Data and demographics 2012-13

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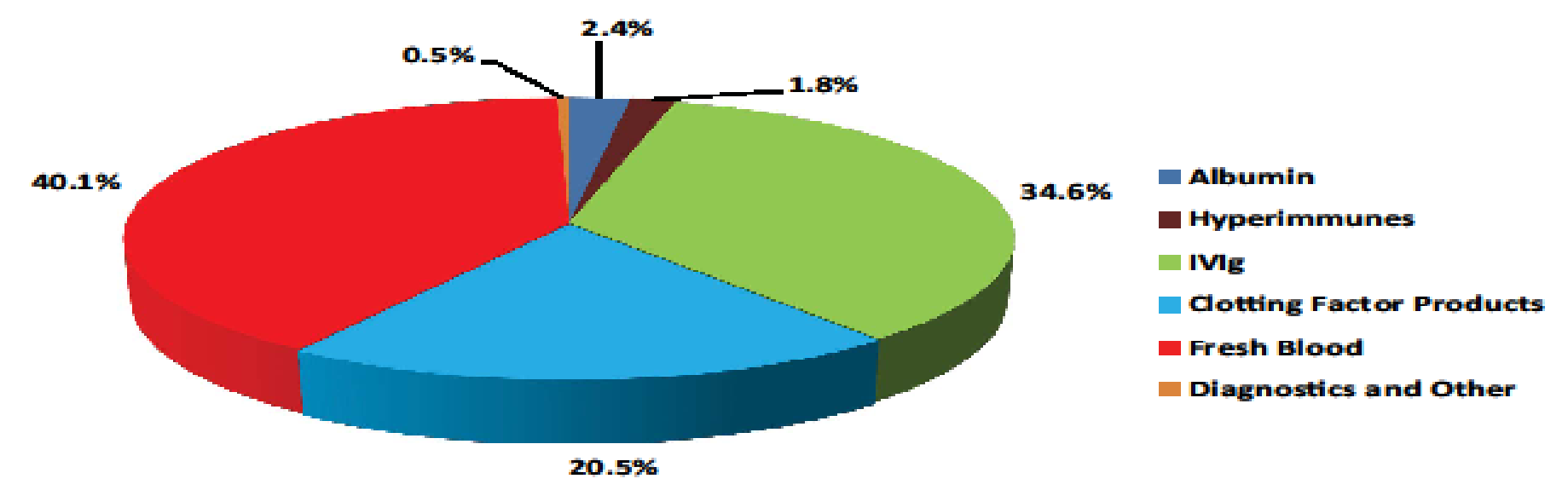
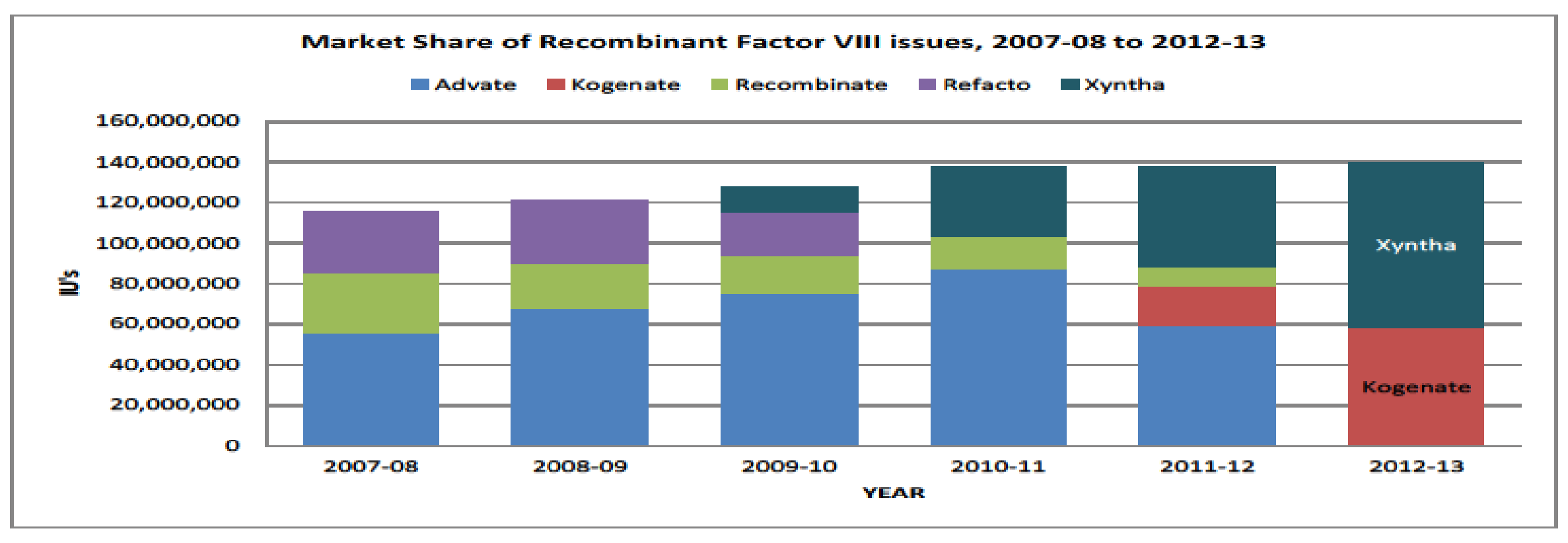
ABDR

The current ABDR is an internet based clinical registry that includes demographic, clinical and product use data for persons with bleeding disorders. Governance is managed by the ABDR Steering Committee (ABDRSC). Representatives are drawn from AHCDO– a group of clinicians responsible for haemophilia care in Australia, HFA – Australia wide patient support group and the NBA – a federally funded agency responsible for procurement and supply of blood and recombinant products used in management of bleeding disorders.

