



UK Bleeding Disorder Statistics for 2007

Dr CRM Hay

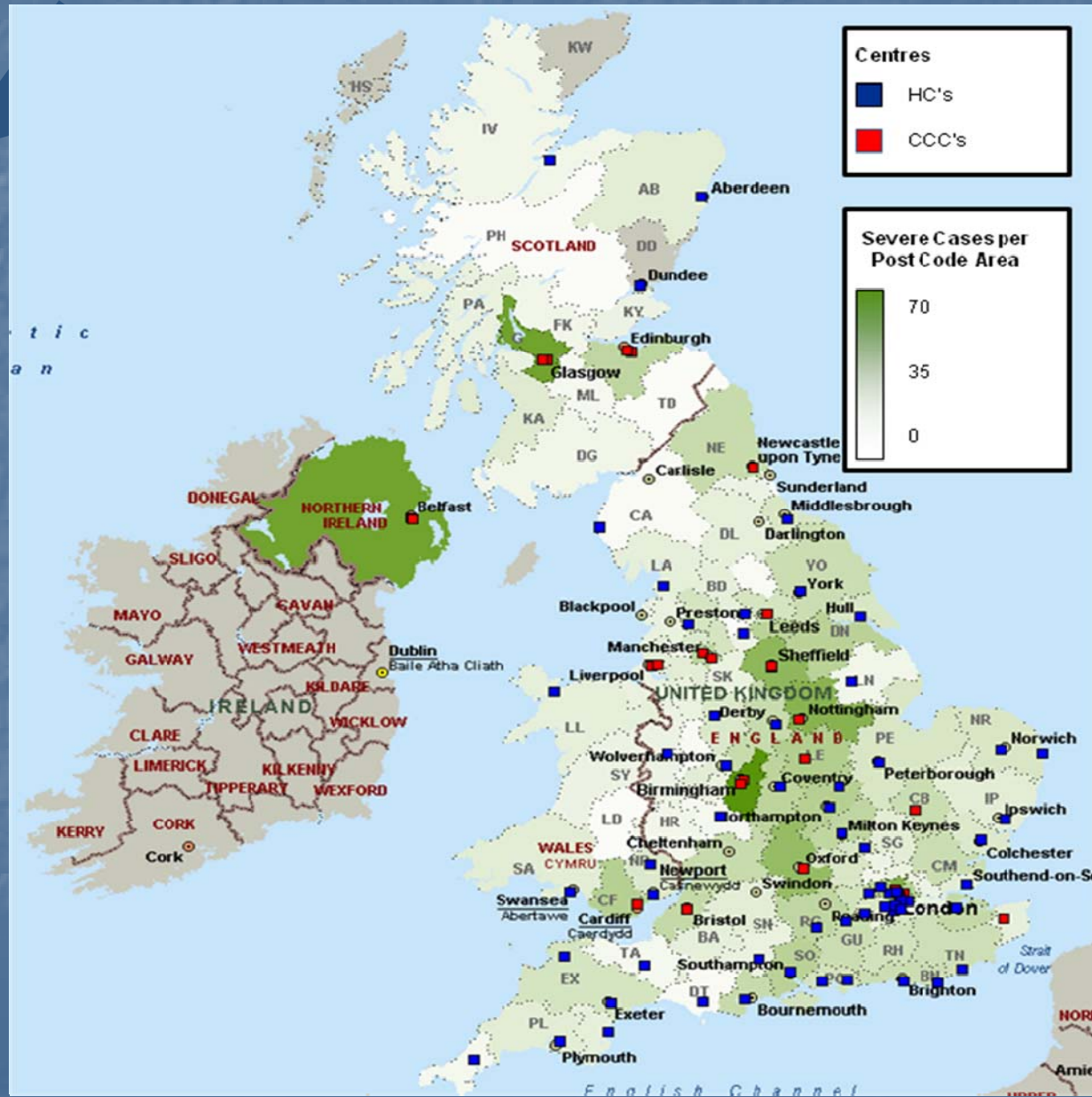
UK BCD 2008



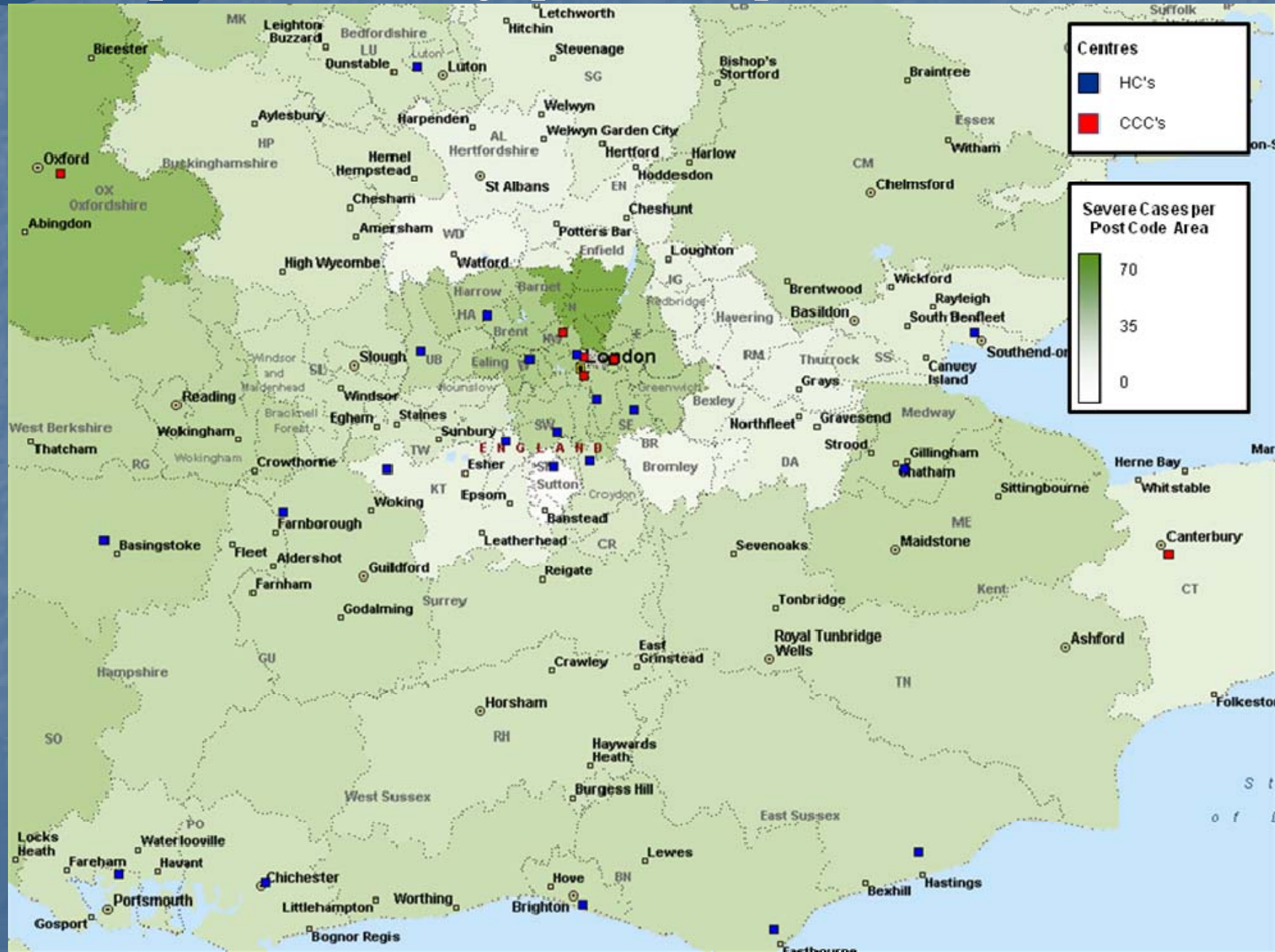
Registrations: -

		<u>In 2007</u>	<u>Total in Register</u>
Haem A	Severe	44	1,756
	Total	137	6,303
	De-registered	400+	
Haem B	Severe	13	363
	Total	34	1,340
VWD	male	126	8,610
	female	229	
Total all diagnoses		959	23,629

