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The logo for UKHCDO, consisting of the letters 'UKHCDO' in a bold, white, sans-serif font, each letter contained within a dark blue square. The squares are arranged in a horizontal row.

UNITED KINGDOM HAEMOPHILIA CENTRES DOCTORS' ORGANISATION



UKHCDO Bleeding Disorder Statistics for April 2010 to March 2011

A report from the National Haemophilia Database

New Registrations -
 Number of patients
 newly registered at
 UK Haemophilia
 Centres between
 April 2010 & March
 2011 showing their
 coagulation defect
 and gender

Coagulation Defect	M	F	Grand Total
Haemophilia A	132	0	132
Haemophilia B	30	0	30
Females with VIII deficiency	0	51	51
Females with IX deficiency	0	18	18
von Willebrand disease	119	212	331
F.V deficiency	2	4	6
F.VII deficiency	33	25	58
FIX Leyden	2	0	2
F.X deficiency	1	3	4
F.XI Deficiency	43	59	102
F.XIII Deficiency	2	1	3
Fibrinogen Deficiency	2	3	5
Dysfibrinogenaemia	7	12	19
Combined V+VIII Deficiency	1	0	1
Other Combined Diagnoses	4	4	8
Acquired Haemophilia A	38	33	71
Acquired von Willebrands	2	3	5
Acquired Prothrombin Deficiency	1	0	1
Probable von Willebrands disease	3	9	12
Glanzmanns Thrombasthenia	3	3	6
Bernard Soulier	1	1	2
Other platelet defects	30	54	84
Miscellaneous	1	20	21
Unclassified	0	8	8
Total	457	523	980

In Register – The total Number of patients with all types of bleeding disorder currently registered and the number treated during April 2010 & March 2011

Coagulation Defect	Number of Patients		Percent Treated
	In Register	Treated	
Haemophilia A	5,372	2,919	54.34%
Females with VIII deficiency	1,119	63	5.63%
Haemophilia B	1,134	611	53.88%
Females with IX deficiency	347	47	13.54%
FIX Leyden	10	2	20.00%
FIX Leyden Carrier	2	1	50.00%
F.XI Deficiency	1,905	61	3.20%
von Willebrand disease	9,124	1,054	11.55%
Probable von Willebrand's disease	54	12	22.22%
F.VII deficiency	680	49	7.21%
F.V deficiency	137	12	8.76%
F.X deficiency	184	28	15.22%
F.XIII Deficiency	58	44	75.86%
Fibrinogen Deficiency	172	18	10.47%
Prothrombin Deficiency	10	2	20.00%
Dysfibrinogenaemia	162	20	12.35%
Combined II+VII+IX+X Deficiency	4	0	0.00%
Combined V+VIII Deficiency	23	6	26.09%
Other combined diagnoses	220	30	13.64%
Glanzmann's Thrombasthenia	109	35	32.11%
Bernard Soulier	58	4	6.90%
Other platelet defects	1,317	56	4.25%
Pseudo vW	1	0	0.00%
Acquired Haemophilia A	320	70	21.88%
Acquired Haemophilia B	1	0	0.00%
Acquired von Willebrands	62	13	20.97%
Acquired Prothrombin Deficiency	1	0	0.00%
Acquired F.XIII Deficiency	1	0	0.00%
Acquired Deficiency (other)	4	1	25.00%
Haemophilia A with Liver Transplant	10	0	0.00%
Haemophilia B with Liver Transplant	6	0	0.00%
von Willebrand with Liver Transplant	1	0	0.00%
Miscellaneous	139	15	10.79%
Unclassified	108	6	5.56%
Total	22,855	5,179	22.66%

New Registrations of Haemophilia A & B between April 2010 & March 2011, by age at the end of September 2010 and disease severity

Coagulation Defect	Age (years)	Number of Patients - Factor VIII/IX level iu/dl			
		≤1	>1 and <5	≥5	Total
Haemophilia A	0 : 9	35	6	33	74
	10 : 19	1	1	12	14
	20 : 29	5	1	7	13
	30 : 39	1	0	5	6
	40 : 49	1	1	3	5
	50 : 59	0	0	6	6
	60 : 69	0	0	5	5
	70 : +	0	0	9	9
	Total		43	9	80
Haemophilia B	0 : 9	6	5	7	18
	10 : 19	0	0	4	4
	20 : 29	0	1	2	3
	30 : 39	0	0	1	1
	40 : 49	0	1	0	1
	50 : 59	0	1	1	2
	70 : +	0	0	1	1
	Total		6	8	16

New Registrations of selected rarer bleeding disorders between April 2010 & March 2011, by disease severity

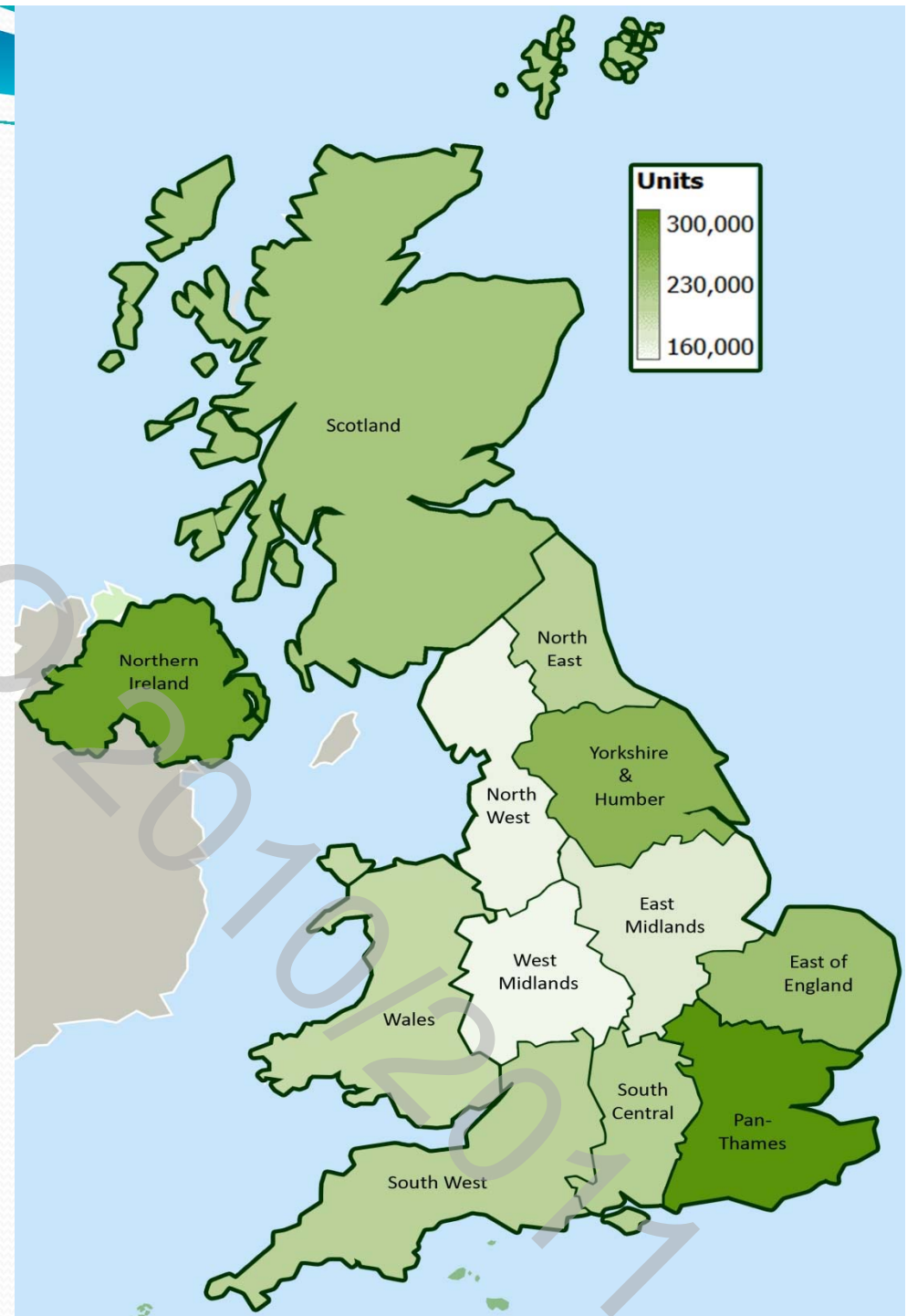
Coagulation Defect	≤5		>5		Not Known		Total	
	In Reg	Treated	In Reg	Treated	In Reg	Treated	In Reg	Treated
F.V deficiency	46	10	88	2	3	0	137	12
F.VII deficiency	99	22	556	25	25	2	680	49
FIX Leyden Carrier	0	0	2	1	0	0	2	1
FIX Leyden	1	1	9	1	0	0	10	2
F.X deficiency	37	22	143	6	4	0	184	28
F.XI Deficiency	182	21	1642	37	81	3	1905	61
Total	365	76	2,440	72	113	5	2,918	153

Coagulation Defect	≤2		>2		Not Known		Total	
	In Reg	Treated	In Reg	Treated	In Reg	Treated	In Reg	Treated
F.XIII Deficiency	29	24	27	19	2	1	58	44
Total	394	100	2,467	91	115	6	2,976	197

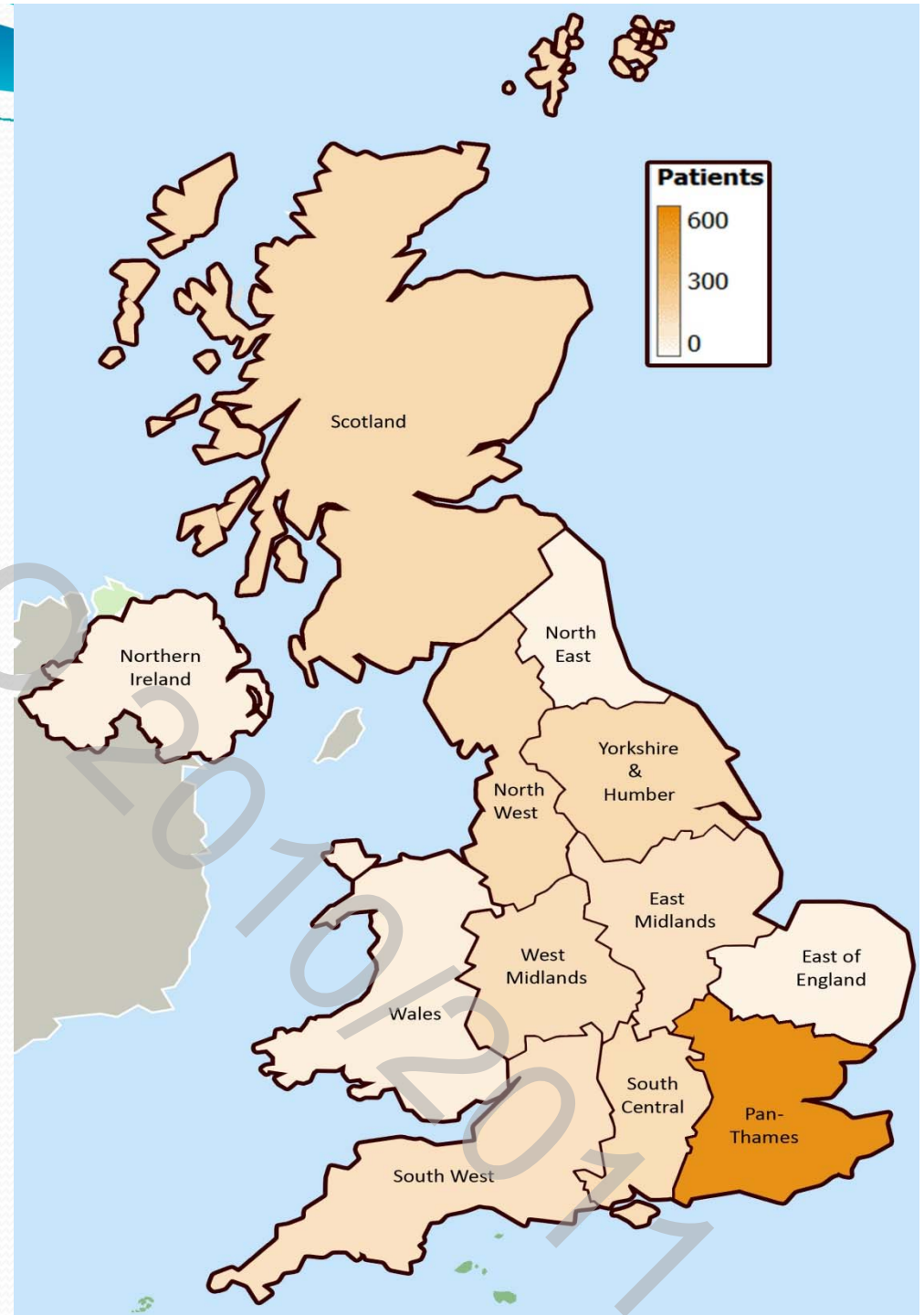
In Register – The total number of haemophilia A, B and von Willebrand's disease patients currently in the register, by severity, age group and gender

Coagulation Defect	Males										Total Males
	<18 years					=>18 years					
	≤ 1	>1 & <5	≥ 5	N/K	Sub Total	≤ 1	>1 & <5	≥ 5	N/K	Sub Total	
Haemophilia A	655	141	650	0	1446	1204	390	2326	1	3921	5367
Haemophilia B	123	62	93	0	278	278	181	393	3	855	1133
von Willebrand disease	24	20	766	118	928	40	47	2239	88	2414	3342
Coagulation Defect	Females										Total Females
	<18 years					=>18 years					
	≤ 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	8	87	26	125	33	15	879	64	991	1116
Female with IX deficiency	3	2	44	12	61	6	7	246	25	284	345
von Willebrand disease	10	27	684	122	843	51	67	4515	294	4927	5770