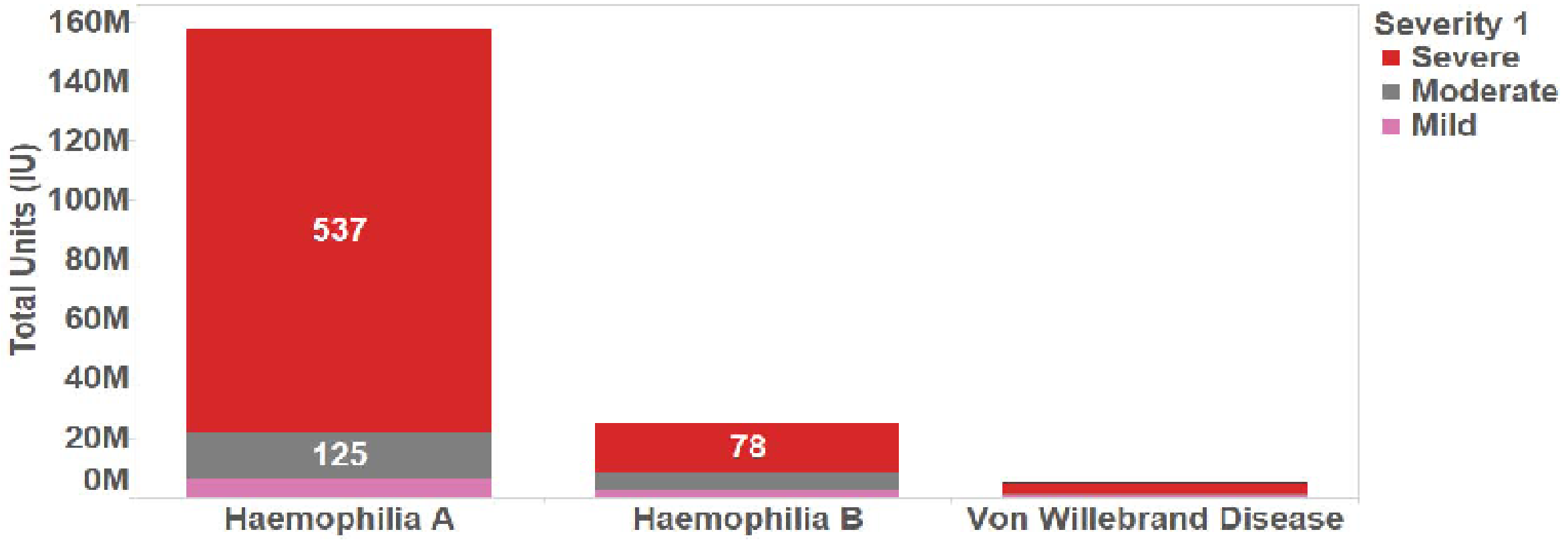
NBA Expenditure by Product Category for 2012-13