Density of Severe Haemophilia A & B population - by patient post code area



Density of Severe Haemophilia A & B Population - by patient post code area – SE



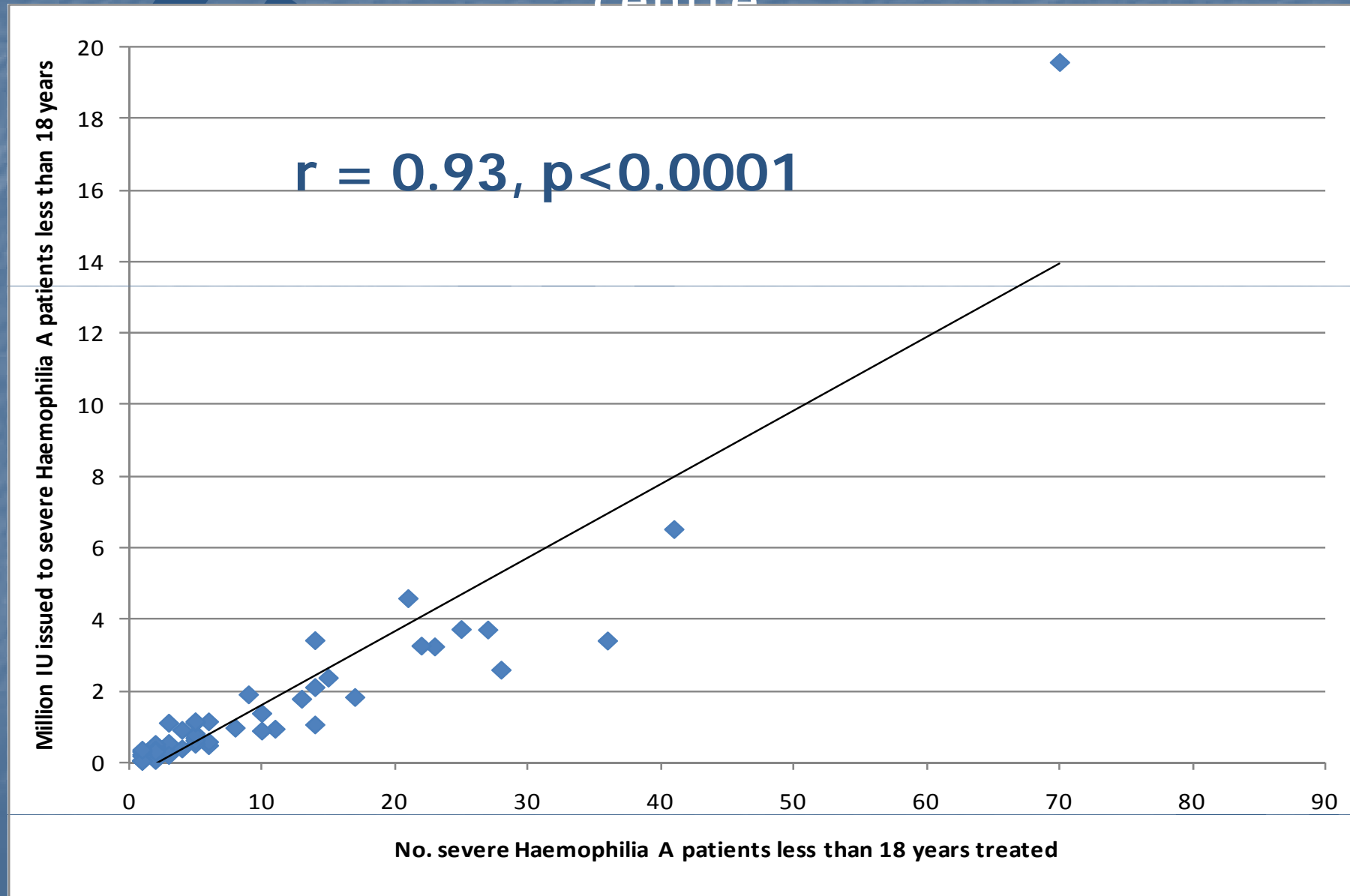
Total Factor VIII / IX Usage (inc. inhibitor) by patient post code area



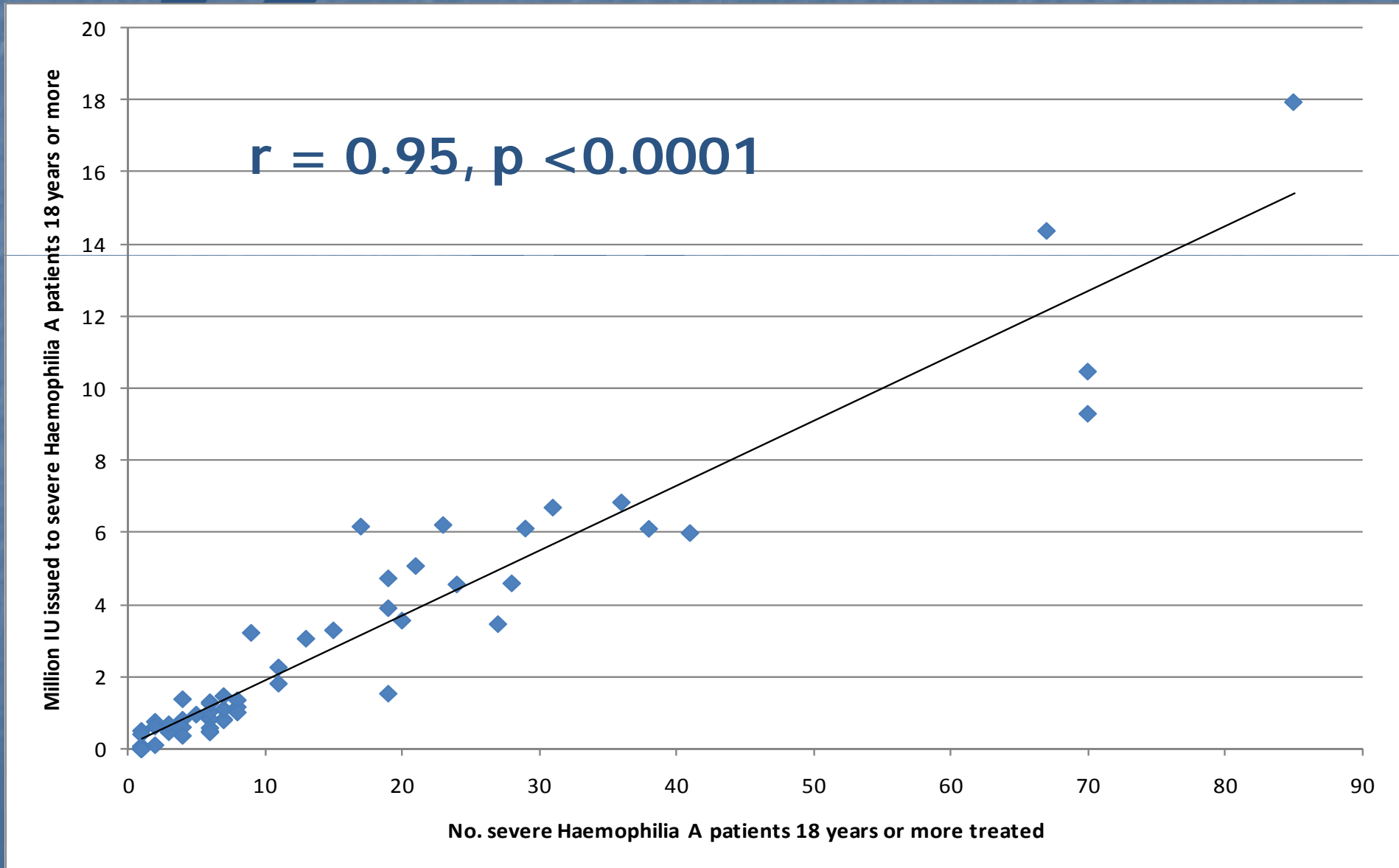
Total Factor VIII / IX Usage (inc. inhibitor) by patient post code area - London