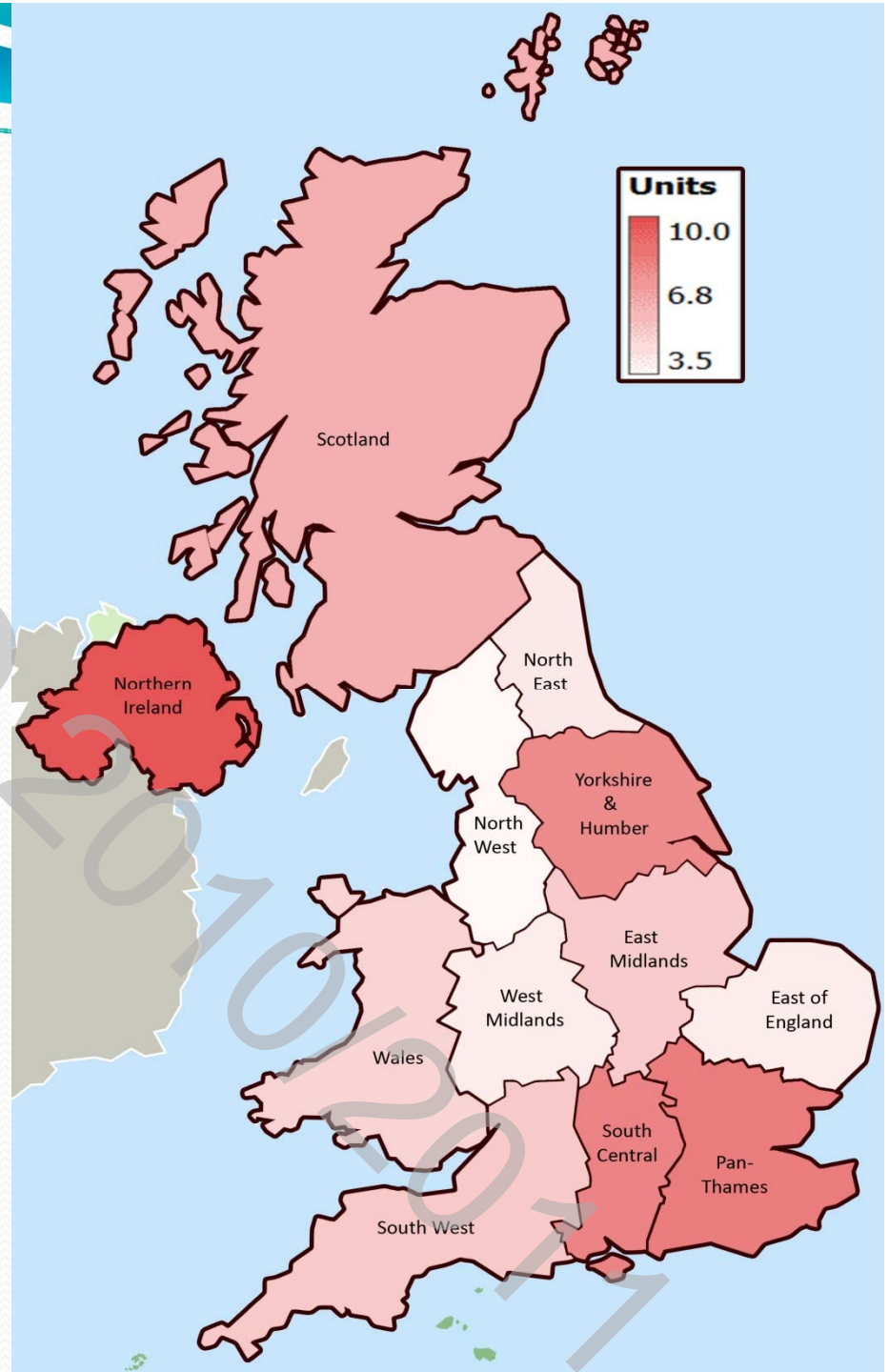
Factor VIII Usage (inc. inhibitor) divided by number of Severe Haemophilia A patients by commissioning region



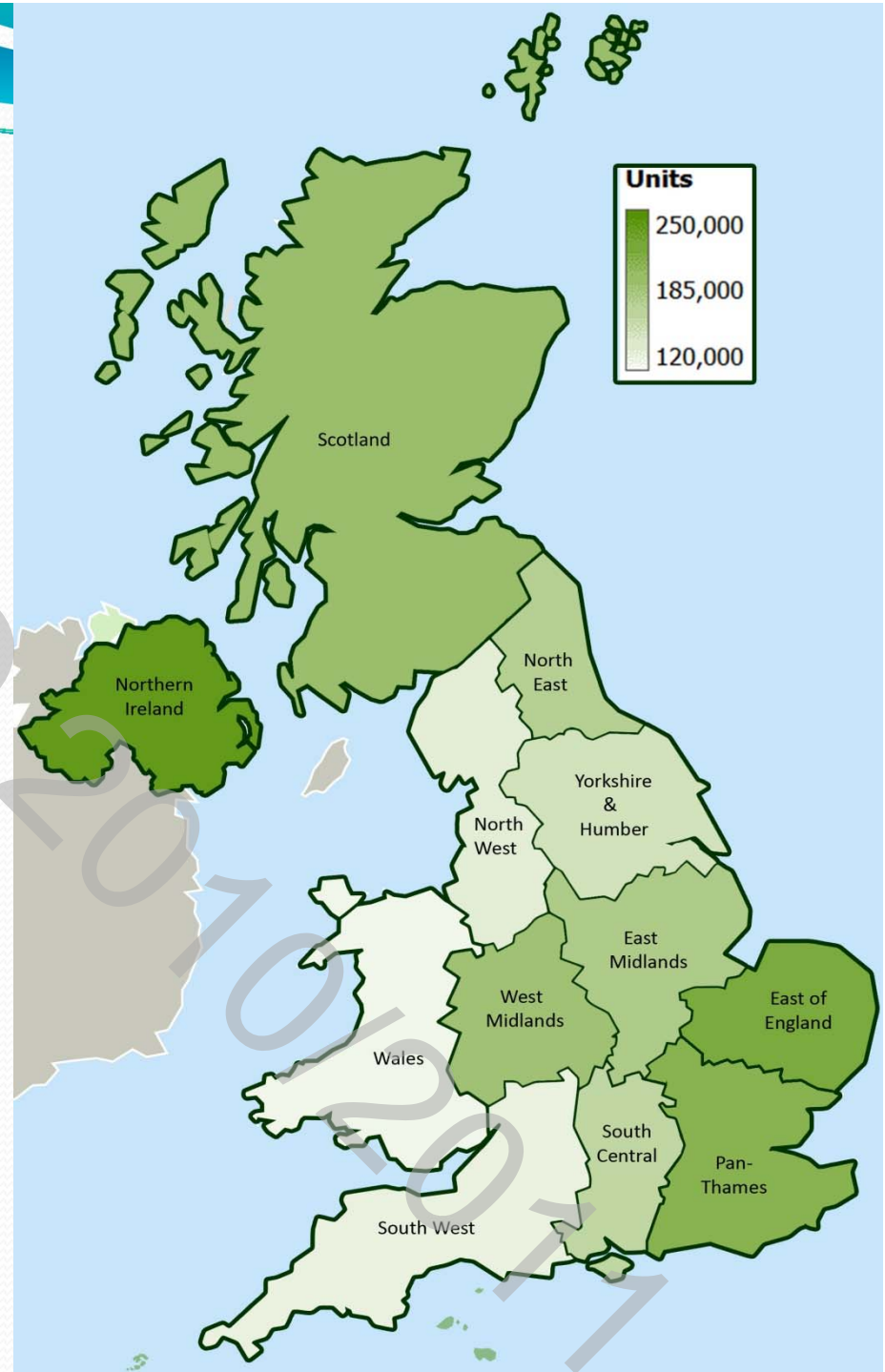
Total Number of Severe Haemophilia A & B Patients by commissioning region



FVIII Units – usage per capita of population



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



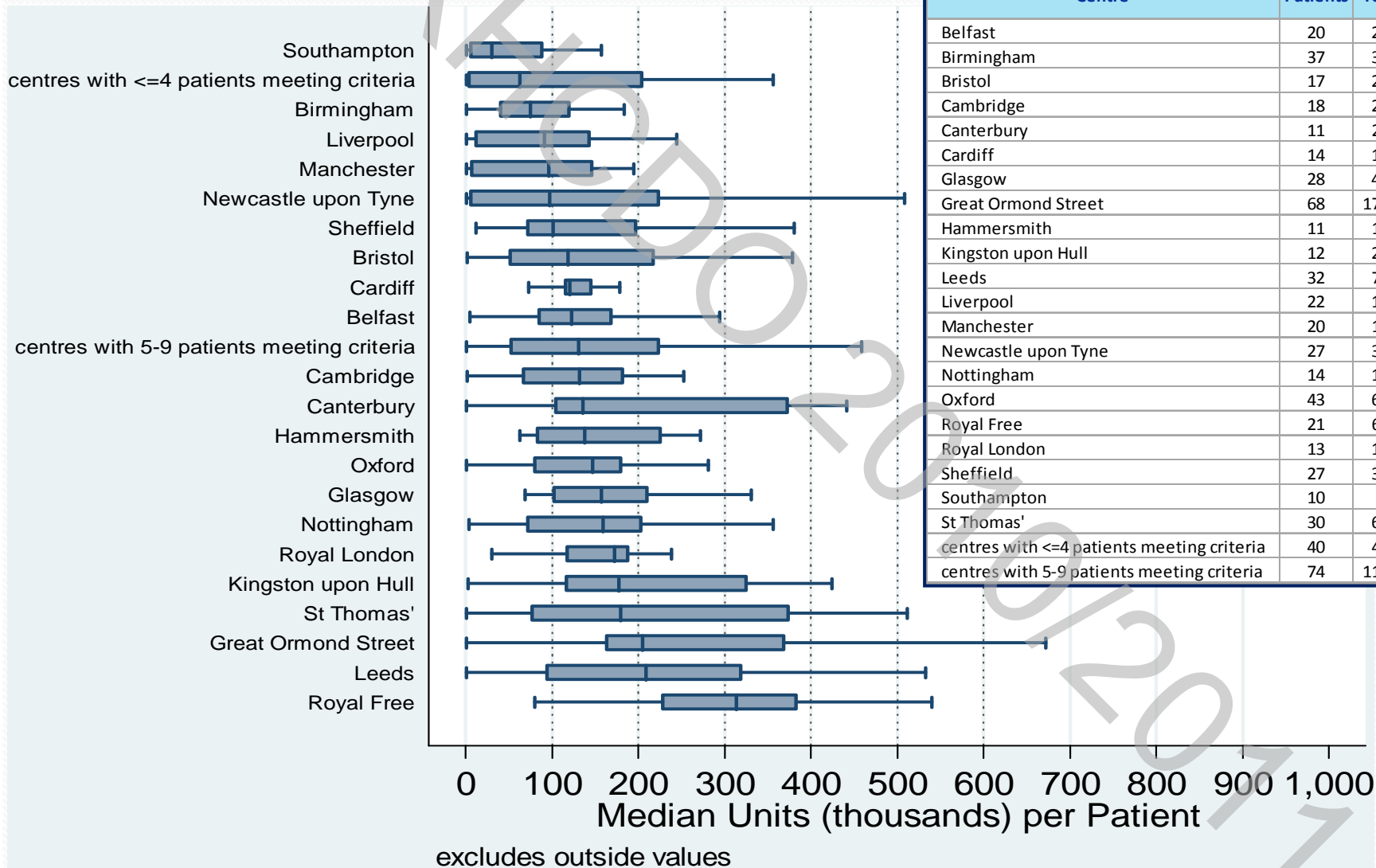
Factor VIII Usage by commissioning region for Severe Haemophilia A patients only (inc. inhibitor)

Commissioning Group / Region	Population *	Number of Severe Haemophilia A Patients	Total FVIII Units Used For Severe Haemophilia A Only	Mean Usage Severe Haemophilia A	FVIII Units Used For Severe Haemophilia A Per Capita
West Midlands Specialised Commissioning Group	5,431,100	131	22,602,028	172,535	4.16
North West Specialised Commissioning Group	6,897,900	148	25,889,000	174,926	3.75
East Midlands Specialised Commissioning Group	4,451,200	127	23,588,025	185,732	5.30
Wales	2,999,300	73	15,326,394	209,951	5.11
South West Specialised Commissioning Group	5,231,200	133	28,964,937	217,781	5.54
North East Specialised Commissioning Group	2,584,300	51	11,113,218	217,906	4.30
South Central Specialised Commissioning Group	4,095,400	149	33,207,562	222,870	8.11
Scotland	5,194,000	143	33,050,164	231,120	6.36
East of England Specialised Commissioning Group	2,345,500	41	9,884,000	241,073	4.21
Yorkshire and Humber Specialised Commissioning Group	5,258,100	163	40,938,448	251,156	7.79
Northern Ireland	1,788,900	62	17,426,750	281,077	9.74
Pan-Thames Haemophilia Consortium	15,502,100	436	128,688,237	295,157	8.30

Factor FIX Usage by commissioning region for Severe Haemophilia B patients only (inc. inhibitor)