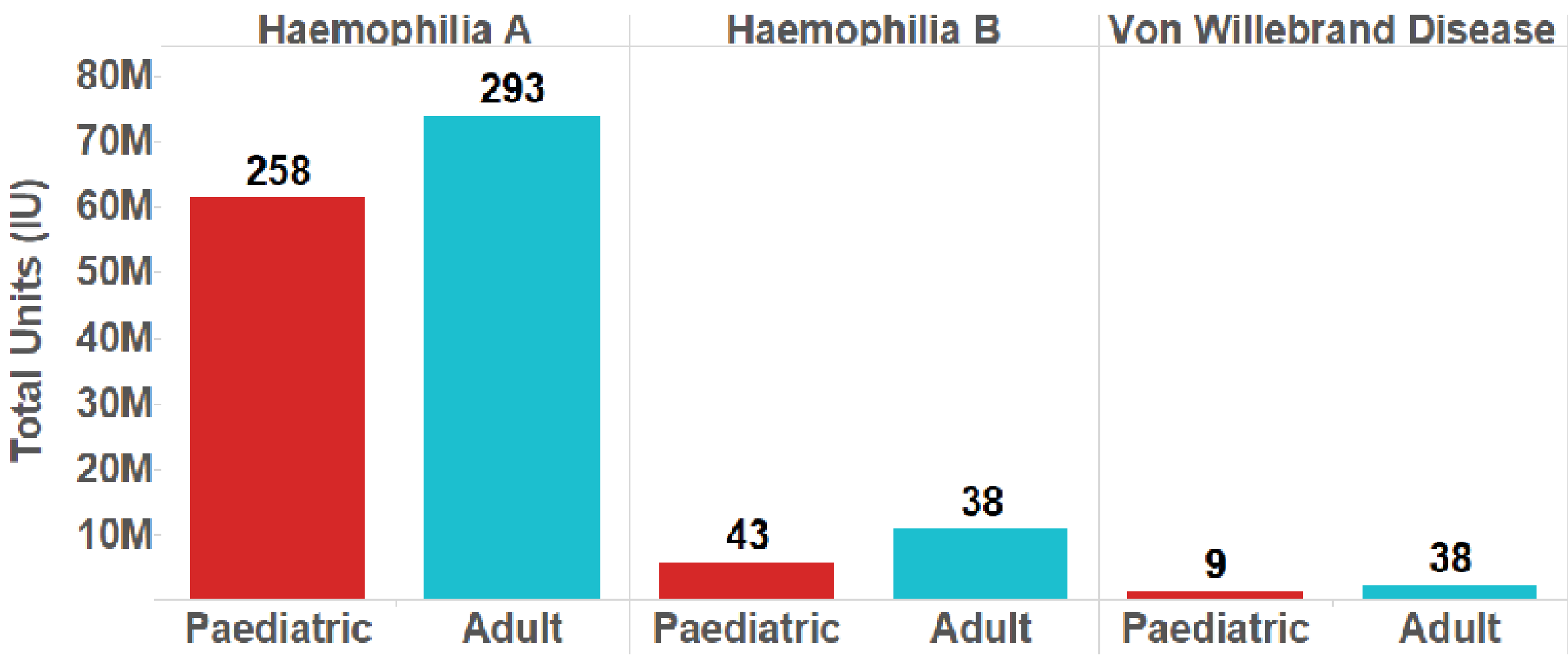


Under the national blood arrangements expenditure for clotting factor products funded by the NBA was $202.2M which represented 20.5% of the total blood and blood product spend in 2012-13. The range of products available to clinicians has changed over the years as this was influenced by periodic tenders governing availability for new contacts. The figure above shows the total issues and market share for recombinant products from 2008-09 to 2012-13.

HMA, HMB and vWD Total Factor IX and VIII IU's Product used by Severity with Patient Counts in 2012-13



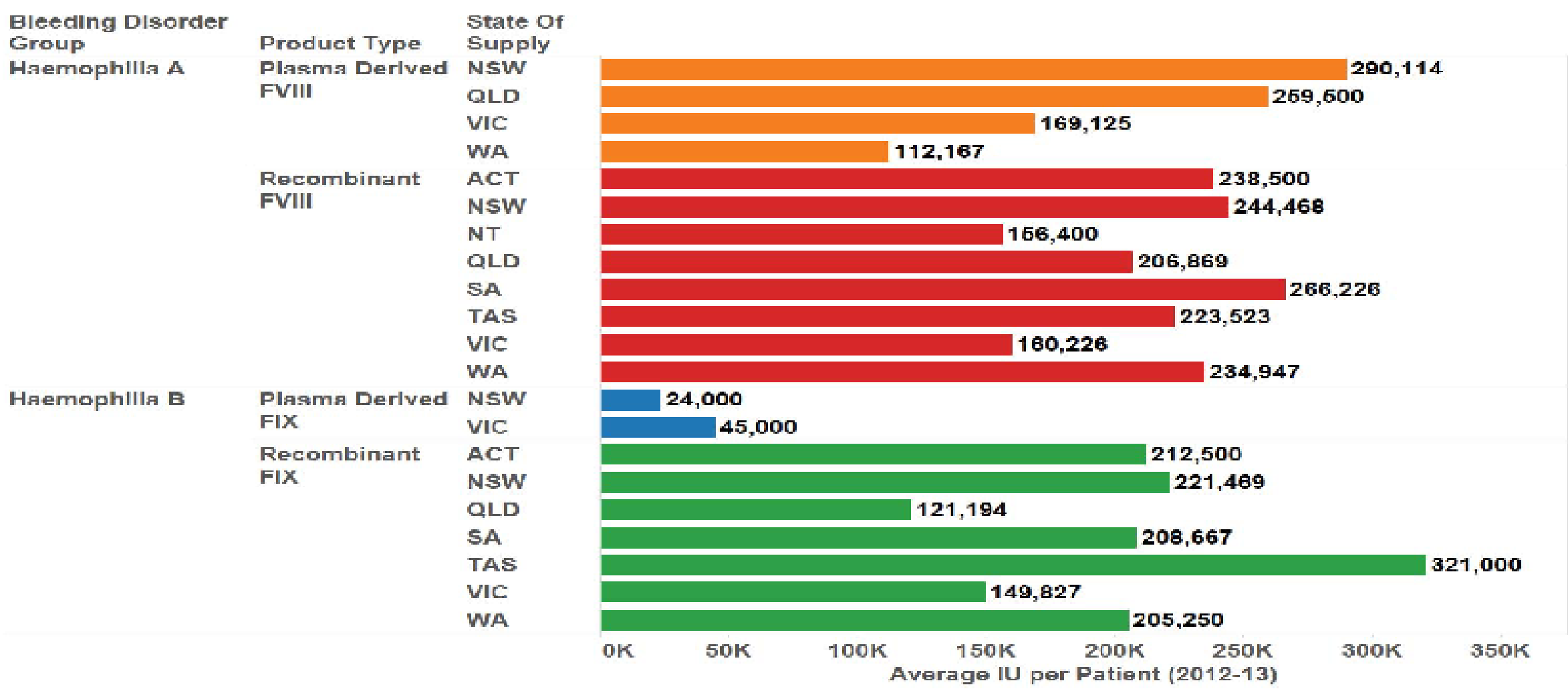
Severe HMA, HMB and vWD Total Factor IX and VIII IU's Product used with Patient Counts in 2012-13



Note: 0-17 year olds are classified as paediatric and 18 and over as adult.

Of the 5,807 patients in the registry only 1,222 patients received product in 2012-13. The proportion of adult to paediatric severe patients for HMA was approximately 33:67 in the registry however the proportion of product used for adult to paediatric patients for severe HMA was 45:55. Patient counts for severe product use are above the bars in the second graph. For example 38 severe HMB adult patients used approximately 11,000,000 IUs - represented in the blue bar.