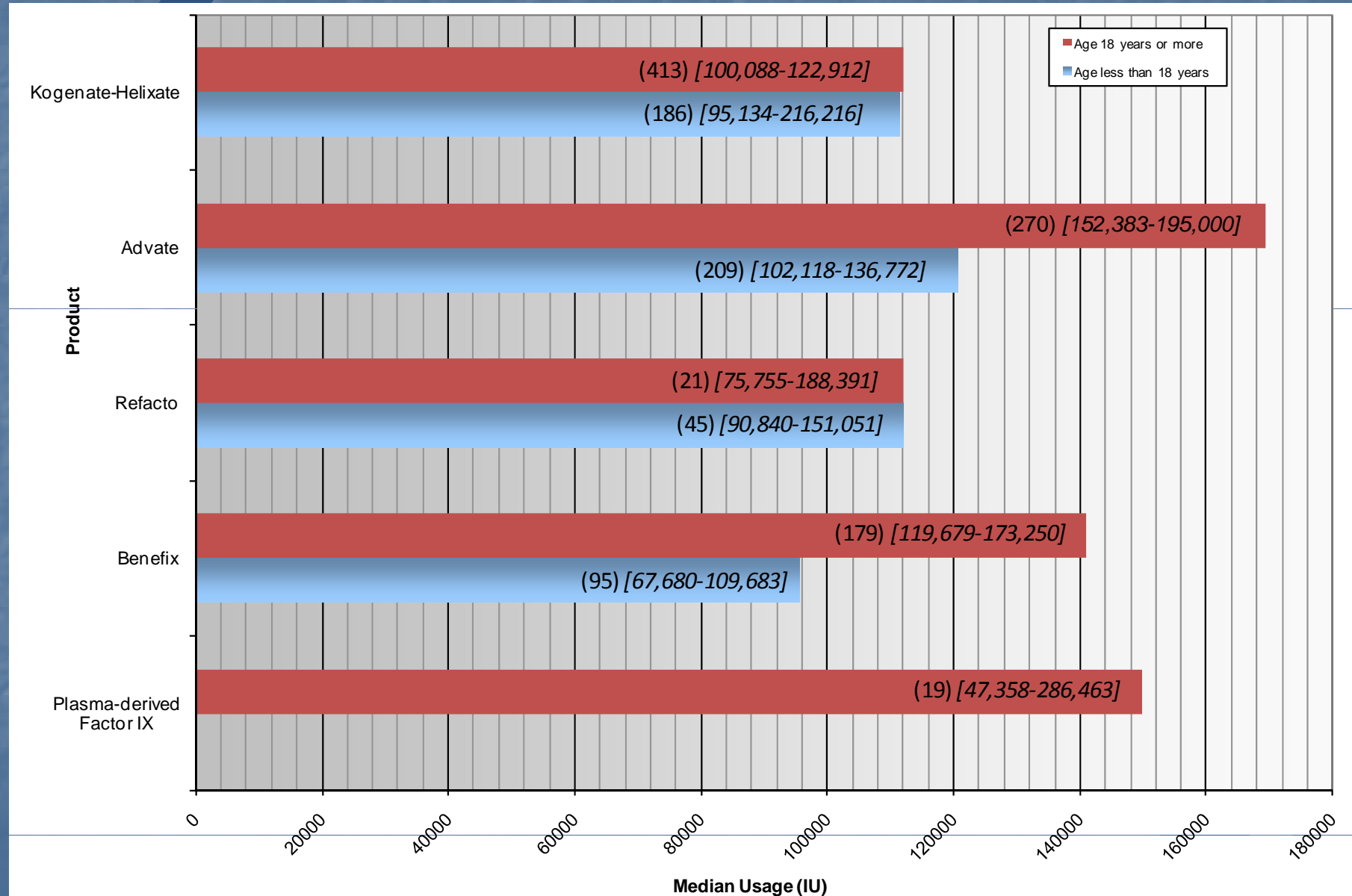
Severe Haemophilia A – No. pts without inhibitor <18 years, treated by factor VIII issued by each centre



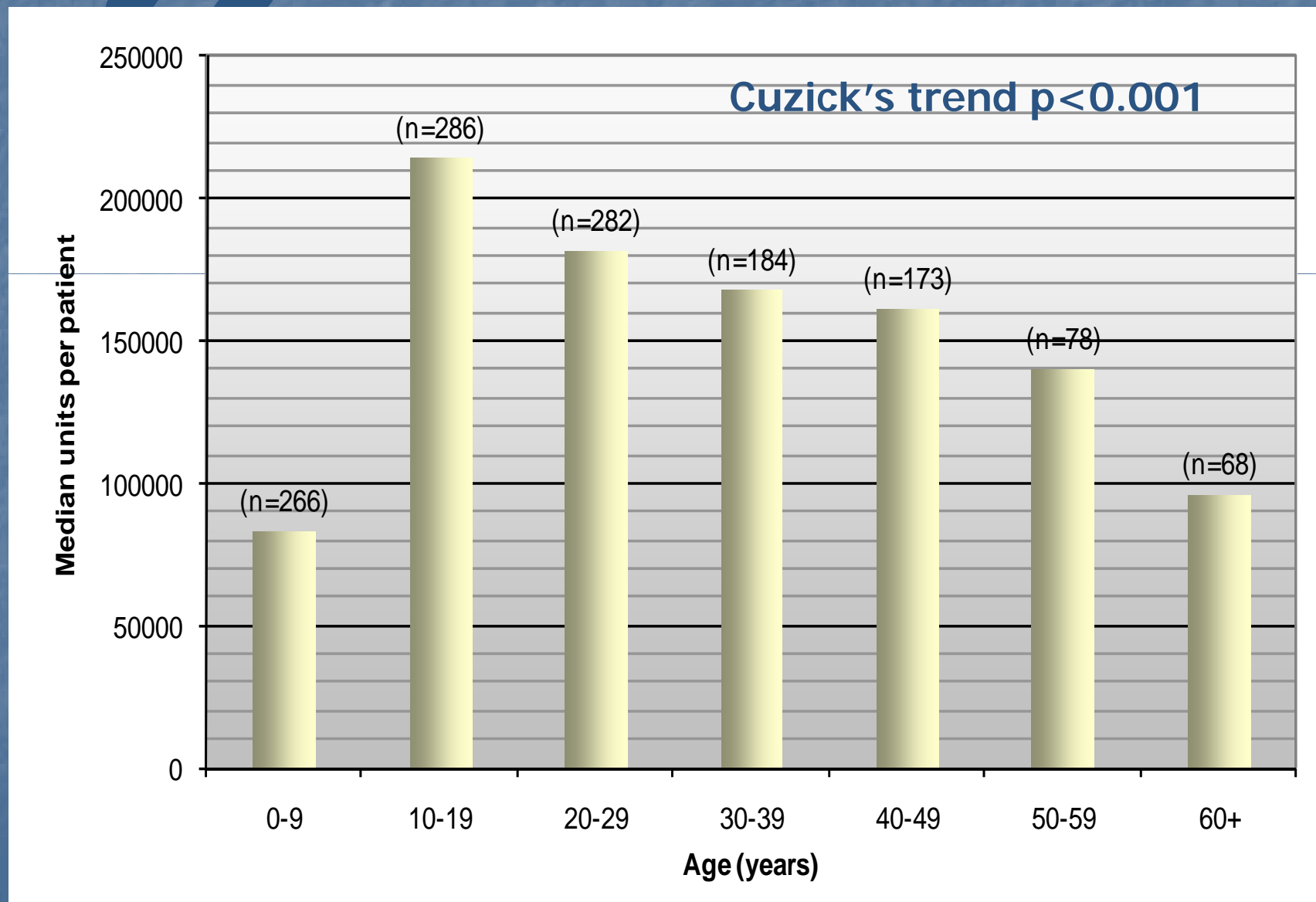
Severe Haemophilia A – N°. pts lacking inhibitor ≥ 18 yrs, treated by factor VIII units issued by each centre