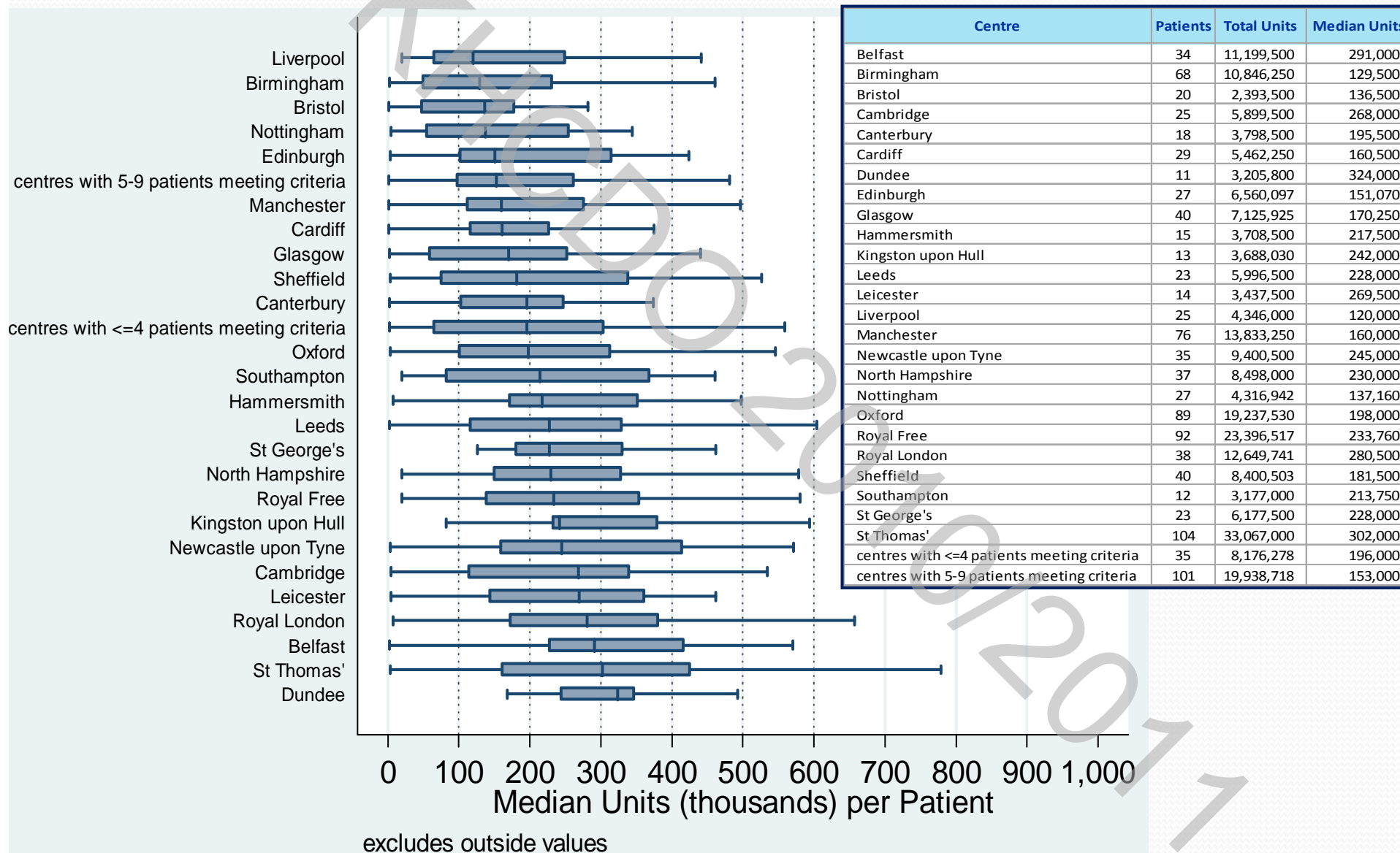
Commissioning Group / Region	Population *	Number of Severe Haemophilia B Patients	Total FIX Units Used For Severe Haemophilia B Only	Mean Usage Severe Haemophilia B	FIX Units Used For Severe Haemophilia B Per Capita
Wales	2,999,300	11	1,431,500	130,136	0.48
South West Specialised Commissioning Group	5,231,200	17	2,331,657	137,156	0.45
North West Specialised Commissioning Group	6,897,900	31	4,404,215	142,071	0.64
Yorkshire and Humber Specialised Commissioning Group	5,258,100	25	3,736,825	149,473	0.71
South Central Specialised Commissioning Group	4,095,400	23	3,854,260	167,577	0.94
North East Specialised Commissioning Group	2,584,300	10	1,759,000	175,900	0.68
East Midlands Specialised Commissioning Group	4,451,200	22	4,005,148	182,052	0.90
West Midlands Specialised Commissioning Group	5,431,100	27	5,145,290	190,566	0.95
Scotland	5,194,000	34	6,716,403	197,541	1.29
Pan-Thames Haemophilia Consortium	15,502,100	112	23,487,296	209,708	1.52
East of England Specialised Commissioning Group	2,345,500	18	3,968,782	220,488	1.69
Northern Ireland	1,788,900	6	1,436,250	239,375	0.80

FVIII usage in severe haemophilia A patients with no current inhibitor by centre, aged less than 18 years

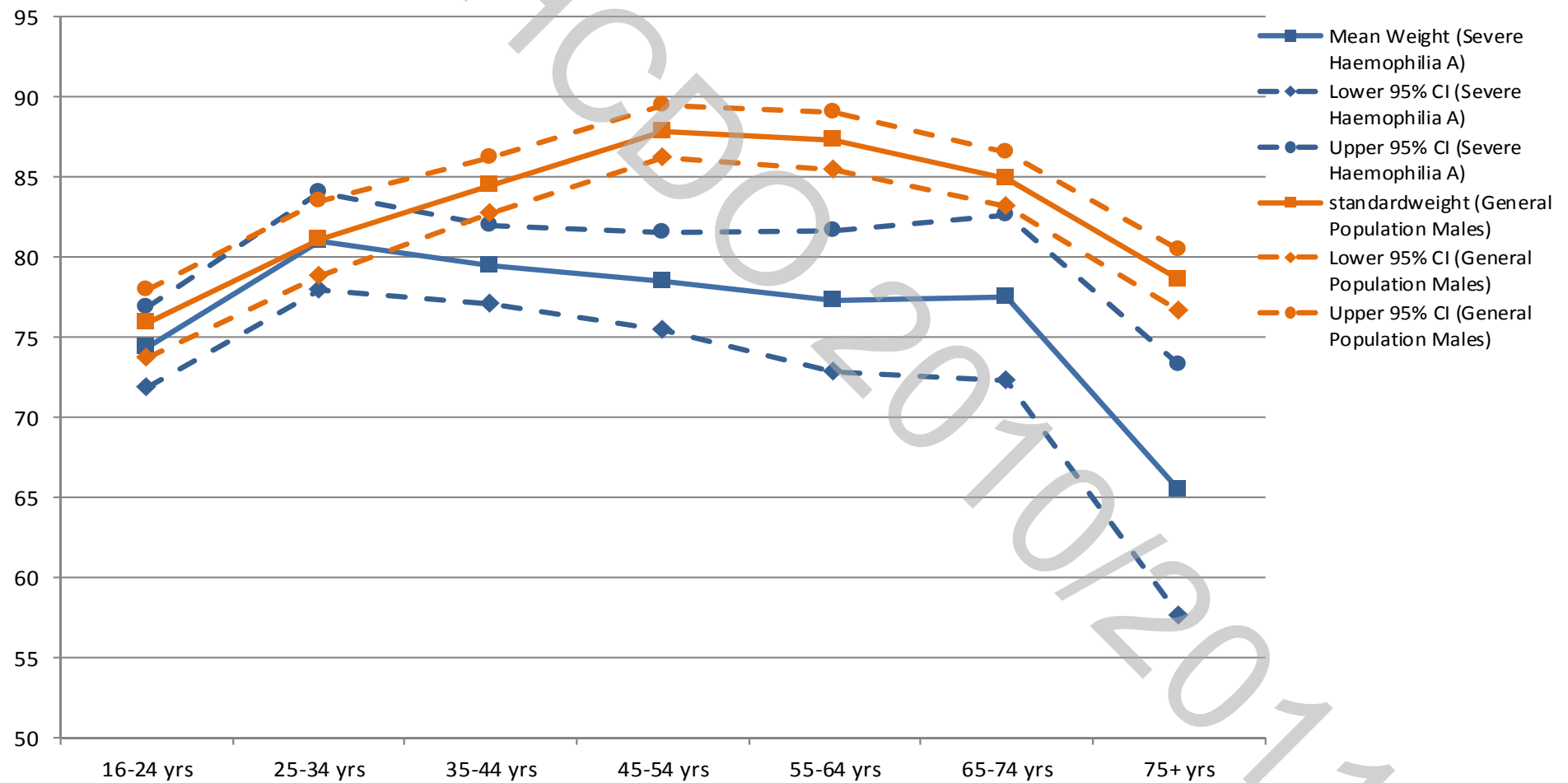


Centre	Patients	Total Units	Median Units
Belfast	20	2,853,500	122,750
Birmingham	37	3,339,250	75,000
Bristol	17	2,684,500	118,500
Cambridge	18	2,369,000	132,000
Canterbury	11	2,097,000	136,000
Cardiff	14	1,881,250	120,250
Glasgow	28	4,925,250	157,000
Great Ormond Street	68	17,072,750	204,500
Hammersmith	11	1,896,250	138,000
Kingston upon Hull	12	2,439,158	177,625
Leeds	32	7,486,000	209,250
Liverpool	22	1,961,500	90,875
Manchester	20	1,741,500	96,375
Newcastle upon Tyne	27	3,519,750	97,000
Nottingham	14	1,973,796	159,500
Oxford	43	6,291,530	147,250
Royal Free	21	6,345,188	313,700
Royal London	13	1,985,262	172,000
Sheffield	27	3,712,500	101,500
Southampton	10	542,000	30,000
St Thomas'	30	6,276,750	179,750
centres with ≤4 patients meeting criteria	40	4,951,246	62,823
centres with 5-9 patients meeting criteria	74	11,542,094	130,375

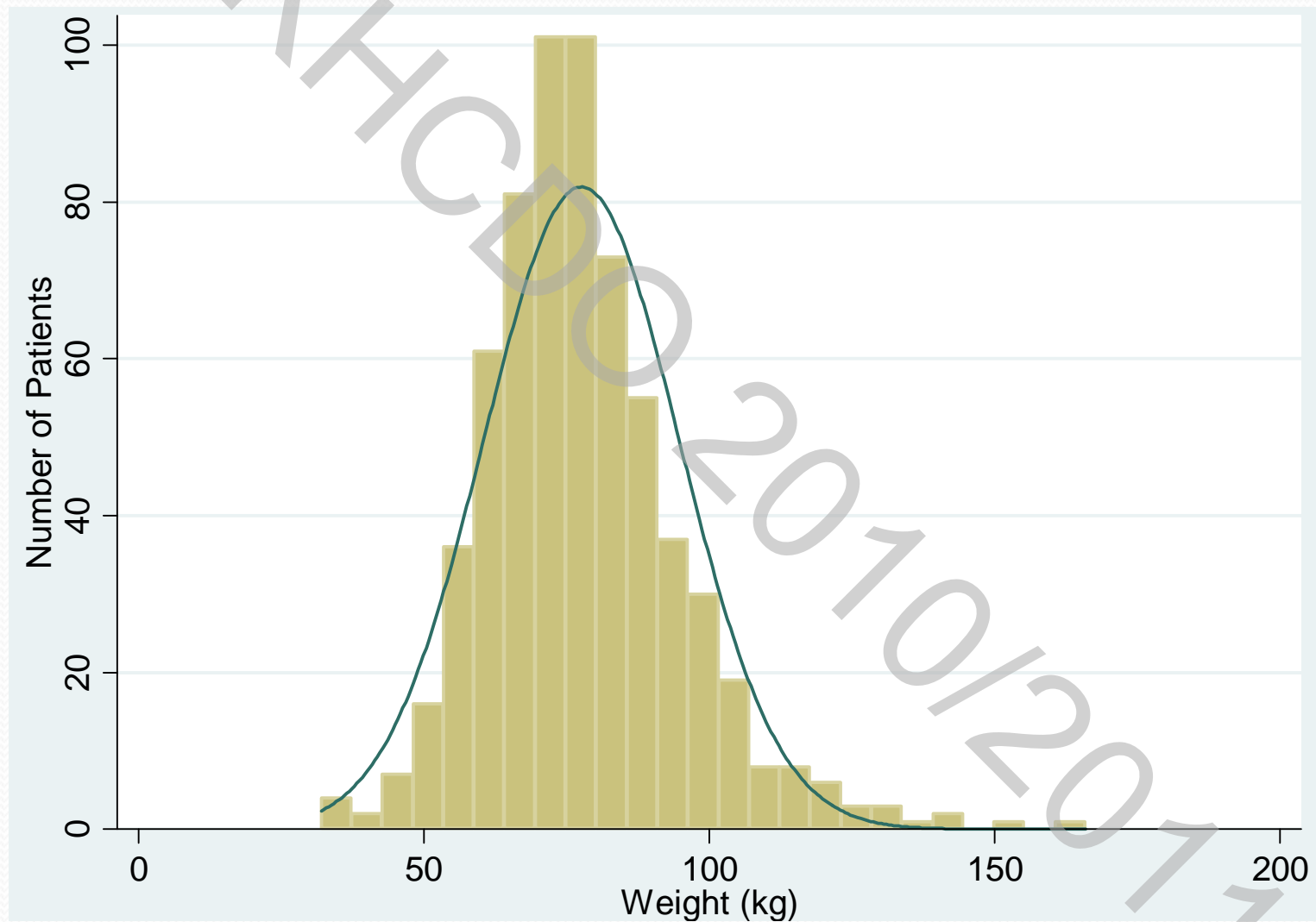
FVIII usage in severe haemophilia A patients with no current inhibitor by centre, aged 18 years or more



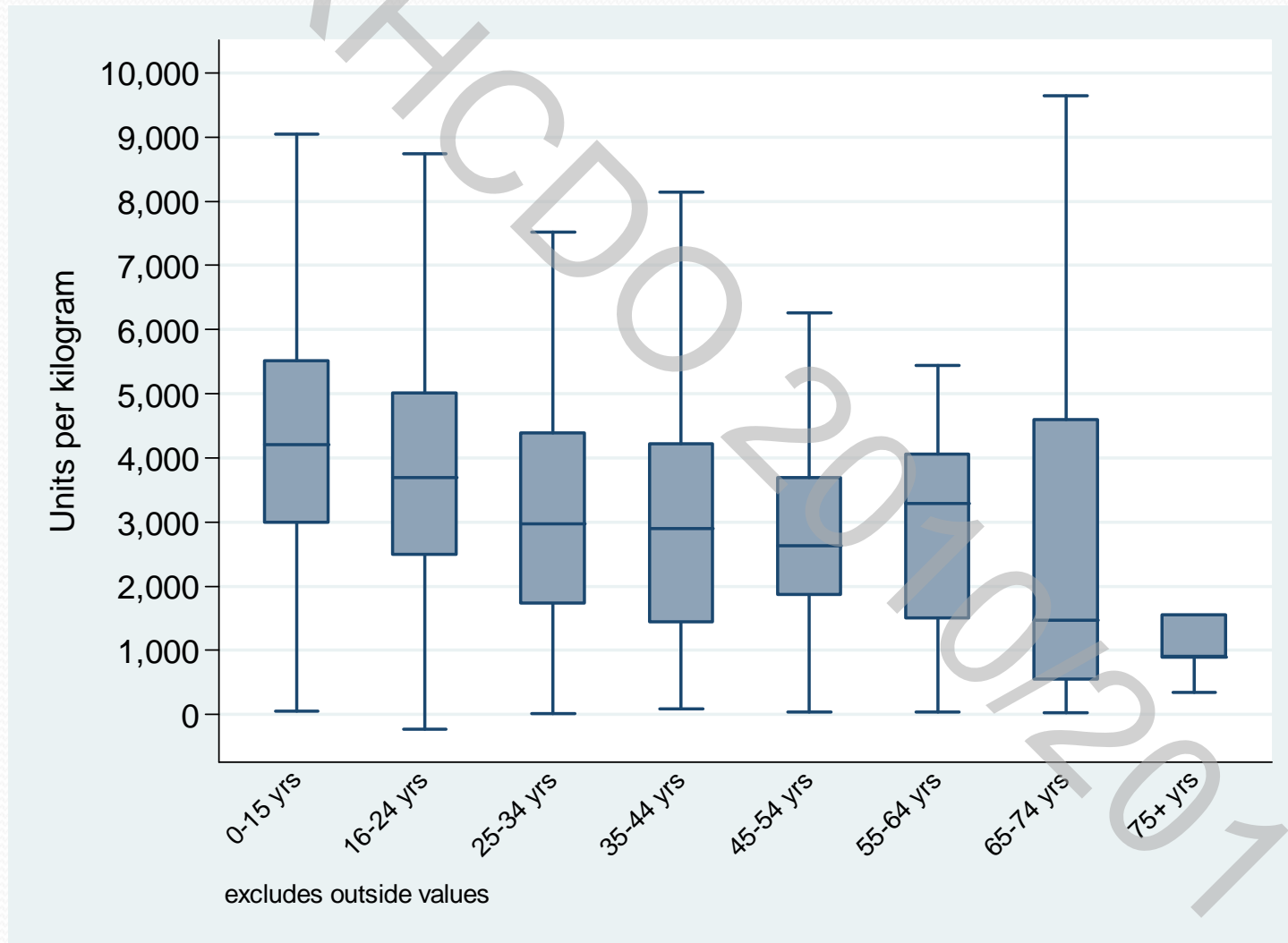
Mean weight of Severe Haemophilia A males compared to the general population