Severe HMA, HMB - Avg IU per Patient by Product and State in 2012-13



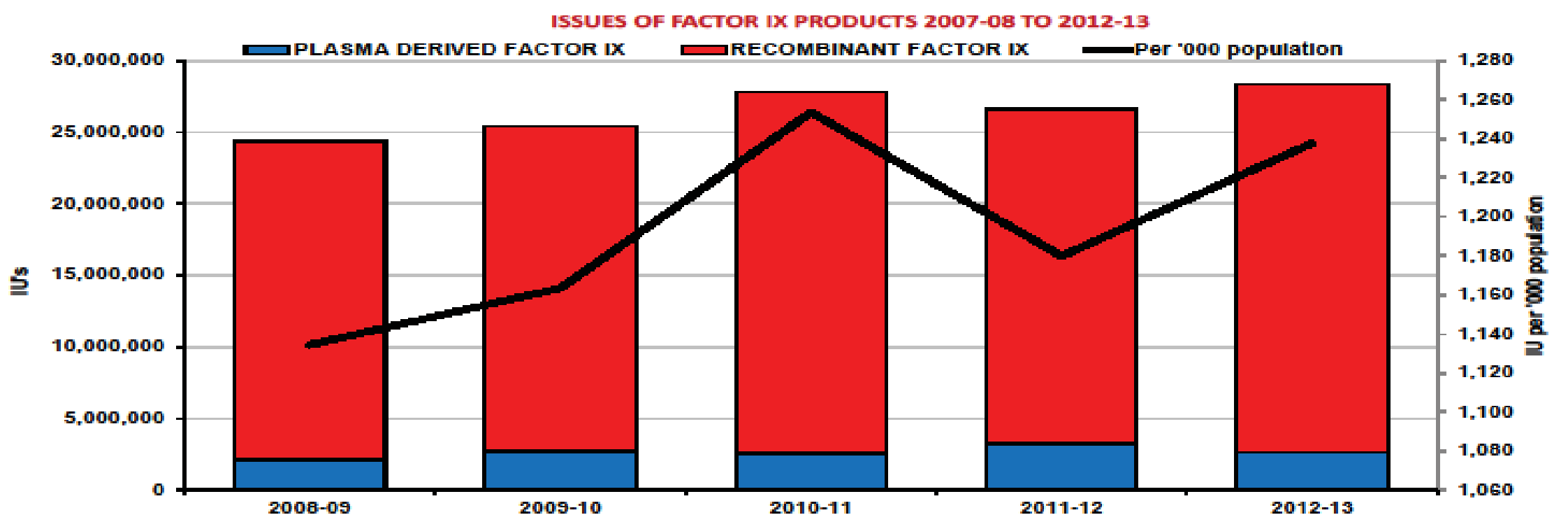
Note: Excludes ten patients with total expenditure >$1.2M in 2012-13

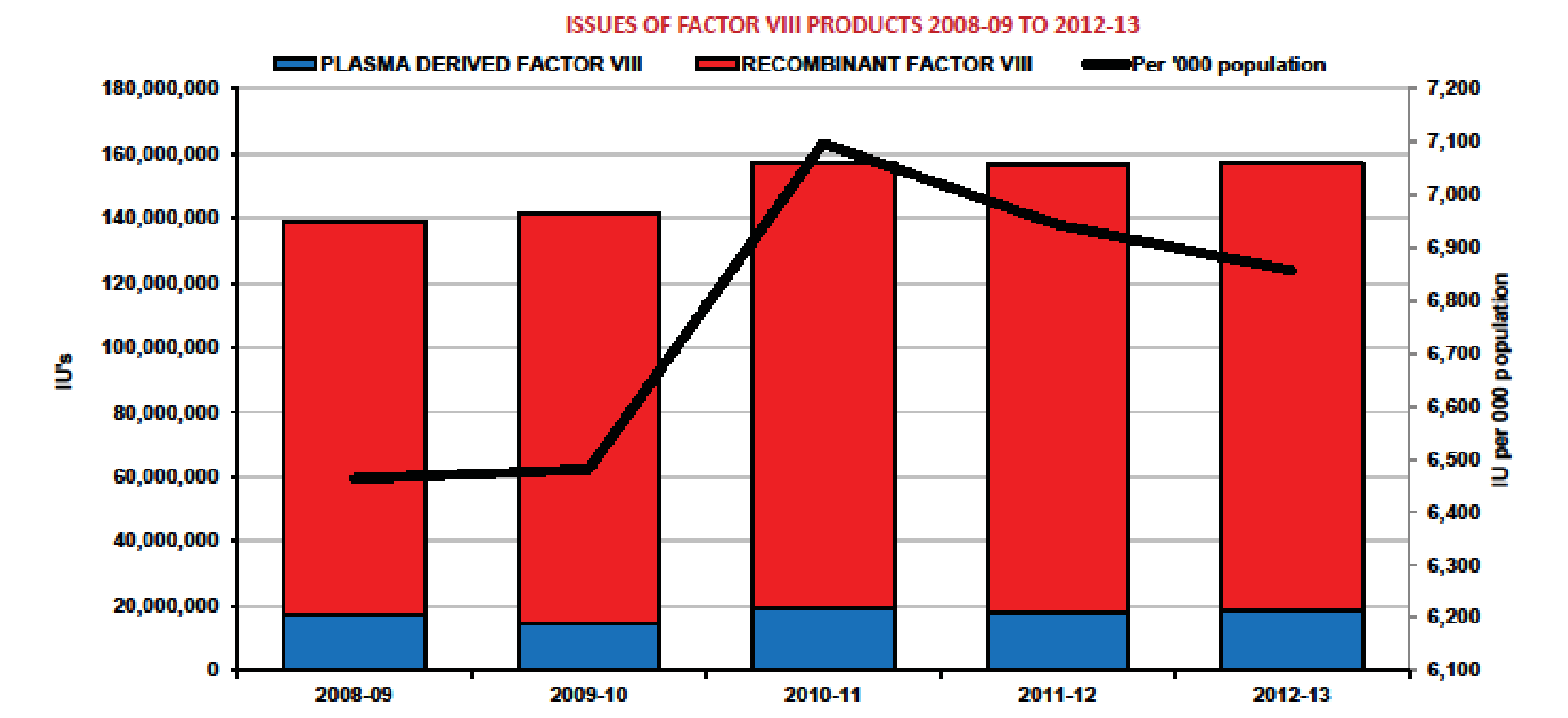
In Australia there are 16 HTCs in 8 states and territories, and each jurisdictional model varies in relation to provision of services, numbers, size of patient population and age of patient population as can be seen in the chart above where average IU by state of supply of recombinant FVII varies from 156,400 IU in the Northern Territory to 266,226 IU per year in South Australia. This variance could be the result of cross border HTC patient sharing or differences in the proportion of patients receiving prophylaxis.

