DATA AND DEMOGRAPHICS 2013-14

**ABDR**

The current ABDR is an internet based clinical registry that includes demographic, clinical and product use data for those persons with bleeding disorders registered. Governance is managed by the ABDR Steering Committee (ABDRSC). Representatives are drawn from AHDCO – a group of clinicians responsible for haemophilia care in Australia, HFA – Australia wide patient support group and the NRA – 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 2013-14

Data collected can be reported at a 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 2009-10 to 2013-14**

**Data and Governance**

The demand for Factor VIII products in 2013-14 increased by 0.8% compared to 2012-13. Demand for Factor IX products in 2013-14 increased by 6.6% compared to 2012-13. Demand for FVIII is fairly stable year on year, however FIX demand continues to grow when compared to the 6.6% growth seen in 2012-13 over 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 2013-14**

Severe HMA, HMB and vWD Total Factor IX and VIII IU's Product used by Severity with Patient Counts in 2013-14

The majority of product is issued for patients on prophylaxis regimens, followed by on demand regimens. There were 725,880 severe HMA with severe HMA, HMB and vWD who used product in 2013-14. Of these 408 were on prophylaxis, 276 on demand and 20 patients were on Immune Tolerance Treatment (ITT) treatment.

**Severe HMA Patients on Prophylaxis [IU/KG] in 2013-14**

The majority of severe HMA patients are on prophylaxis regimens followed by on demand regimens. There were 725,880 severe HMA with severe HMA, HMB and vWD who used product in 2013-14. Of these 408 were on prophylaxis, 276 on demand and 20 patients were on Immune Tolerance Treatment (ITT) treatment.

**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 AHDCO 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, HMB and vWD – People with Bleeding Disorders (Patients) by Severity in the Register at 30 June 2014**

Patients in the register during 2013-14 totalled 5,385 compared to 5,371 in 2012-13 which is an increase of 3.3%. Data integrity reviews have been undertaken and registered patient data updated to reflect current status. 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 2013-14 there were 102 patients with two diagnoses and <5 patients with three diagnoses.

**Sample Statistics from World Federation of Haemophilia Global Survey 2012**

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 respectively) and use of Factor VIII per HMA patients (median 78,791 IU/kg per patient) and use of Factor IX per HMA patients (median 63,551 IU/kg 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/carers 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. 2015 will see a number of reports developed to that will provide further improvements for:

- e-Routine care
- e-HTC management and coordinated care
- Internet HTC benchmarking for practice improvement

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