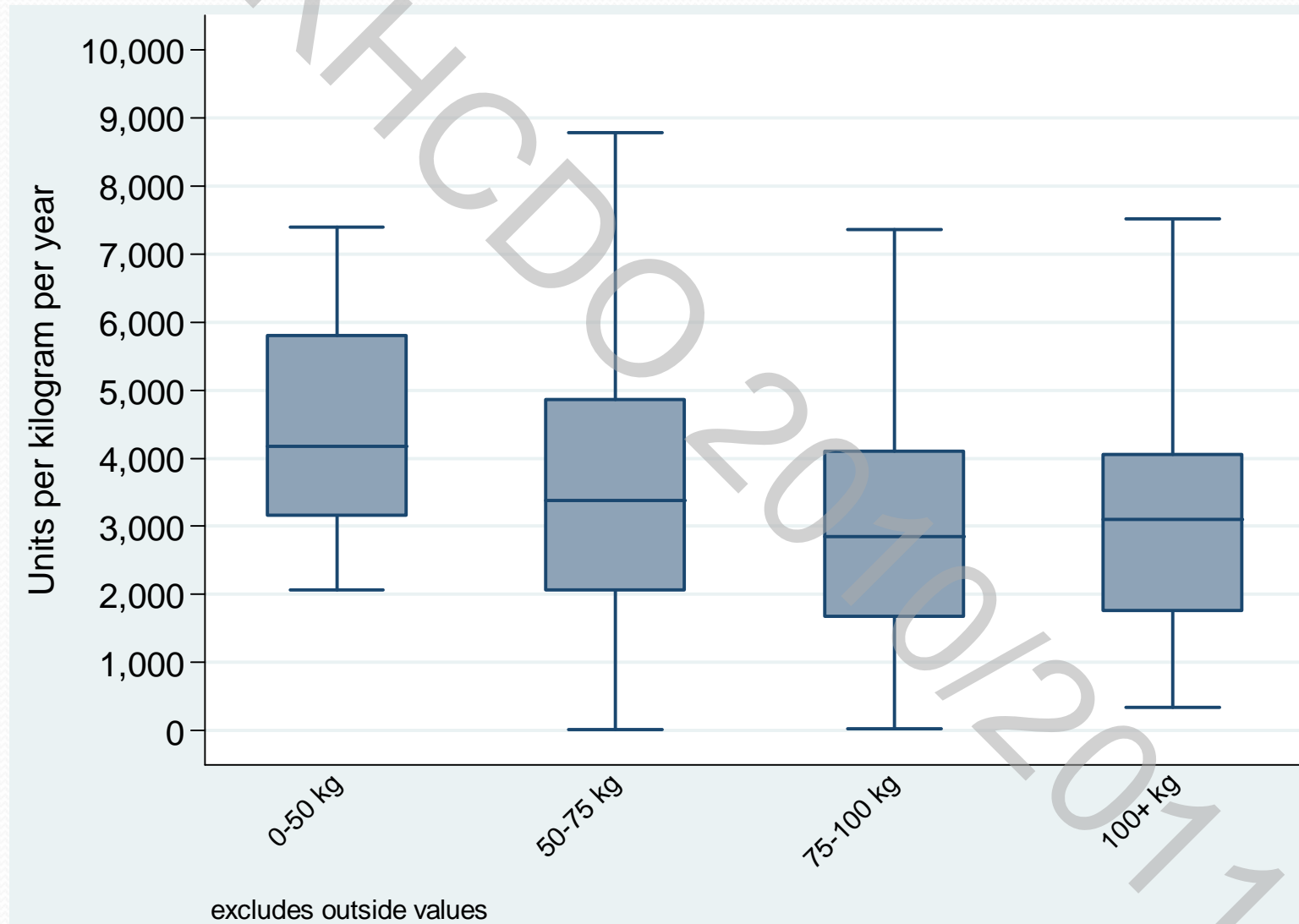
Distribution of weight of Severe Haemophilia A males



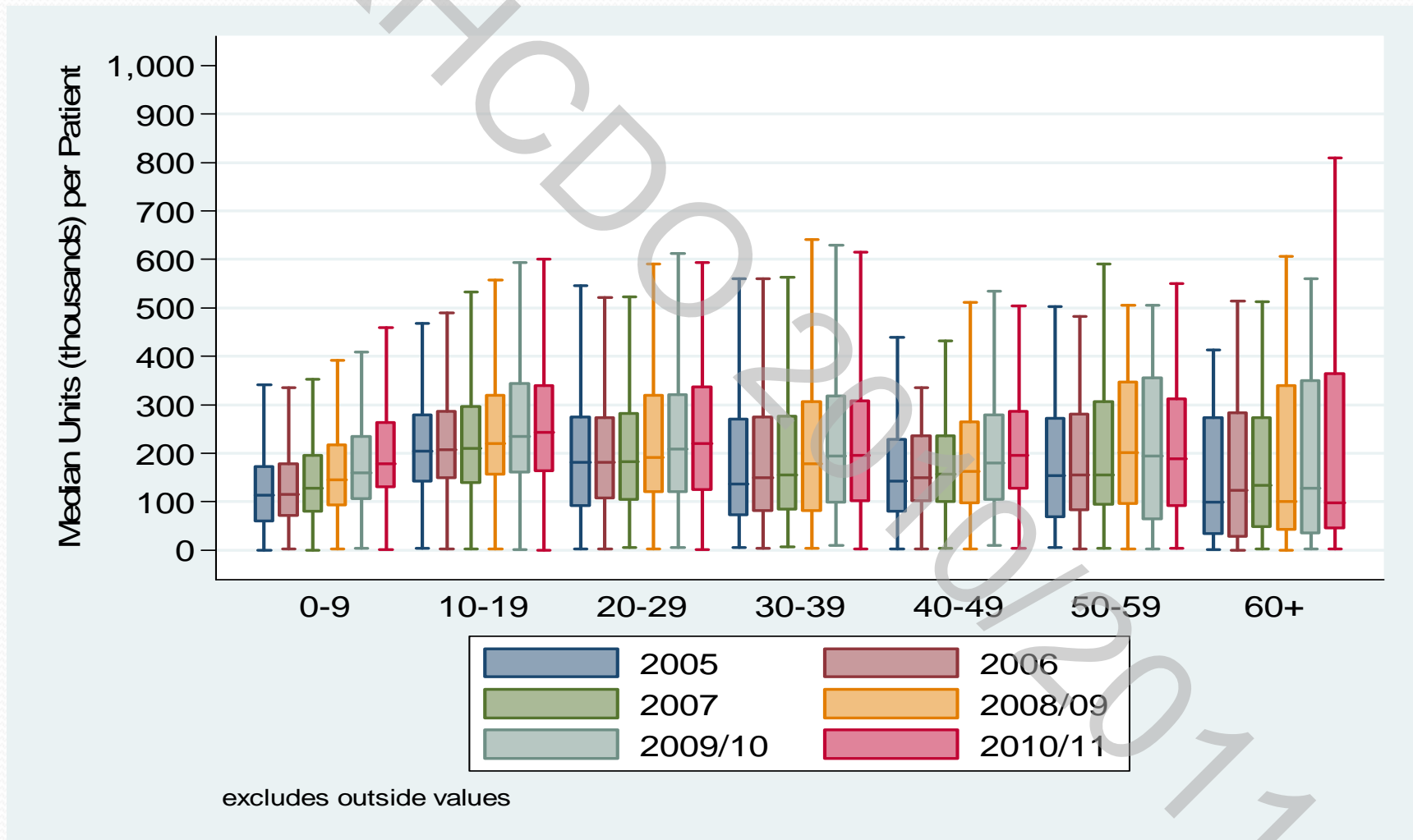
Median factor VIII units used per kilogram body weight per year in Severe Haemophilia A patients, 2010/11, broken down by decades of life



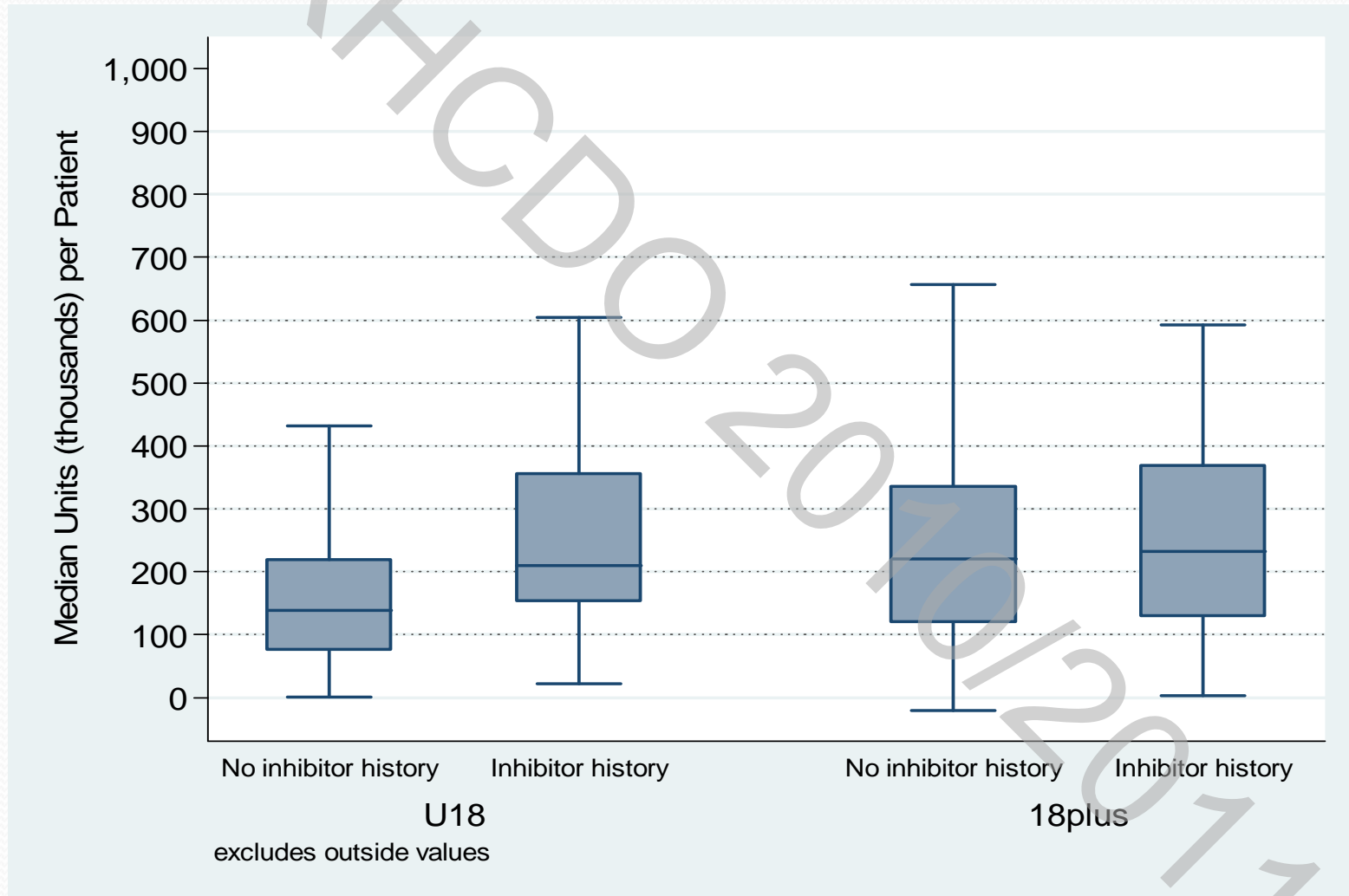
Median factor VIII units used per kilogram body weight per year in Severe Haemophilia A patients, 2010/11



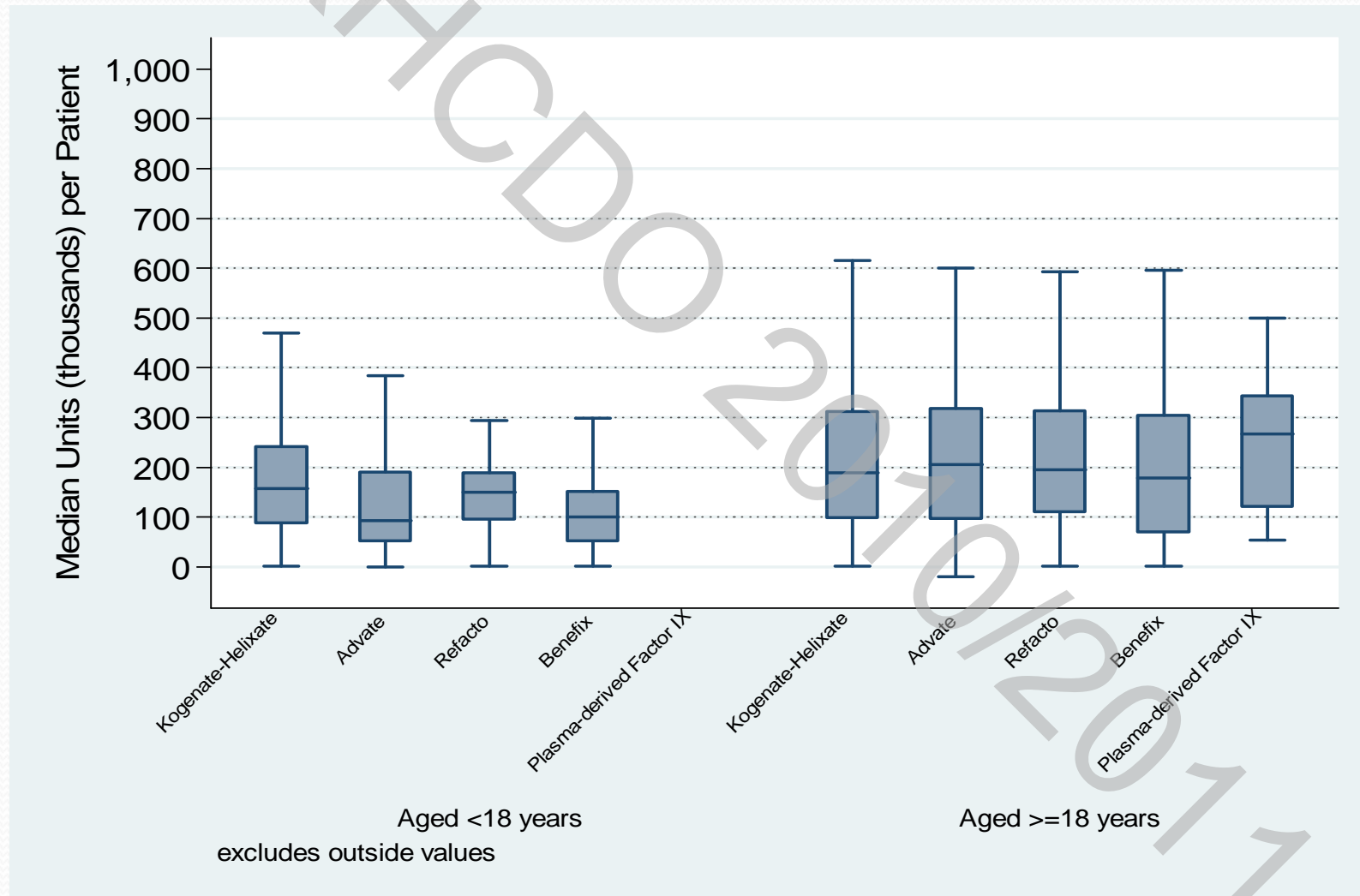
Severe Haemophilia A patients treated with FVIII products with no current inhibitor: median IU issued