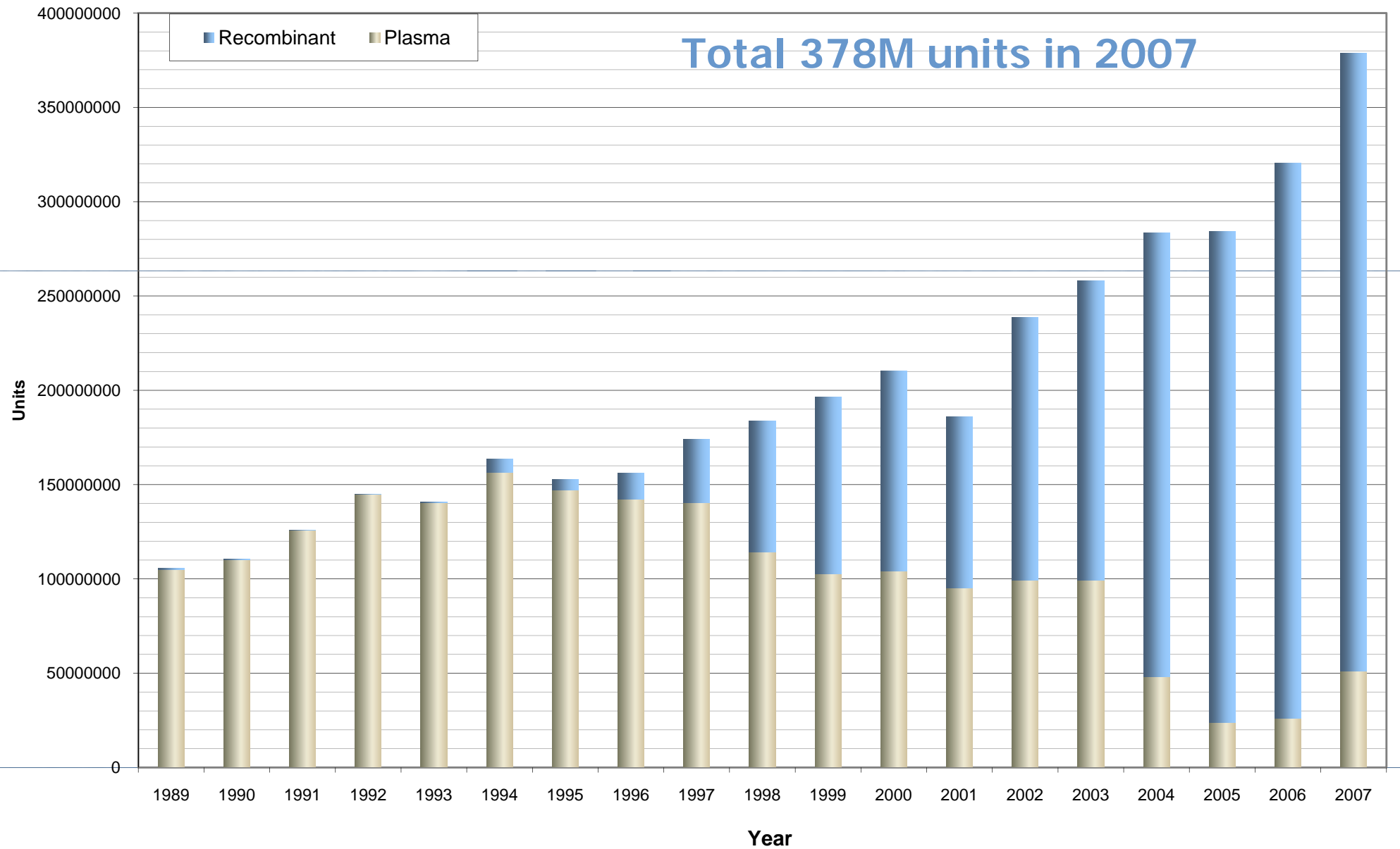
Severe haemophilia A and B lacking inhibitor using only one product during 2007: median usage



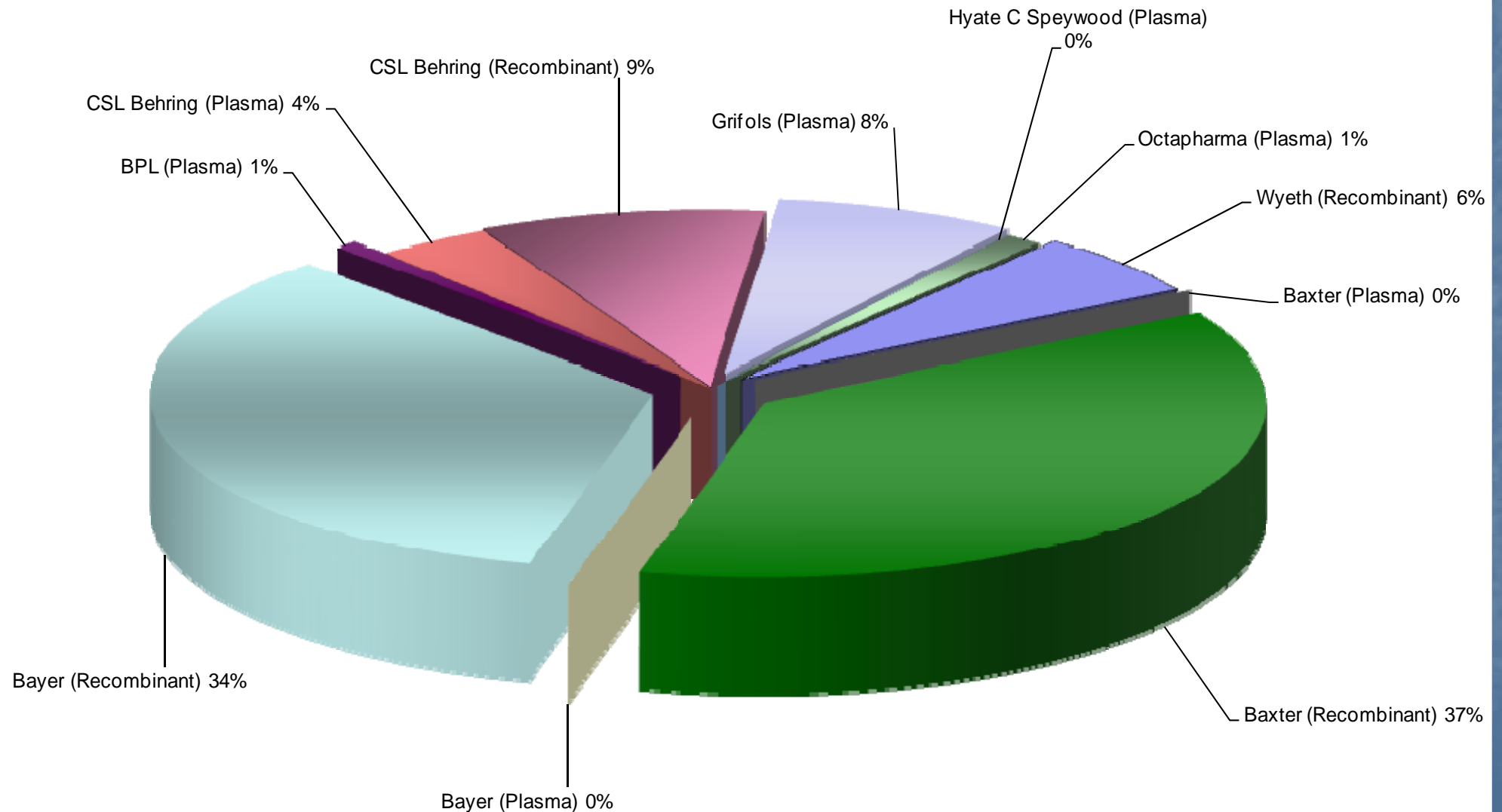
Severe Haemophilia A patients treated with FVIII products with no current inhibitor: median IU issued