Data and Governance

Data collected can be reported at various levels and demographics for review by individual Haemophilia Treatment Centres (HTC). The following are some examples of how data from the registry and other NBA sources can be presented for interrogation and analysis. The governance framework for the ABDR is compliant with privacy legislation. The ABDRSC has oversight for the release of data for public reporting. The NBA provides guidance and expertise in data analysis and reporting to the ABDRSC.

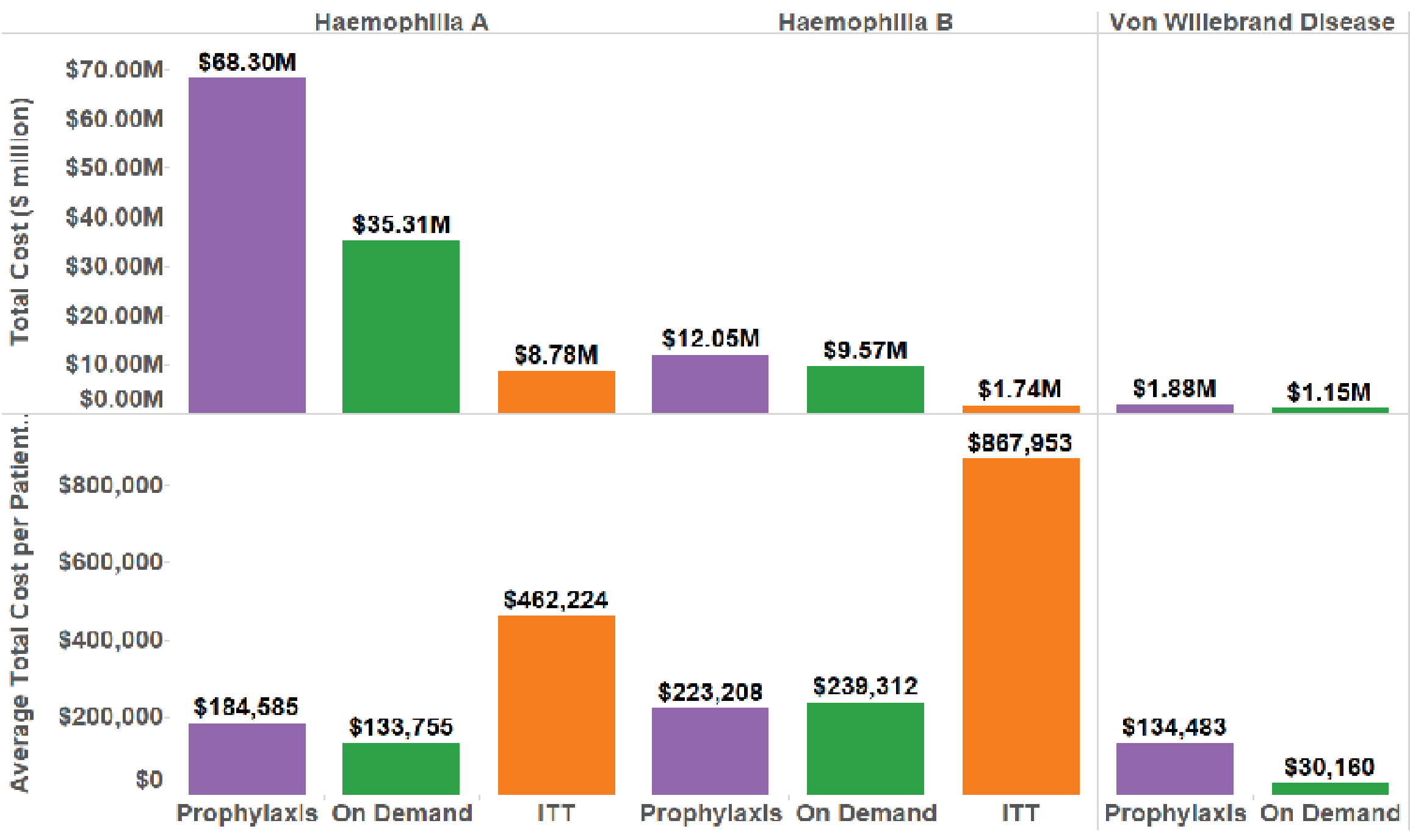
Issues of Factor VIII and Factor IX Products 2008-09 to 2012-13