Severe haemophilia A patients with no current inhibitor between April 2010 & March 2011: median usage by inhibitor history



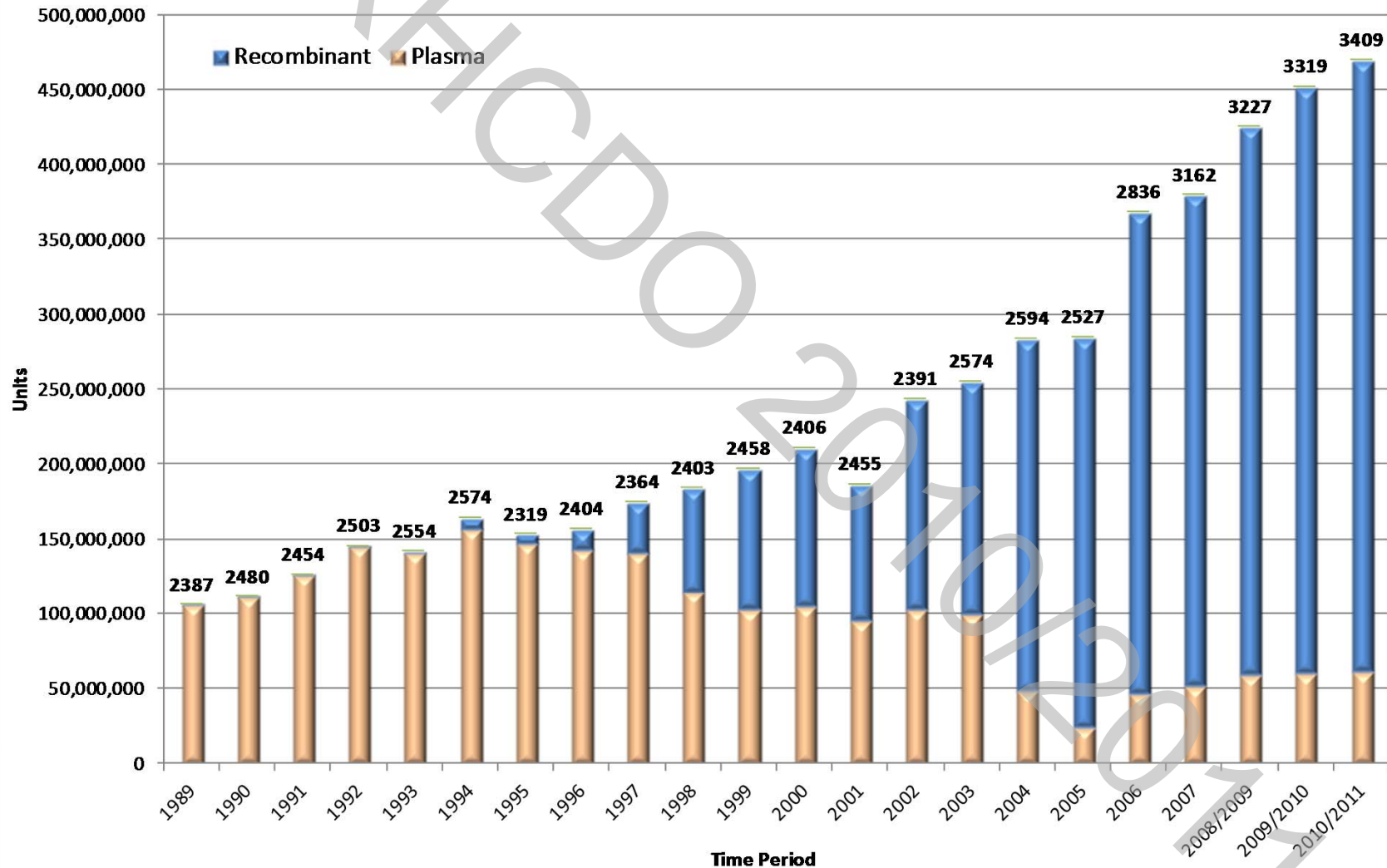
Severe haemophilia A & B patients with no current inhibitor using only one product between April 2010 & March 2011: median usage



Factor VIII units used by UK Haemophilia Centres

Coagulation Defect	Patients Treated	Plasma FVIII	Recombinant FVIII	Total FVIII
Haemophilia A	2,725	42,527,225	406,722,483	449,249,708
Haemophilia B	1	-	250	250
Females with VIII deficiency	35	12,000	586,725	598,725
von Willebrand disease	594	16,413,260	202,583	16,615,843
Combined V+VIII Deficiency	4	-	17,500	17,500
Other Combined Defects	16	1,139,280	1,042,500	2,181,780
Acquired Haemophilia A	9	112,854	143,304	256,158
Acquired von Willebrands	12	246,000	-	246,000
Platelet defects (misc)	2	40,000	4,000	44,000
Miscellaneous	8	71,000	1,000	72,000
Probable von Willebrands disease	3	8,000	-	8,000
Total	3,409	60,569,619	408,720,345	469,289,964

Factor VIII units by UK Haemophilia Centres: by calendar year between 1989 and 2007 and by financial year from April 2008 onwards

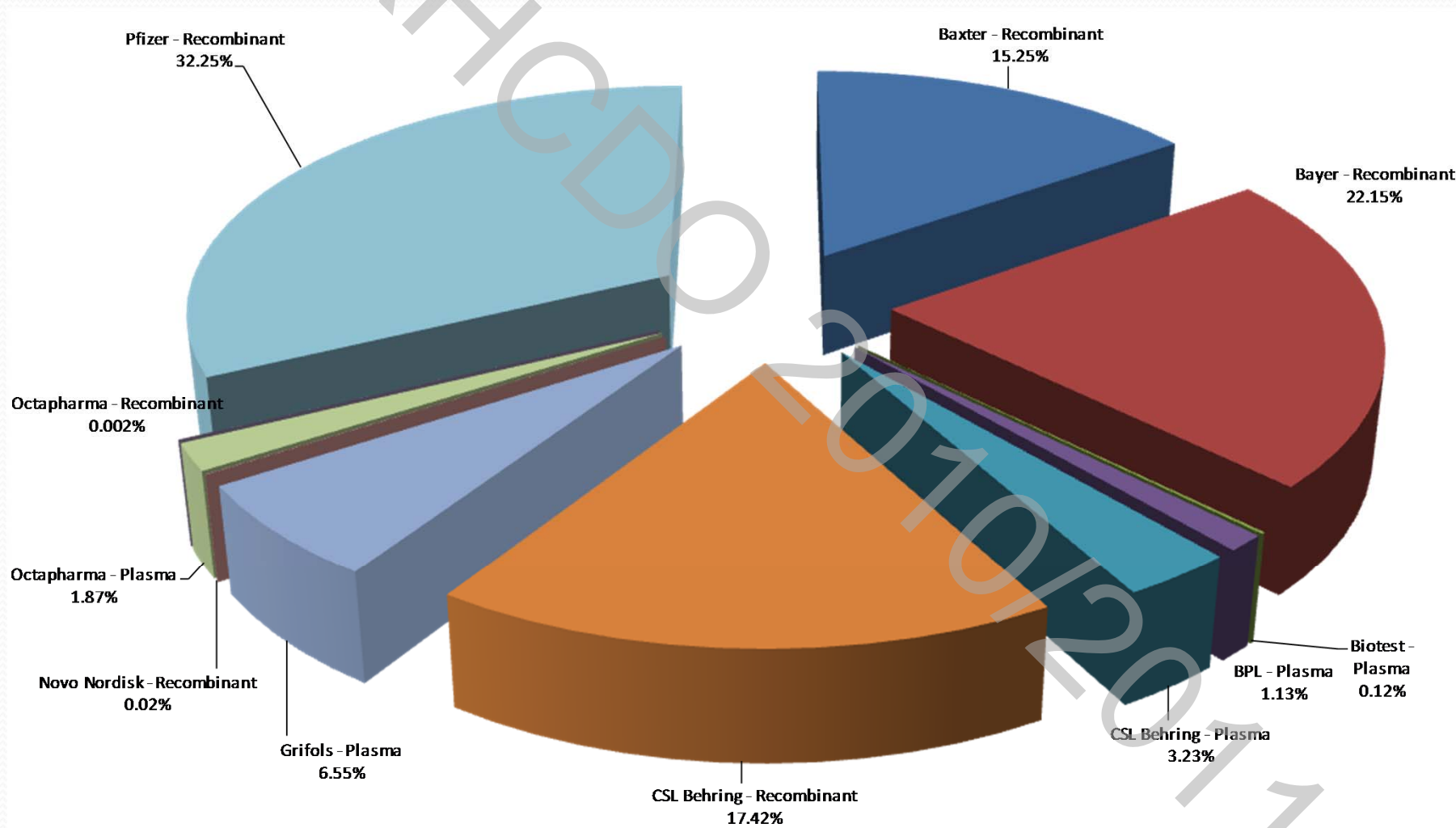


Products used to treat Haemophilia A (including inhibitors)

Total Use I.U unless otherwise stated

Manufacturer	Product	Total Units
	Desmopressin (4mcg/ml)	1,027.90
	Desmopressin Nasal Spray	11,301.25
	Desmopressin Sub Cut (15mcg/ml)	5,709.35
	Haemocompletten P (g)	39
	Tranexamic Acid	8,430
Baxter	Advate	71,291,104
	FEIBA	20,484,005
Bayer	Kogenate	103,659,500
Biotest	Haemoctin	557,000
BPL	BPL FVIII	8,000
	BPL FVIII 8Y	2,627,549
	Optivate	1,939,120
CSL Behring	Beriplex	4,000
	Haemate P	739,500
	Helixate Nexgen	80,659,174
	Riastap (mg)	21
Grifols	Alphanate	47,140
	Fanhdi	27,824,416
Novo Nordisk	NovoSeven (mg)	22,159
	N8 (rVFIII) (Trial)	90,480
Octapharma	GENA08 (Trial)	9,283
	Octanate	8,784,500
	Wilate	5,400
Pfizer	BeneFIX	13,000
	ReFacto AF	151,012,942