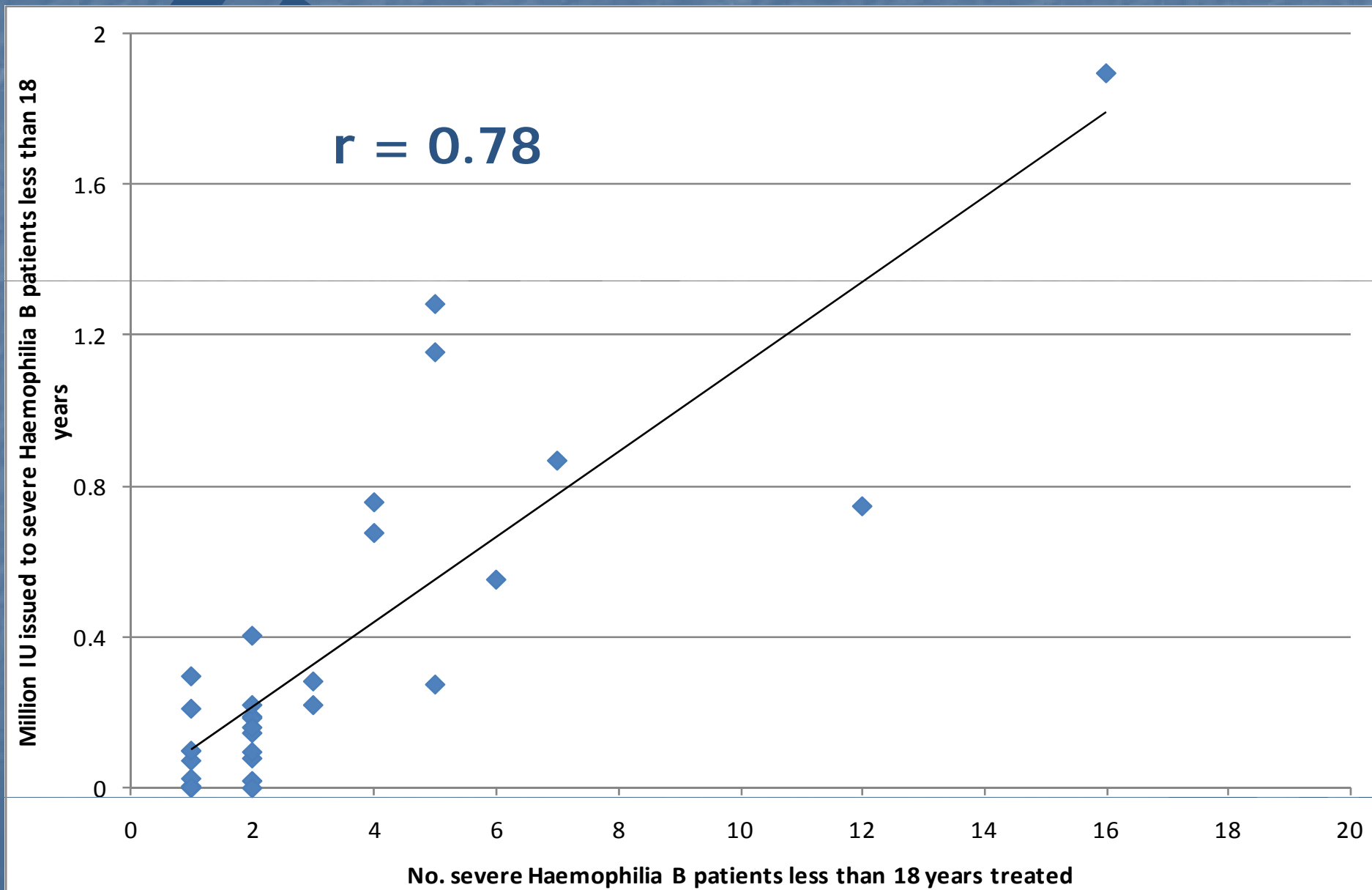
Factor VIII usage by UK Haemophilia Centres: 1989-2007



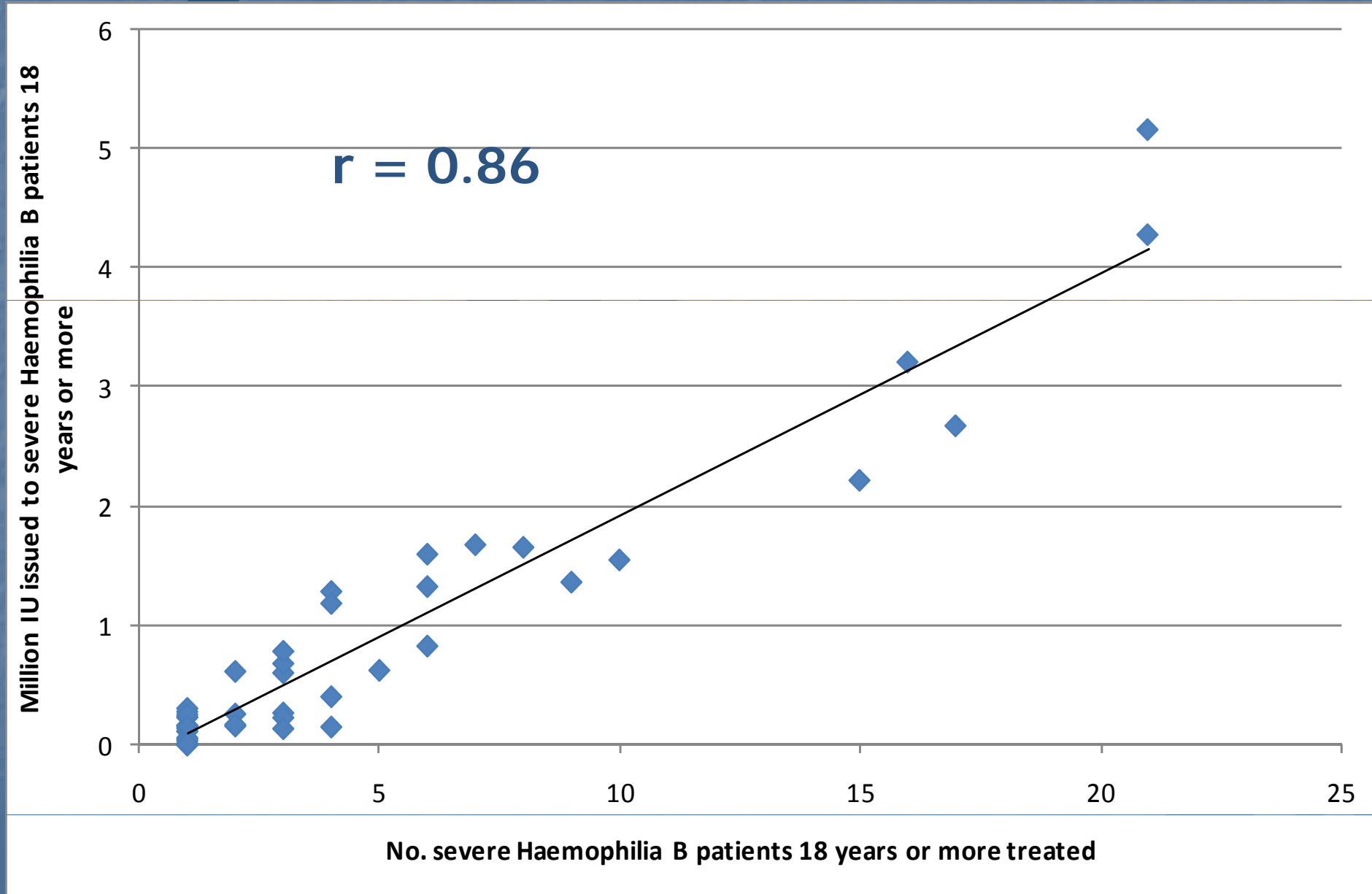
Market Share of factor VIII concentrates known to have been used by UK Haemophilia Centres