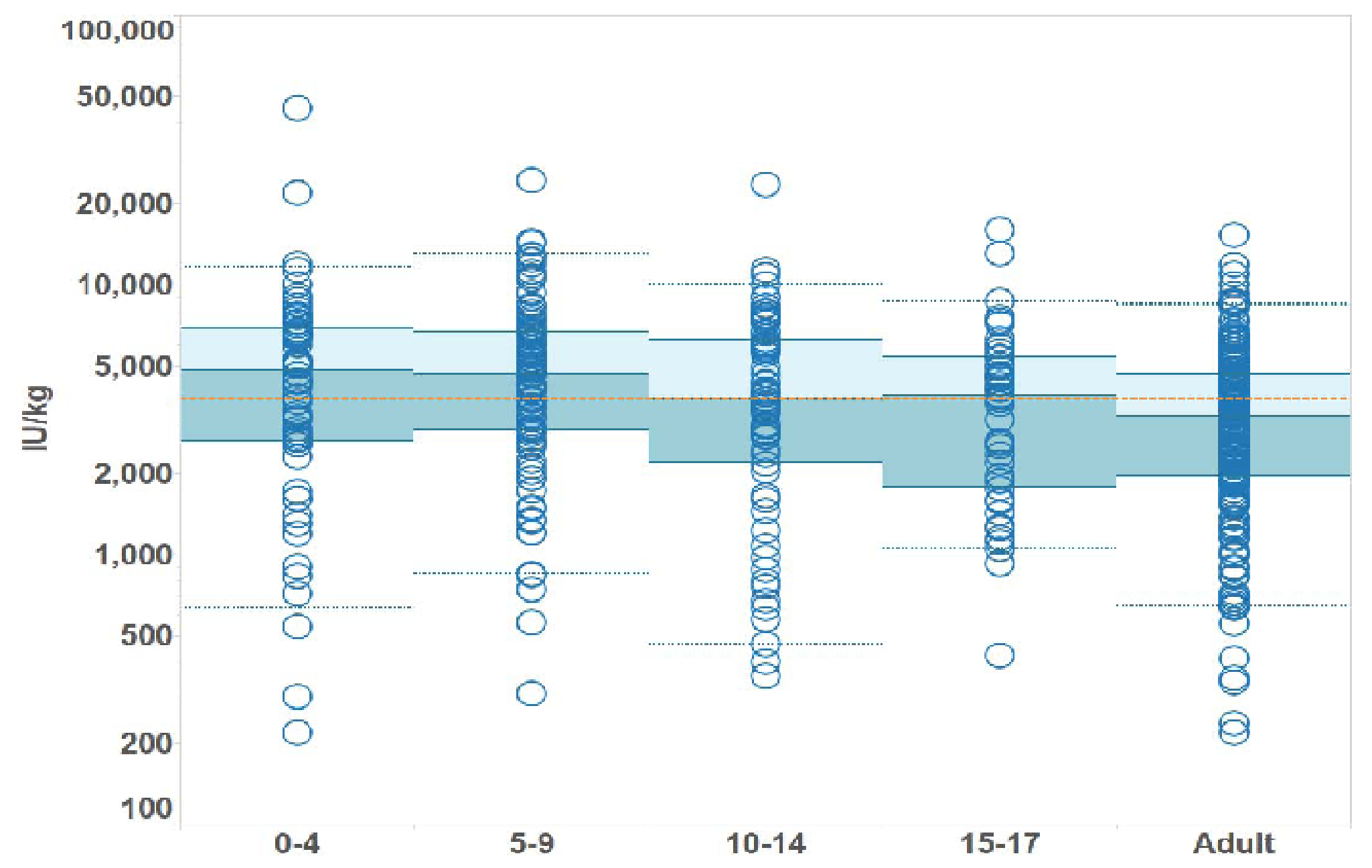
The demand for Factor VIII products in 2012-13 grew by just 1.9% compared to 2011-12. Demand for Factor IX products in 2012-13 increased by 6.8% compared to 2011-12. This is a significant adjustment in demand when compared to the 4.4% reduction seen in 2011-12. The variability in year-to-year growth rates for both products may be partly due to people with bleeding disorders commencing and ceasing participation in company clinical trials.

Severe HMA, HMB and vWD Total and Average Cost per Patient by Treatment Reason 2012-13



The majority of product issued is for patients on prophylaxis regimens, followed by on demand regimens. Of the 1,222 patients who received product in 2012-13 there were 679 distinct patients with severe HMA, HMB and vWD used product in 2012-13. Some of these patients moved from paediatric to adult during the year and also used products for different treatment reasons. There were 21 patients on Immune Tolerance Therapy (ITT) treatment.