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

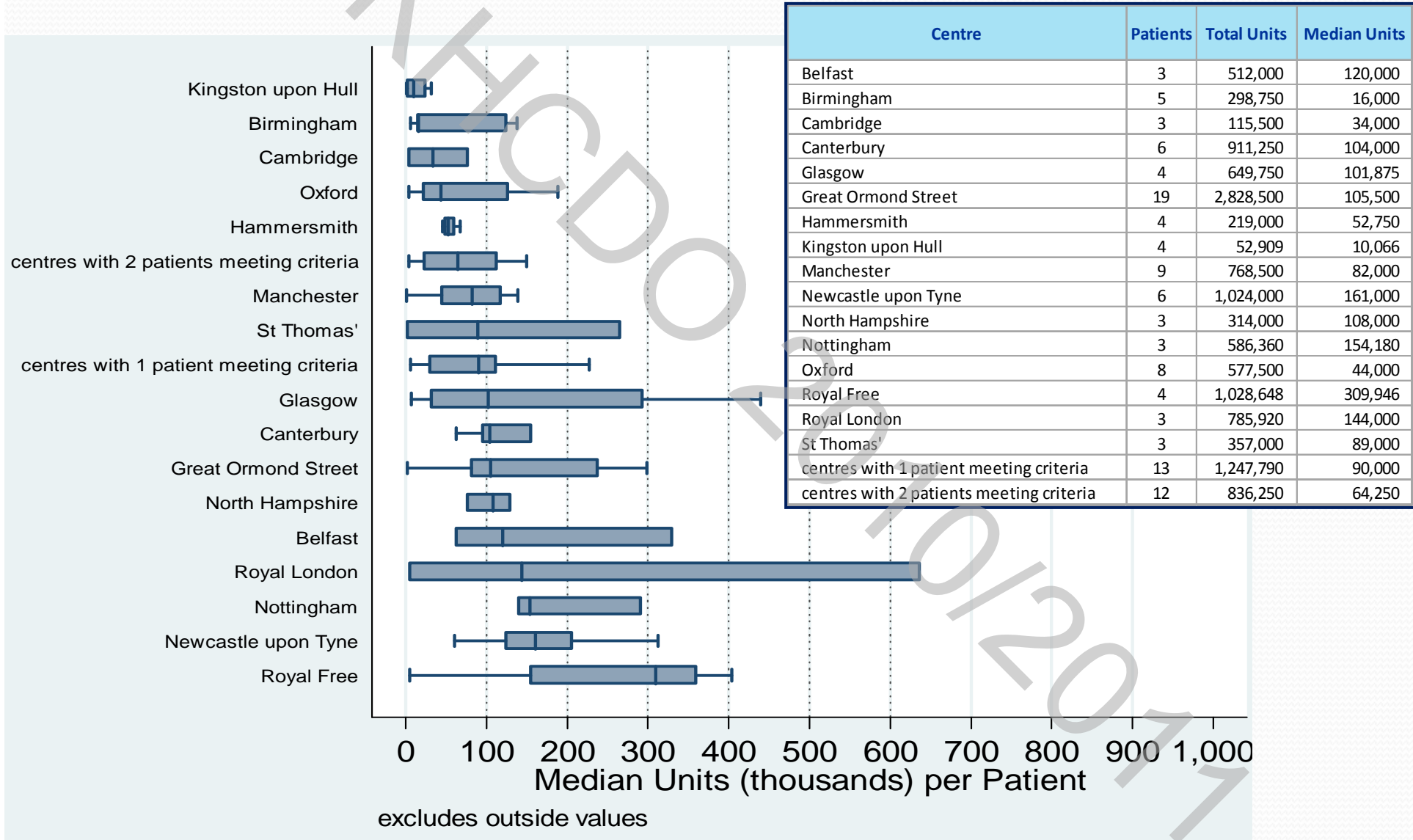


Inhibitors by disease severity

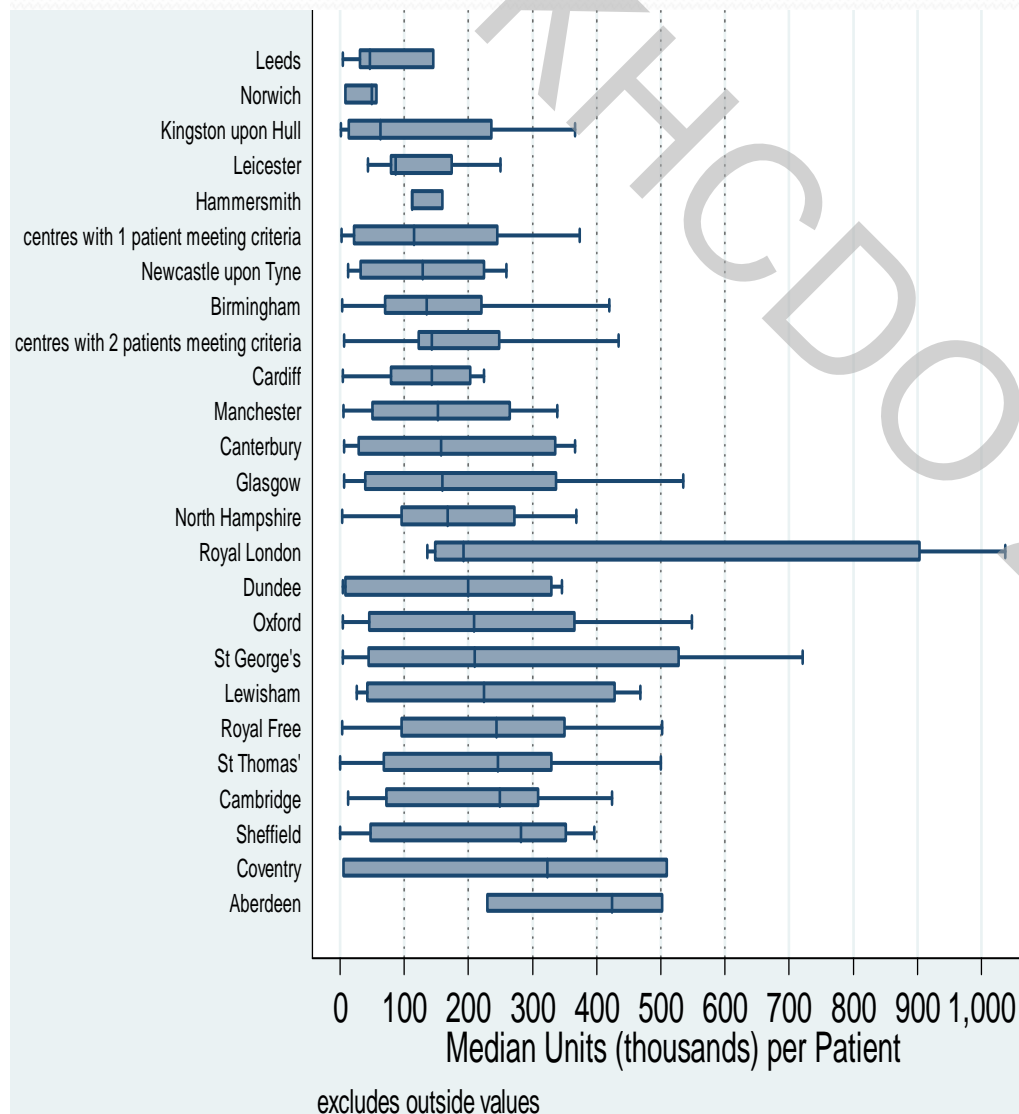
Diagnosis	Number of Patients ever known to have an inhibitor by disease severity								
	≤ 1 iu/dl			>1 and <5 iu/dl			≥ 5 iu/dl		
	In Reg *	Inhib. Pts	%	In Reg *	Inhib. Pts	%	In Reg *	Inhib. Pts	%
Haemophilia A	1860	374	20.11%	534	36	6.74%	2976	59	1.98%
Haemophilia B	401	15	3.74%	244	0	0.00%	486	1	0.21%
von Willebrand disease	125	6	4.80%	161	2	1.24%	8214	4	0.05%

Diagnosis	Patients with a current inhibitor between April 2010 and March 2011 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	1860	156	8.39%	534	13	2.43%	2976	23	0.77%
Haemophilia B	401	10	2.49%	244	0	0.00%	486	0	0.00%
von Willebrand disease	125	6	4.80%	161	2	1.24%	8214	2	0.02%

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



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

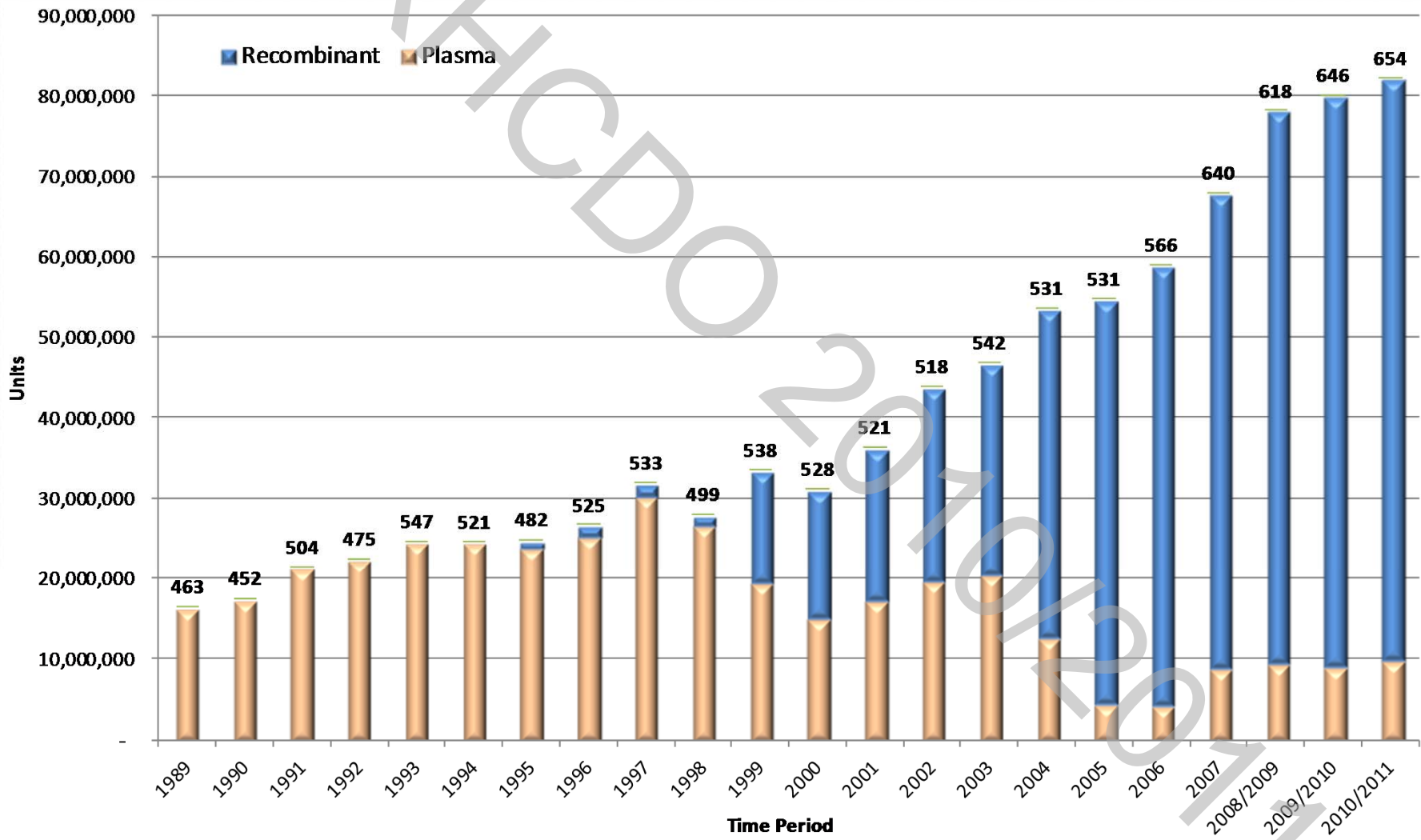


Centre	Patients	Total Units	Median Units
Aberdeen	3	1,155,885	423,328
Birmingham	10	1,902,000	135,000
Cambridge	15	3,142,000	249,000
Canterbury	6	1,050,500	157,000
Cardiff	8	1,080,000	143,000
Coventry	3	838,000	323,000
Dundee	6	1,085,289	198,995
Glasgow	17	3,290,280	159,000
Hammersmith	3	384,000	112,000
Kingston upon Hull	5	680,261	62,738
Leeds	6	1,014,500	46,000
Leicester	5	633,000	86,000
Lewisham	4	942,340	224,105
Manchester	19	3,029,715	152,000
Newcastle upon Tyne	10	1,306,000	129,000
North Hampshire	7	1,287,000	168,000
Norwich	3	115,000	49,000
Oxford	22	4,889,040	208,350
Royal Free	28	6,835,700	243,625
Royal London	7	2,775,050	192,000
Sheffield	7	1,639,791	282,000
St George's	4	1,145,700	210,000
St Thomas'	18	4,100,000	246,000
centres with 1 patient meeting criteria	11	1,572,452	115,500
centres with 2 patients meeting criteria	16	2,747,996	142,795

Factor IX units used by UK Haemophilia Centres

Coagulation Defect	Patients Treated	Plasma FIX	Recombinant FIX	Total FIX Units
Haemophilia A	3		13,000	13,000
Haemophilia B	600	9,892,040	71,408,731	81,300,771
Females with IX deficiency	46	20,000	499,193	519,193
FIX Leyden Carrier	1		36,000	36,000
FIX Leyden	2		2,000	2,000
Combined Haemophilia A, Haemophilia B	1		155,000	155,000
Total	653	9,912,040	72,113,924	82,025,964

Total factor IX units by UK Haemophilia Centres: by calendar year between 1989 and 2007 and by financial year from April 2008 onwards



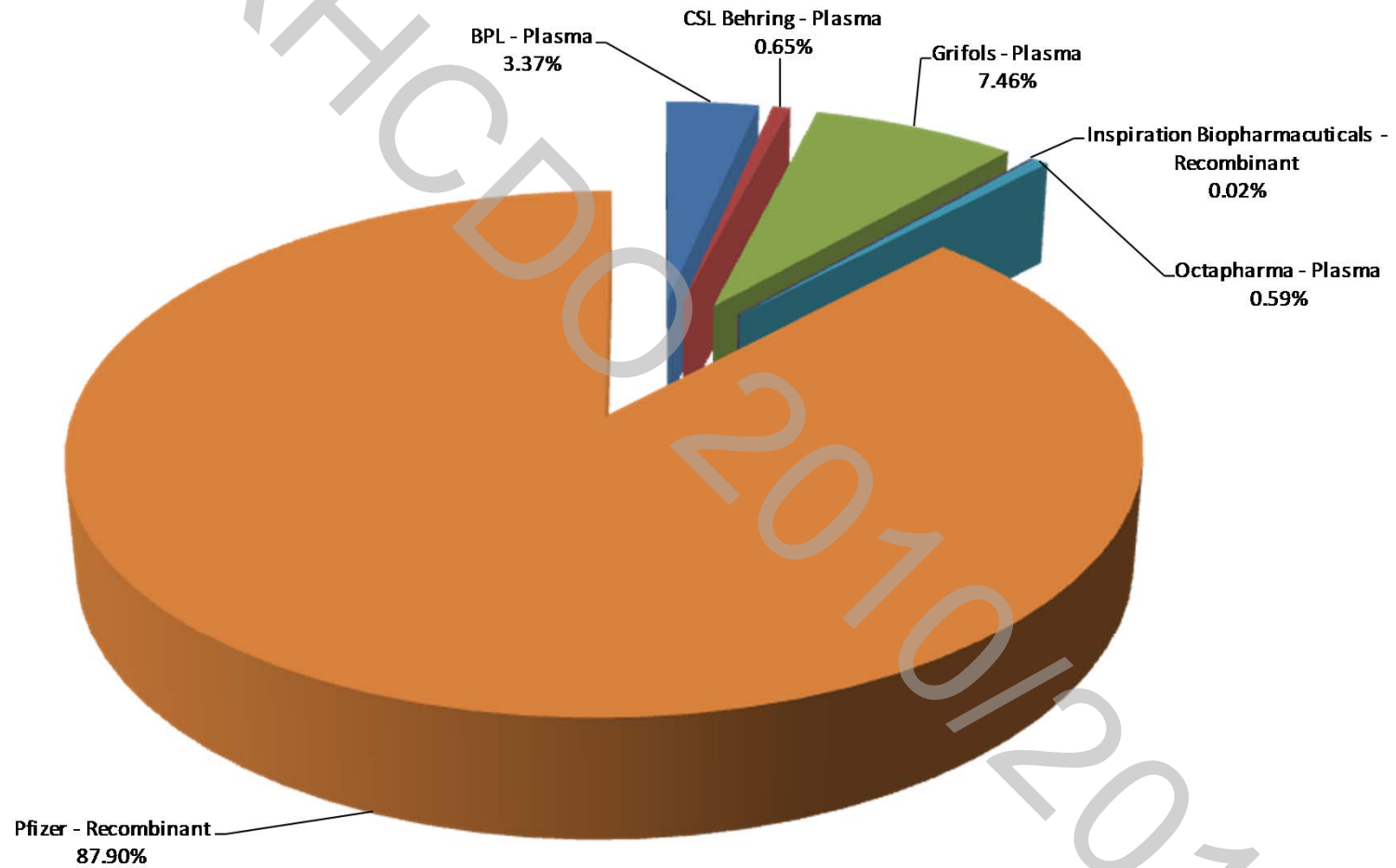
Products used to treat Haemophilia B (including inhibitors)

Manufacturer	Product	Total Units
	Fibrinogen	10,000
	Tranexamic Acid	1,500
	Recombinant FIX Trial Products	17,076
Baxter	FEIBA	2,091,000
Bayer	Kogenate	250
BPL	Replenine	2,768,130
CSL Behring	Mononine	534,000
Grifols	Alphanine	6,101,910
Novo Nordisk	NovoSeven (mg)	4,142
Octapharma	Nanotiv	488,000
Pfizer	BeneFIX	71,391,655