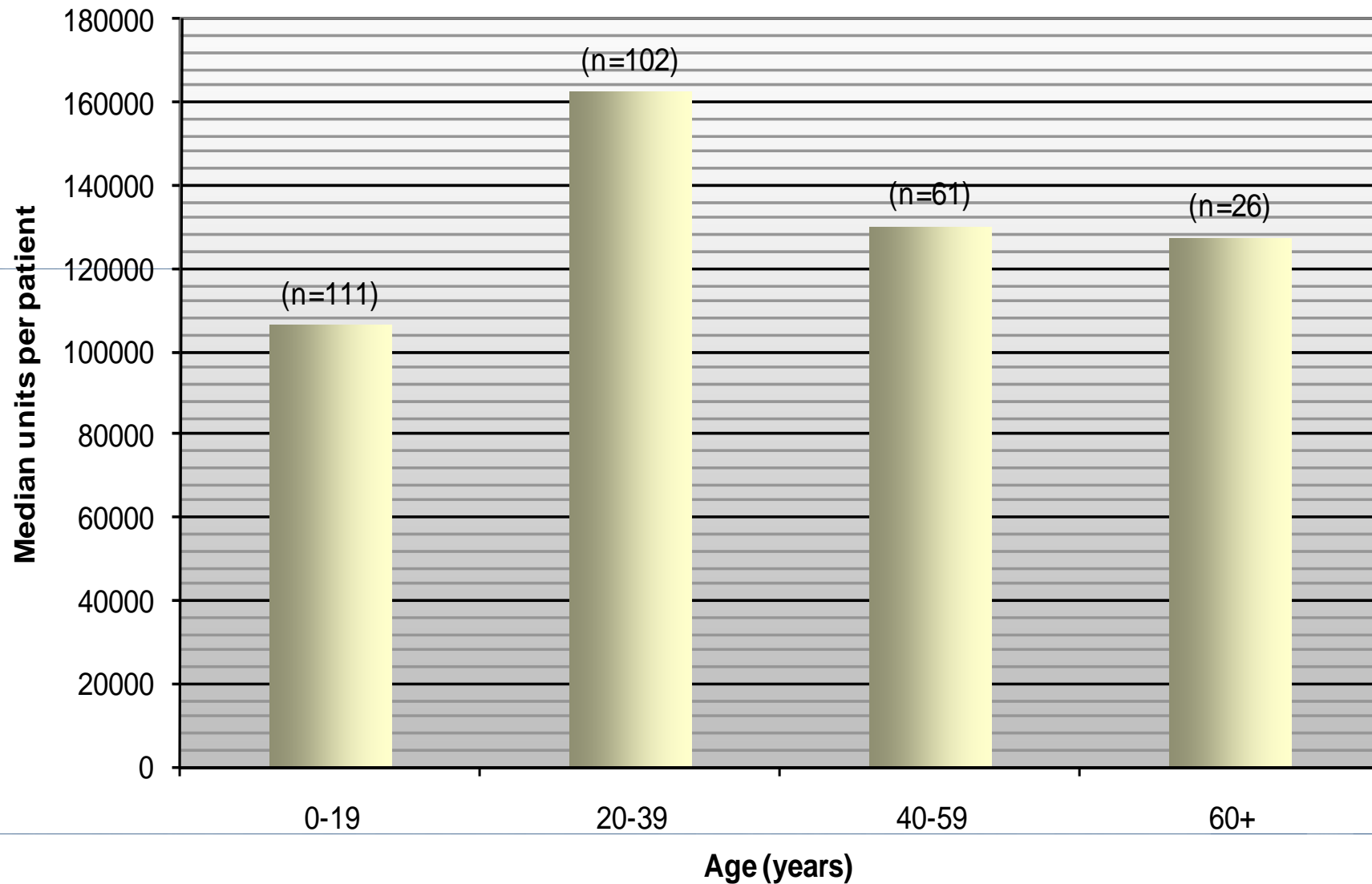
Severe Haemophilia B: Pts lacking inhibitor < 18 yrs, compared to number of units issued



Severe Haemophilia B: Pts lacking inhibitor ≥ 18 yrs compared to number of units issued