Severe HMA Patients on Prophylaxis (IU/KG) in 2012-13

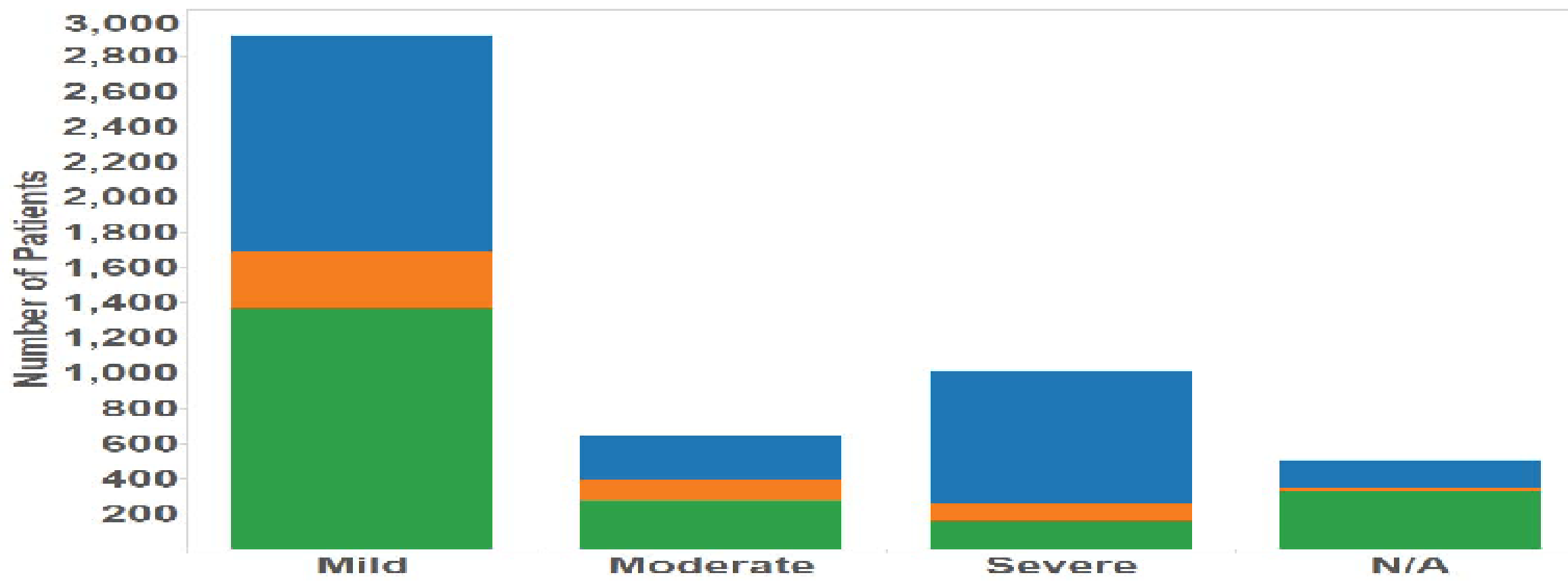


The figure above shows clotting factors used in IU per kg per patient during 2012-13 for severe HMA patients on prophylaxis by age ranges. There is a wide range of use per patient aross these age groups with the median value for 0-4 years at 4,862 IU/kg/year and adults at 3,260 IU/kg/year.

Quality Improvement

Continued system enhancements and the provision of additional reports have enabled individual HTCs to review and correct data within the registry over the past couple of years, to ensure data consistency, completeness and accuracy. The NBA is working with AHCDO on the provision of benchmark reports that will allow a HTCs performance to be compared against other HTCs. This will also enable HTC directors to monitor and review practice and drive further quality improvement processes.

HMA and HMB – People with Bleeding Disorders (Patients) by Severity in the Register at 30 June 2013