Total Use I.U unless otherwise stated

The use of 250 IU of Kogenate to treat a Haemophilia B patient was accidental

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



Products used to treat von Willebrand's Disease

Manufacturer	Product	Total Units
	Desmopressin (4mcg/ml)	2,080
	Desmopressin Nasal Spray	34,693
	Desmopressin Sub Cut (15mcg/ml)	9,941
Baxter	Advate	50,333
Bayer	Kogenate	43,250
BPL	FVIII 8Y	211,605
	Optivate	400,335
CNTS	VW Factor	5,400
CSL Behring	Haemate P	13,677,800
	Helixate Nexgen	96,000
Grifols	Alphanate	2,035,520
	Fanhdi	93,000
	Wilfactin	419,560
Novo Nordisk	NovoSeven (mg)	389
Octapharma	Wilate	2,431,250
Pfizer	ReFacto AF	15,500

Acquired defects: Materials used by number of patients

Manufacturer	Product	Acquired Haemophilia A		Acquired von Willebrands	
		No. Pts	No. Units	No. Pts	No. Units
	Desmopressin Sub Cut (15mcg/ml)			1	19
	Haemocompletten P (g)	1	2		
Baxter	Advate	1	1,000		
	FEIBA	62	5,159,808		
Bayer	Kogenate	2	6,000		
BPL	FVIII	1	1,600		
CSL Behring	Haemate P			11	241,000
	Helixate Nexgen	1	3,000		
Grifols	Alphanate			1	5,000
	Fanhdi	1	111,254		
	Wilfactin			1	9,000
Novo Nordisk	NovoSeven (mg)	19	1,610		
Pfizer	ReFacto AF	4	133,304		

Adverse events

Adverse Event	Number of Events
New Inhibitor	18
Thrombotic Events	4
Transfusion Event	8
Other events	8
Total	38

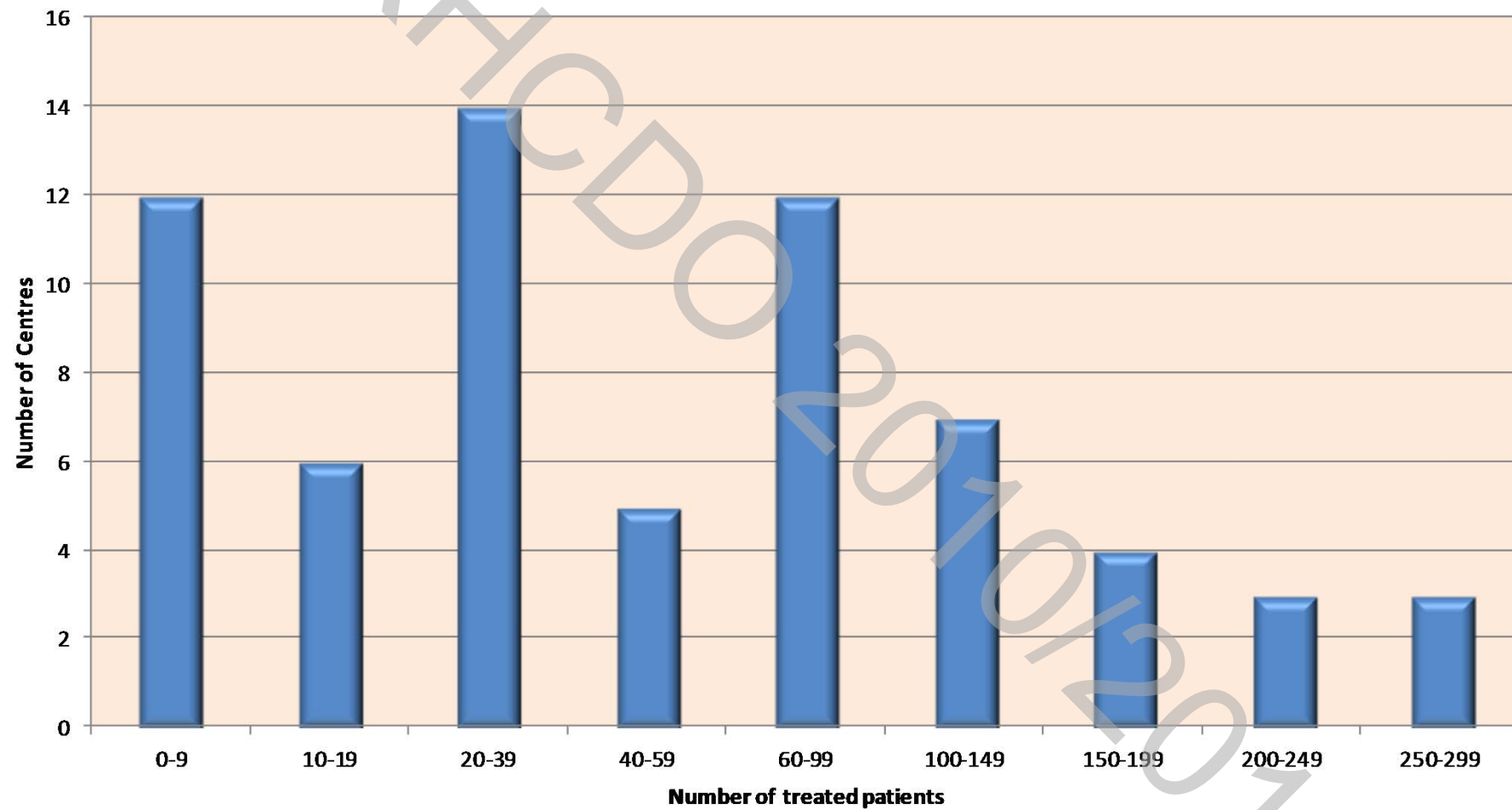
Causes of death in
Haemophilia A, B,
Females with FVIII/FIX
deficiency & von
Willebrand's disease
patients

Cause of Death	Severity		
	≤1	>1 and <5	≥5
Aortic stenosis	0	0	1
ARDS	1	0	0
Carcinoma	5	2	26
Cerebral haemorrhage	3	1	4
COAD	1	0	2
Epilepsy	0	0	1
Haemorrhage (Misc)	2	1	1
Hepatocellular Carcinoma	0	0	3
Hypothermia	1	0	0
Infection (Bacterial)	3	1	19
Intestinal Obstruction	0	0	1
Ischaemic Heart Disease	0	1	5
Liver failure	2	0	2
Lymphoproliferative Malignancy	2	0	1
Motor Neurone Disease	0	0	1
Renal Failure	1	0	3
Senility/Alzheimer's disease	1	0	1
Stroke (thrombotic)	0	0	1
Stroke (Unknown)	0	0	2
Suicide	0	0	1
Unknown	1	0	6
Total	23	6	81

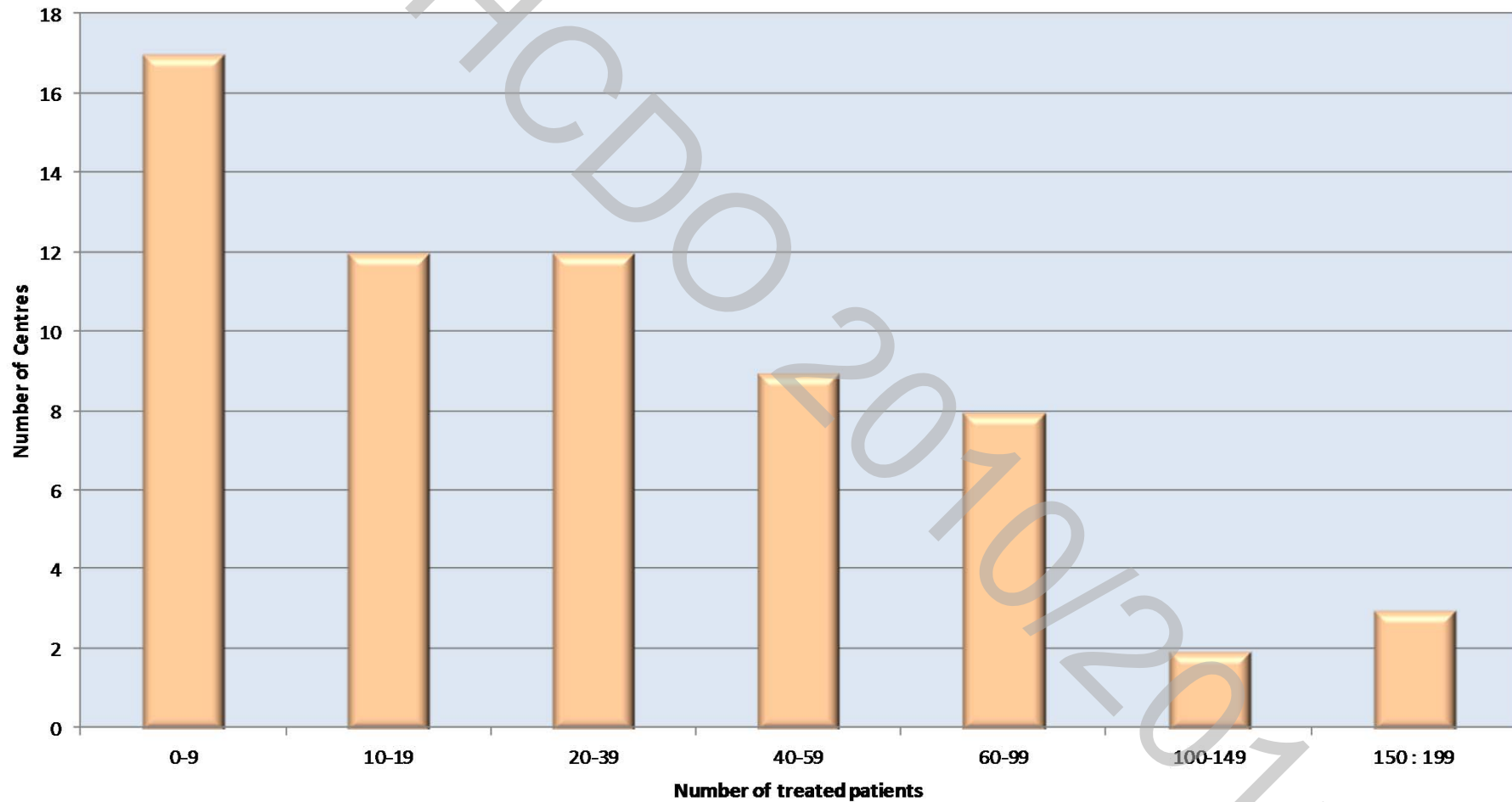
Causes of death - Rarer Defects

Coagulation Defect	Cause of Death	Total	
Acquired Haemophilia A	AIDS	1	
	Carcinoma	6	
	Cardiomyopathy	1	
	Cerebral haemorrhage	2	
	Haemorrhage (Misc)	2	
	Infection (Bacterial)	17	
	Ischaemic Heart Disease	6	
	Lymphoproliferative Malignancy	1	
	Renal Failure	1	
	Stroke (Unknown)	1	
	Unknown	4	
	Acquired von Willebrands	Stroke (Unknown)	1
		Unknown	1
Dysfibrinogenaemia	Ischaemic Heart Disease	1	
F.VII deficiency	Carcinoma	1	
	COAD	1	
	Infection (Bacterial)	2	
	Renal Failure	1	
F.X deficiency	Unknown	1	
F.XI Deficiency	ARDS	1	
	Cerebral haemorrhage	1	
	Encephalopathy	2	
	Infection (Bacterial)	5	
	Ischaemic Heart Disease	2	
	Motor Neurone Disease	1	
	Stroke (Unknown)	3	
	Unknown	1	
	F.XIII Deficiency	Cerebral haemorrhage	1
	Haemophilia A with Liver Transplant	Encephalopathy	1
Haemophilia B with Liver Transplant	Infection (Bacterial)	1	
Multiple Diagnoses	Carcinoma	1	
	Unknown	1	
Platelet defects (misc)	Carcinoma	1	
	Cerebral haemorrhage	1	
	Infection (Bacterial)	3	
	Lymphoproliferative malignancy	1	
	Unknown	1	
Total		79	

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



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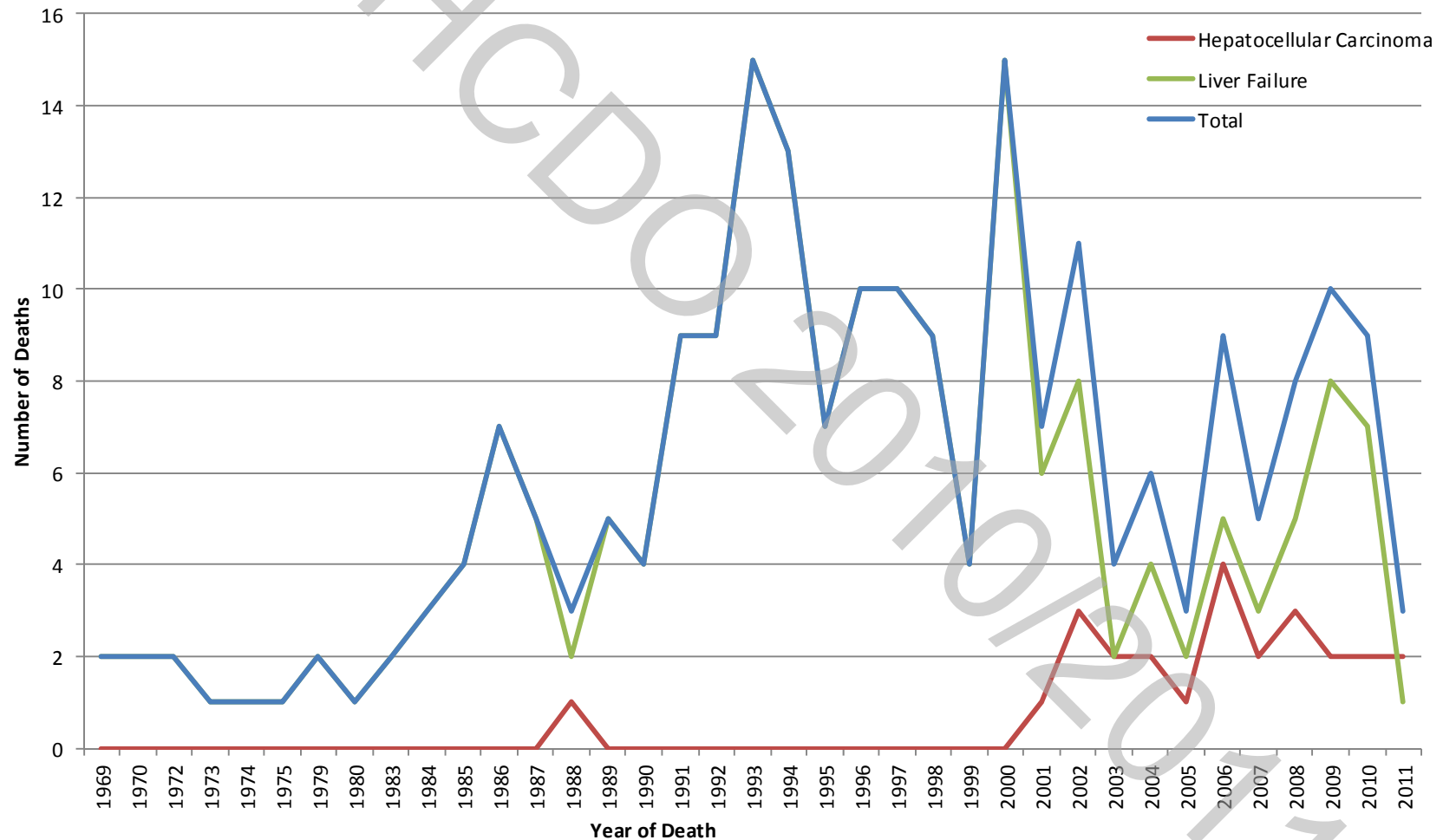
Estimate of number of patients exposed to hepatitis C Based on historical clotting factor concentrate exposure