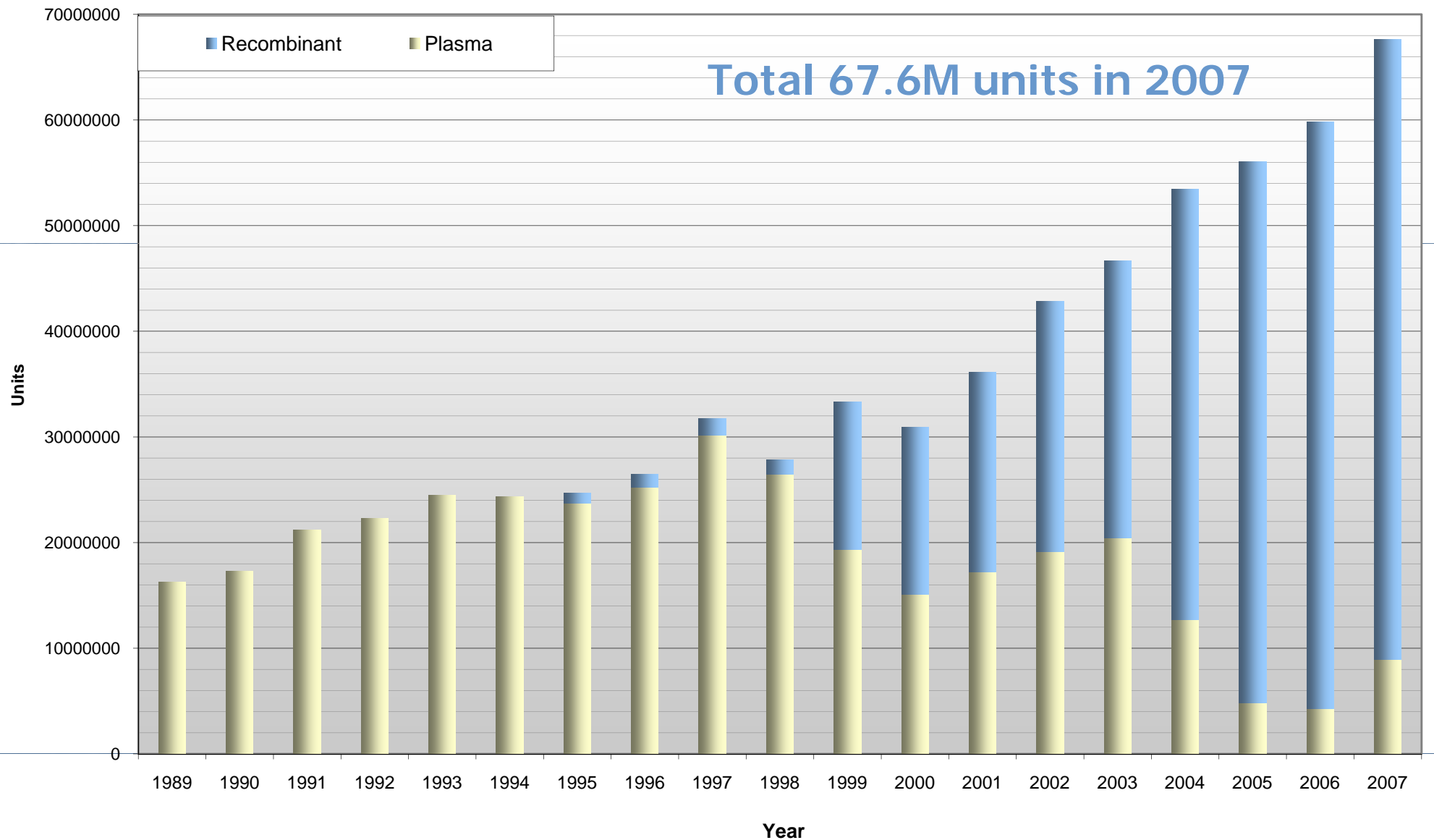


Severe Haemophilia B patients with no current inhibitor: median IU issued

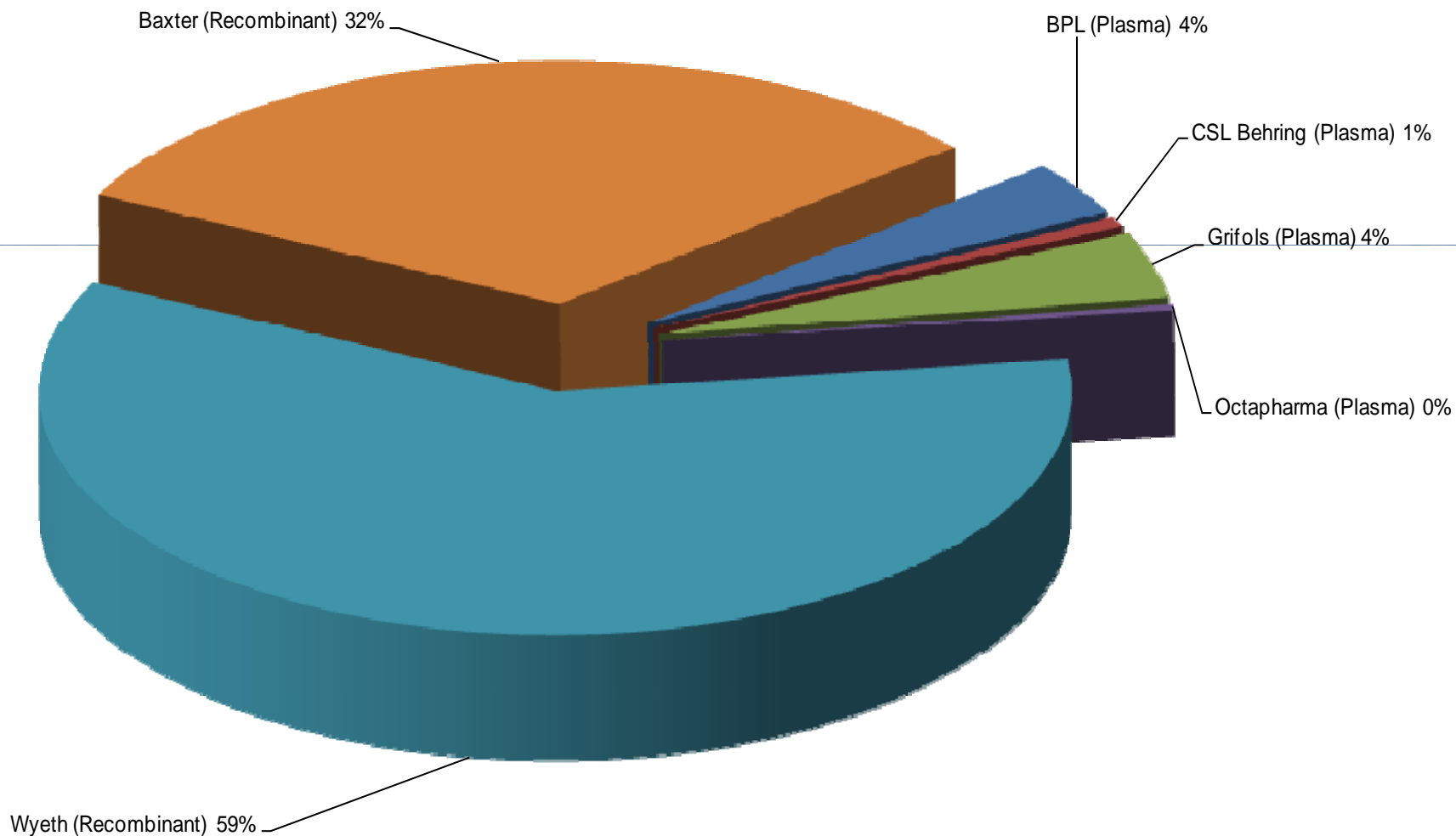




Total factor IX units used by UK Haemophilia Centres 1989-2007



Market share of Factor IX concentrates known to have been used by UK Haemophilia Centres





Von Willebrand's Disease

Total registered	Type 1	2,223
Male	Type 1A/B	7
Female	Type 2	95
	Type 2A	169
	Type 2B	76
	Type 2D	1
	Type 2M	88
	Type 2N	43
	Type 3	69
	Subtotal Typed	2,795
	Un-typed	5,992

