	
	Bleeds (n)	%	Bleeds (n)	%	Bleeds (n)	%	Bleeds (n)	%
Spontaneous	4,126	56.50%	1,350	43.79%	105	37.23%	396	45.46%
Trauma / Activity	3,173	43.45%	1,722	55.85%	141	50.00%	470	53.96%
Surgery / Dental	4	0.05%	11	0.36%	36	12.77%	5	0.57%
Total	7,303		3,083		282		871	

Bleed Location and Cause Comparison by Treatment Regime – Haemophilia A, aged less than 18 years of age

Cause of bleed	Joint		Muscle / Soft Tissue		Mouth		Other	
	Bleeds (n)	%	Bleeds (n)	%	Bleeds (n)	%	Bleeds (n)	%
Prophylaxis in patients under the age of 18 years								
Spontaneous	136	38.75%	121	31.84%	2	5.88%	27	30.00%
Trauma / Activity	215	61.25%	259	68.16%	26	76.47%	63	70.00%
Surgery / Dental	-	0.00%	-	0.00%	6	17.65%	-	0.00%
Total	351		380		34		90	
On-Demand in patients under the age of 18 years								
Spontaneous	51	52.58%	25	40.98%	-	0.00%	2	6.90%
Trauma / Activity	46	47.42%	36	59.02%	14	100.00%	26	89.66%
Surgery / Dental	-	0.00%	-	0.00%	-	0.00%	1	3.45%
Total	97		61		14		29	

Bleed Location and Cause Comparison by Treatment Regime – Haemophilia A, aged 18 years and over

Cause of bleed	Joint		Muscle / Soft Tissue		Mouth		Other	
	Bleeds (n)	%	Bleeds (n)	%	Bleeds (n)	%	Bleeds (n)	%
>=18 Prophylaxis								
Spontaneous	852	56.95%	172	39.09%	13	46.43%	50	49.02%
Trauma / Activity	643	42.98%	265	60.23%	11	39.29%	50	49.02%
Surgery / Dental	1	0.07%	3	0.68%	4	14.29%	2	1.96%
Total	1,496		440		28		102	
>=18 On-Demand								
Spontaneous	1,303	54.77%	433	48.49%	22	34.38%	70	35.00%
Trauma / Activity	1,075	45.19%	457	51.18%	39	60.94%	129	64.50%
Surgery / Dental	1	0.04%	3	0.34%	3	4.69%	1	0.50%
Total	2,379		893		64		200	

Bleed Location and Cause Comparison by Treatment Regime – by bleed rate incidence

Joint Bleeds								
Cause of bleed	Patients under the age of 18 years				Patients 18 years and over			
	Prophylaxis n = 126 pts		On-Demand n = 21 pts		Prophylaxis n = 298 pts		On-Demand n = 152 pts	
	Bleeds (n)	Incidence per patient	Bleeds (n)	Incidence per patient	Bleeds (n)	Incidence per patient	Bleeds (n)	Incidence per patient
Spontaneous	136	1.08	51	2.43	852	2.86	1,303	8.57
Trauma / Activity	215	1.71	46	2.19	643	2.16	1,075	7.07
Total	351	2.79	97	4.62	1,495	5.02	2,378	15.64

Muscle / Soft Tissue Bleeds								
Cause of bleed	Patients under the age of 18 years				Patients 18 years and over			
	Prophylaxis n = 126 pts		On-Demand n = 21 pts		Prophylaxis n = 298 pts		On-Demand n = 152 pts	
	Bleeds (n)	Incidence per patient	Bleeds (n)	Incidence per patient	Bleeds (n)	Incidence per patient	Bleeds (n)	Incidence per patient
Spontaneous	121	0.96	25	1.19	172	0.58	433	2.85
Trauma / Activity	259	2.06	36	1.71	265	0.89	457	3.01
Total	380	3.02	61	2.90	437	1.47	890	5.86

Bleed Severity

Bleed Severity	Bleeds (n)	% of Total
Severe	21	0.20%
Moderate	1,485	14.16%
Mild	8,980	85.64%
Total	10,486	

Bleeds Impacting on Regular Activity

Cause of Bleed	Bleeds (n)	% of Total
Spontaneous	1,108	48.53%
Trauma / Activity	1,167	51.12%
Surgery / Dental	8	0.35%
Total	2,283	

Pain Scale of Reported Bleeds

Pain Scale (1 low – 6 high)	Bleeds (n)	% of Total
Not reported	2,102	18.23%
1	1,108	9.61%
2	1,652	14.33%
3	3,054	26.49%
4	2,387	20.71%
5	965	8.37%
6	260	2.26%
Total	11,528	

Pain Scale comparing Joint and Muscle/Soft Tissue Bleeds

Pain Scale (1 low – 6 high)	Joint		Muscle / Soft Tissue	
	Bleeds (n)	% of Total	Bleeds (n)	% of Total
1	617	10.23%	272	10.42%
2	998	16.55%	517	19.80%
3	1,996	33.10%	865	33.13%
4	1,567	25.99%	673	25.78%
5	689	11.43%	218	8.35%
6	163	2.70%	66	2.53%
Total	6,030	100%	2,611	100%

Treatment time following bleed

Hours	Bleeds	Percentage
0	1,928	17.92%
1	3,466	32.21%
2	1,910	17.75%
3	902	8.38%
4	700	6.51%
5	311	2.89%
6	342	3.18%
7	86	0.80%
8	215	2.00%
9	37	0.34%
10	112	1.04%
11	18	0.17%
12	366	3.40%
>12	366	3.40%
Total	10,759	