Coagulation Defect	Alive at 31/03/2011	Died by 31/03/2011	Total
Haemophilia A	1,854	1,607	3,461
Haemophilia B	516	198	714
Females with VIII deficiency	77	20	97
Females with IX deficiency	40	5	45
von Willebrand disease	201	76	277
F.VII deficiency	4	1	5
F.X deficiency	7	1	8
F.XI Deficiency	4	3	7
Prothrombin Deficiency	1	1	2
Combined V+VIII Deficiency	2	-	2
Other combined diagnoses	3	3	5
Acquired Haemophilia A	2	24	26
Acquired Haemophilia B	1	1	2
Acquired von Willebrands	1	1	2
Platelet defects	1	-	1
Haemophilia A with Liver Transplant	9	11	20
Haemophilia B with Liver Transplant	1	3	4
Factor X deficiency with Liver Transplant	-	1	1
Miscellaneous	-	1	1
Unclassified	9	-	9
Total	2,733	1,957	4,689

Annualised UK Deaths from Liver Disease 1969-2011

Year of death	Hepatocellular Carcinoma	Liver Failure	Total
1969	0	2	2
1970	0	2	2
1972	0	2	2
1973	0	1	1
1974	0	1	1
1975	0	1	1
1979	0	2	2
1980	0	1	1
1983	0	2	2
1984	0	3	3
1985	0	4	4
1986	0	7	7
1987	0	5	5
1988	1	2	3
1989	0	5	5
1990	0	4	4
1991	0	9	9
1992	0	9	9
1993	0	15	15
1994	0	13	13
1995	0	7	7
1996	0	10	10
1997	0	10	10
1998	0	9	9
1999	0	4	4
2000	0	15	15
2001	1	6	7
2002	3	8	11
2003	2	2	4
2004	2	4	6
2005	1	2	3
2006	4	5	9
2007	2	3	5
2008	3	5	8
2009	2	8	10
2010	2	7	9
2011	2	1	3
Total	25	196	221

Annualised UK Deaths from Liver Disease 1969-2011



Hepatitis C Look-back forms

Hepatitis C Look-back forms	n	%
Expected Number of forms:	15057	
Expected Number of forms for patients still alive:	11567	77%
Number of forms received:	3266	28%

Of those patients for whom a report has been submitted	n	%
No. of patients Alive	2547	78%
No. of patients Deceased	719	22%

Exposure to blood components or clotting factor concentrate

Exposure type	n	%
Number exposed to blood components only during period of risk	284	9%
Number exposed to concentrate only during period of risk	349	11%
Number exposed to blood components both blood components and clotting factor concentrate period of risk	860	26%
Total	1,493	
Number not exposed to either blood components and clotting factor concentrate period of risk	1773	54%

HCV status compared with treatment

HCV status	No blood product treatment reported	Blood Components Only	Concentrate Only	Both
Antibody +ve	1	31	127	479
Antibody -ve	4	165	78	131
Antigen +ve	0	23	70	305
Antigen -ve	0	5	37	103
Ab +ve and Ag +ve	0	22	70	304

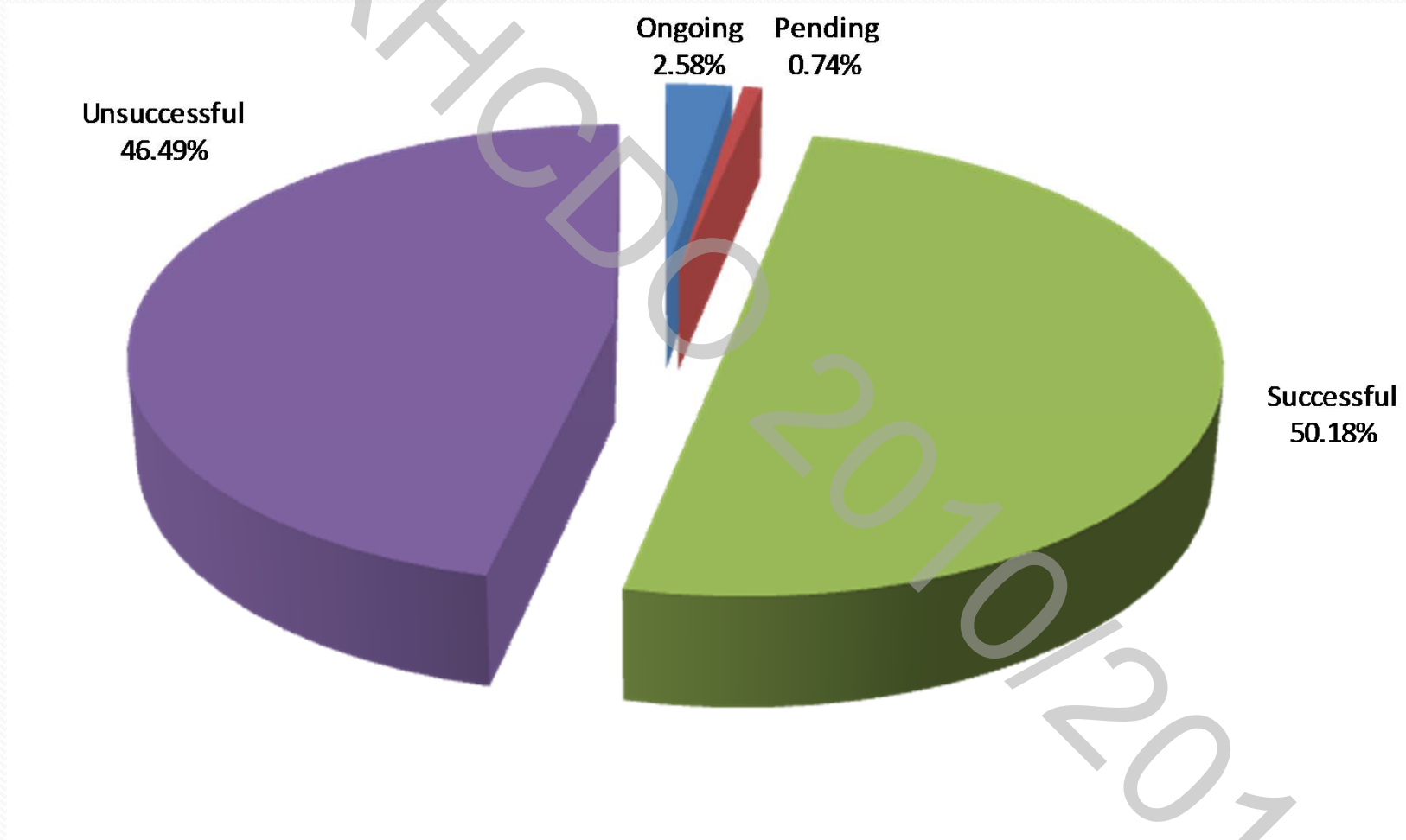
Diagnostic breakdown for patients reported to be HCV antibody positive

Diagnosis	Severe	Moderate	Mild	Total
Haemophilia A	236	59	161	456
Haemophilia B	52	18	33	103
Females with VIII deficiency	0	0	7	7
Females with IX deficiency	0	0	4	4
von Willebrand disease	10	3	39	52
F.X deficiency	1	0	0	1
Fibrinogen Deficiency	0	0	1	1
Combined V+VIII Deficiency	0	0	1	1
Acquired Haemophilia A	1	0	0	1
Platelet defects (misc)	0	0	0	0
Haemophilia A with Liver Transplant	1	1	4	6
Haemophilia B with Liver Transplant	0	0	1	1
Unclassified	0	0	3	3
Total	301	81	254	636

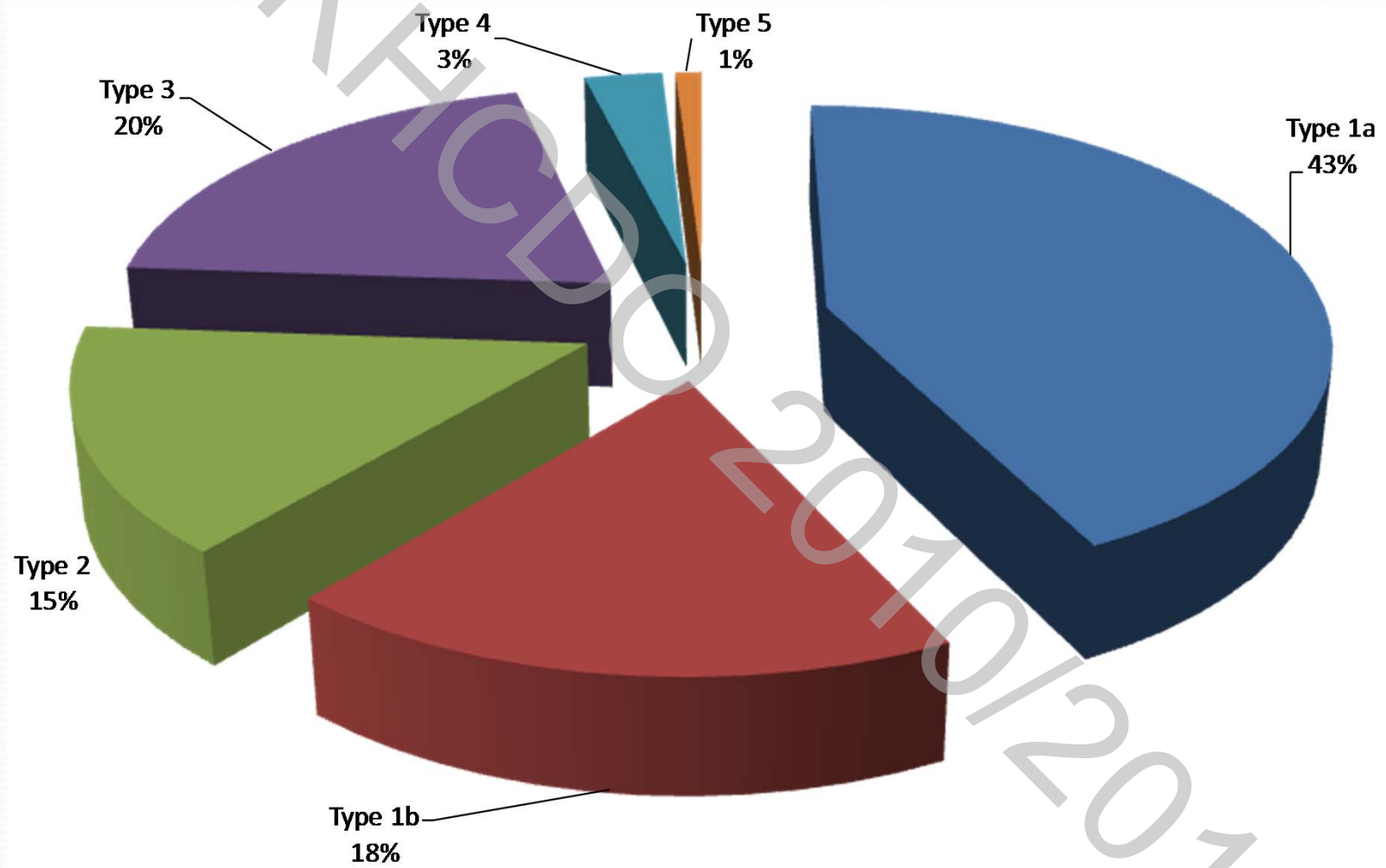
Patients alive with serious liver disease

Disease	Number of patients
Cirrhosis	44
Liver Failure	9
Liver Transplant	4
Hepatocellular Carcinoma	9

Treatment Outcomes



Genotypes



HAEMTRACK Data report



UKHSC
2010/2011

HAEMTRACK Data Report Patient Diagnosis

Diagnosis	Numbers	Percentage of Total
Haemophilia A	642	82%
Haemophilia B	110	14%
Von Willebrand's Disease	27	3.5%
Factor VII	3	0.5%

HAEMTRACK Patient Users - Age Breakdown

Age Range	Number of Patients	Percentage of Total
0-19	254	32.48%
20-39	314	40.15%
40-59	178	22.76%
>= 60	36	4.6%

Treatment Type Breakdown

Treatment Type	Number of Treatments Entered	% of Total
Prophylaxis	64,115	79.0%
Bleeds	6,427	7.9%
Bleed follow-ups	5,407	6.6%
Prescribed treatments	2,135	2.6%
Activity	1,246	1.5%
Immune Tolerance	760	0.9%
Surgery	520	0.6%
Others	501	0.6%
Physiotherapy	109	0.1%

On-Demand or Breakthrough Bleed Category

Bleed Category	Number of Bleeds	Percentage of Total
Joint	4232	64%
Muscle / Soft Tissue	1773	26.7%
Mouth	154	2.3%
Other	482	7%

Cause of Bleeds

Bleed Cause	Number of Bleeds	Percentage of Total
Spontaneous	3315	51.5%
Trauma / Activity	3087	48%
Surgery / Dental Work	35	0.5%

Severity of Bleeds

Bleed Severity	Number of Bleeds	Percentage of Total
Minor	5155	85.5%
Major	869	14.4%
Life or Limb Threatening	6	0.1%

Bleed Pain Scale

Pain Scale (1 low – 6 high)	Numbers	Percentage of Total
1	666	11.80%
2	1,019	18%
3	1,886	33%
4	1,429	25.2%
5	515	9%
6	147	2.6%

Haemarthrosis Position

Haemarthrosis Position	Number of Bleeds	Percentage of Total
Elbow	1183	32.8%
Ankle	1169	32.5%
Knee	958	26.6%
Shoulder	292	8.1%