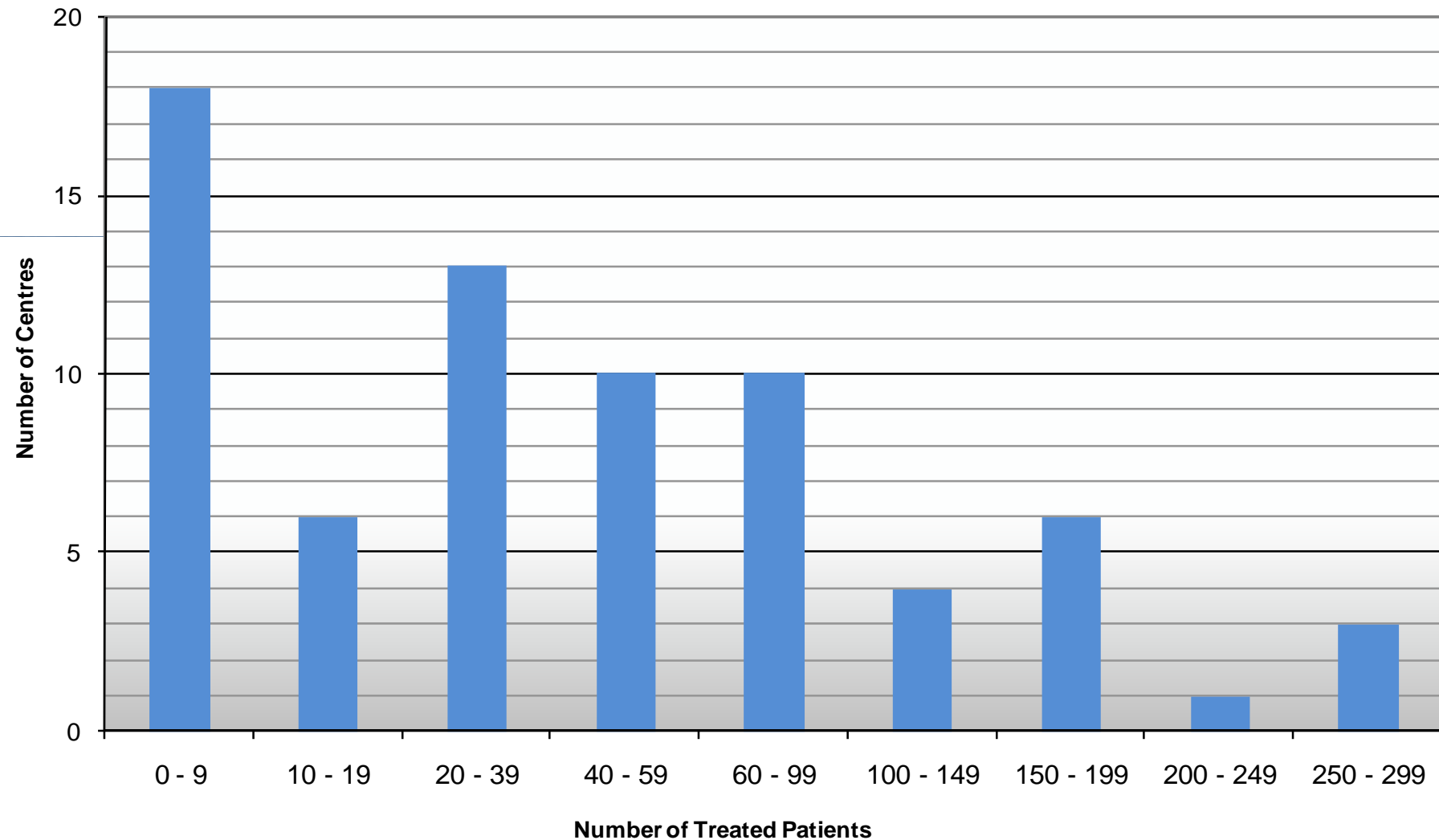
Products used: -

DDAVP +++	
Haemate P	13.03M IU
Alphanate	1.89M IU
Wilfactin	1.04M IU
8Y/Optivate	0.75M IU

Principal causes of death 2007 (Haemophilia A, B and VWD).

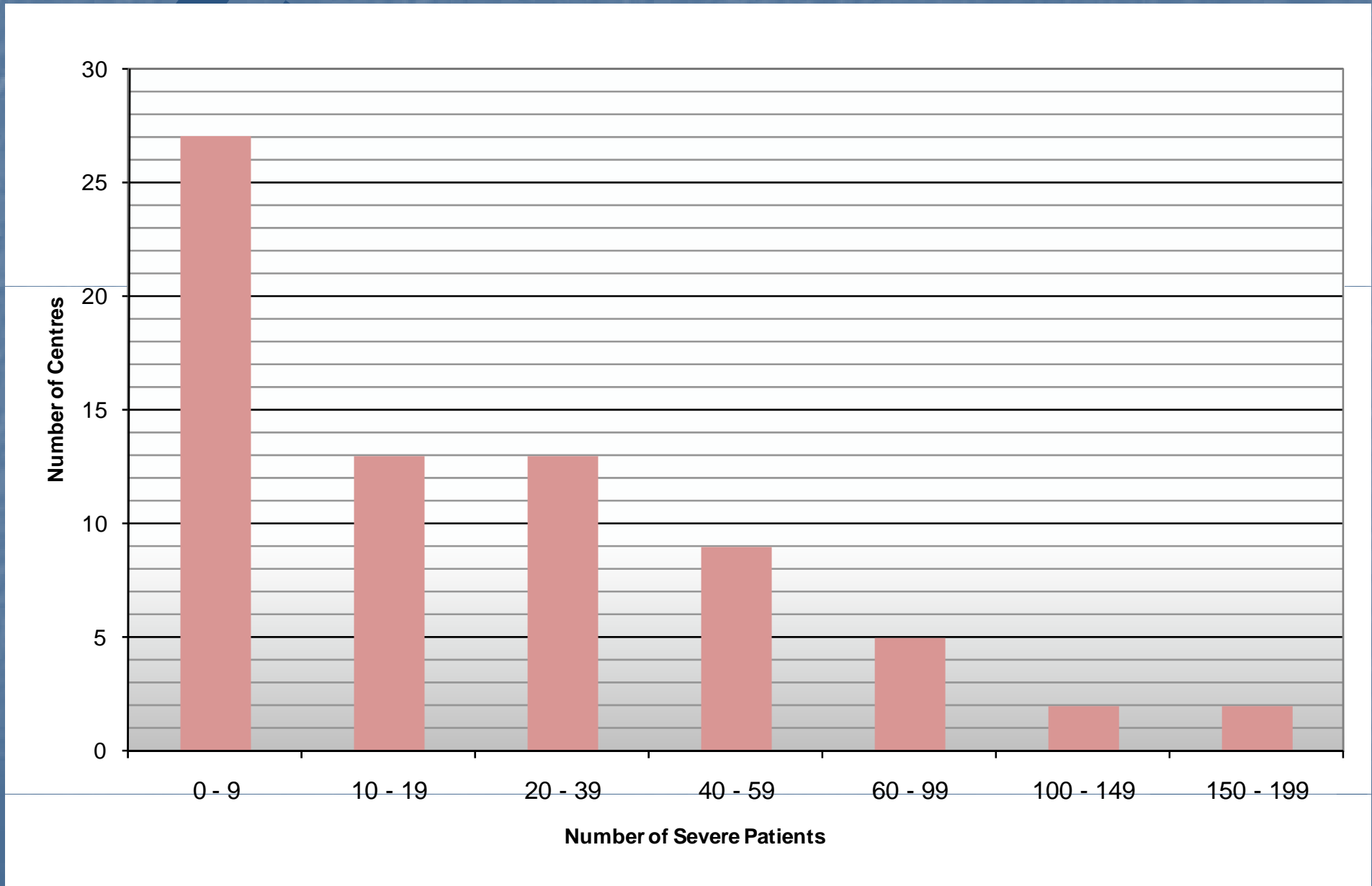
■ Carcinoma	17 (2 Liver)
■ Ischaemic Heart Disease	13
■ Haemorrhage	16
■ Cerebral Haemorrhage	9
■ Liver failure	4
■ Infection	8
■ AIDS	2

Haemophilia A, B and von Willebrand's Disease Pts (all severities) treated by UK Haemophilia Centres





Severe Haemophilia A, B and von Willebrand's Disease pts treated by UK Haemophilia Centres



Data Quality

- Commissioners consider that centres have a contractual obligation to submit data to NHD.
- DoH requires return of data.
- They are increasingly looking to NHD for data to support healthcare planning, benchmarking and reviews of service configuration.
- We therefore all have a duty to ensure the data is therefore as accurate as possible.
- In the last year we have made great strides in improving data quality.
- In the next year we intend to improve data further.

Data Quality

- Internal cross-checks: -
 - Demographics checked with NSTS
 - Automatic reconciliation with HCIS system
 - Centre data compared with previous 2 years
 - No coding data (grossly unreliable) used
 - Deaths cross-checked with ONS
 - Data queries raised
 - Centres should check data annually
- Data cleaning campaigns
 - VWD, inhibitors, registrations of untreated Haem A/B
- 2 data chasers and the appointment of a data quality officer.
 - Will visit centres for training purposes and audit