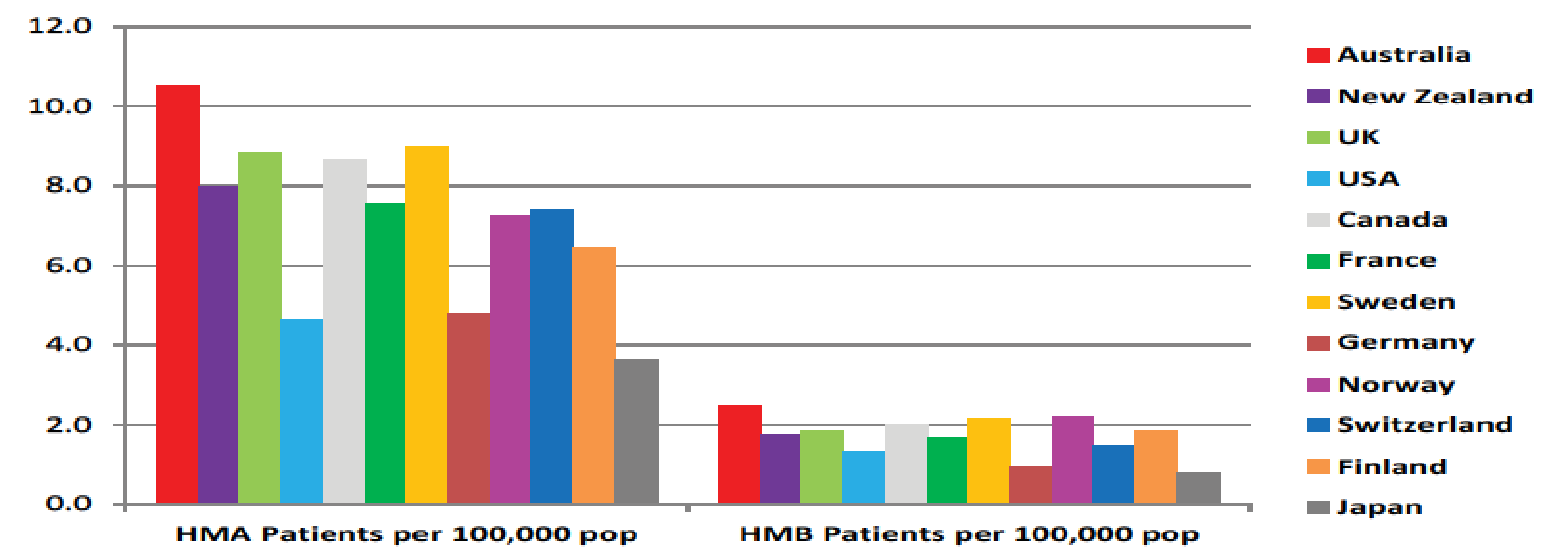


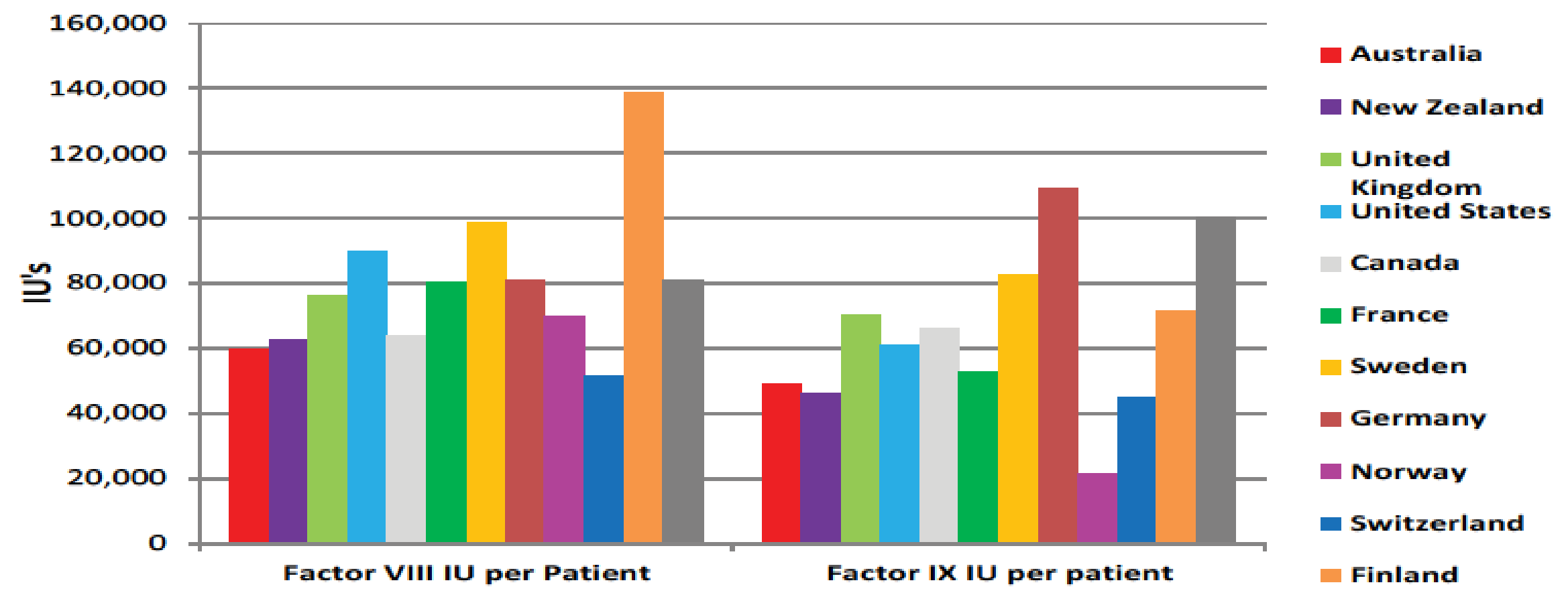
PEOPLE WITH BLEEDING DISORDERS (Patients) DEMOGRAPHICS 2012-13

Haemophilia A	**Mild**	**Moderate**	**Severe**	**N/A**	**Total**
Adult	1,064	190	504	145	1,903
Paediatric	163	64	249	12	488
Total Haemophilia A	**1,227**	**254**	**753**	**157**	**2,391**
Patients who used Product	**192**	**127**	**553**	**4**	**876**
Haemophilia B	**Mild**	**Moderate**	**Severe**	**N/A**	**Total**
Adult	271	94	69	24	458
Paediatric	44	21	37	4	106
Total Haemophilia B	**315**	**115**	**106**	**28**	**564**
Patients who used Product	**47**	**54**	**80**		**181**
von Willebrand Disease	**Mild**	**Moderate**	**Severe**	**N/A**	**Total**
Adult	1,143	229	128	258	1,758
Paediatric	230	46	29	64	369
Total von Willebrand Disease	**1,373**	**275**	**157**	**322**	**2,127**
Patients who used Product	**41**	**33**	**46**	**16**	**136**

Patients in the register at 30 June 2013 totalled 5,807 compared to 5,588 at 30 June 2012 which is an increase of 3.9%. Individual patients may have more than one bleeding disorder, and will be registered with more than one diagnosis. However the table above lists only one diagnosis per patient. In 2012-13 there were 139 patients with two diagnoses and <5 patients with three diagnoses.

Sample Statistics from World Federation of Haemophilia Global Survey 2012





Note: Data from the Survey for Australia relates to 2011-12

The above tables highlight Australia's demographics against 11 other countries from the 2012 survey for HMA and HMB patients in the registry per 100,000 population (median value 7.46 and 1.80 respctively) and use of Factor VIII per HMA patients (median 78,241 IUs per patient) and use of Factor IX per HMB patients (median 63,551 IUs per patient).

Future Data and Demographic Improvements

In 2014 the NBA released MyABDR which is a secure app for smartphones (Android and iOS) and a website for people with bleeding disorders or parents/caregivers to record home treatments and bleeds. At the same time there were enhancements in ABDR to capture MyABDR data and streamline some processes. The introduction of this app and the take up by patients should provide more complete and timely data for further analysis by all stakeholders. 2014 will see a number of reports developed to that will provide further improvements for:

- Patient care
- HTC management and coordinated care
- Inter HTC benchmarking for practice improvement

MyABDR

www.blood.gov.au/myabdr

ABDR Australian Bleeding Disorders Registry

AHCDO

HAEMOPHILIA FOUNDATION AUSTRALIA

NATIONAL BLOOD AUTHORITY AUSTRALIA

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