**National Report on the**

**Issue and Use of Intravenous Immunoglobulin (IVIg)**

**2010-2011**











































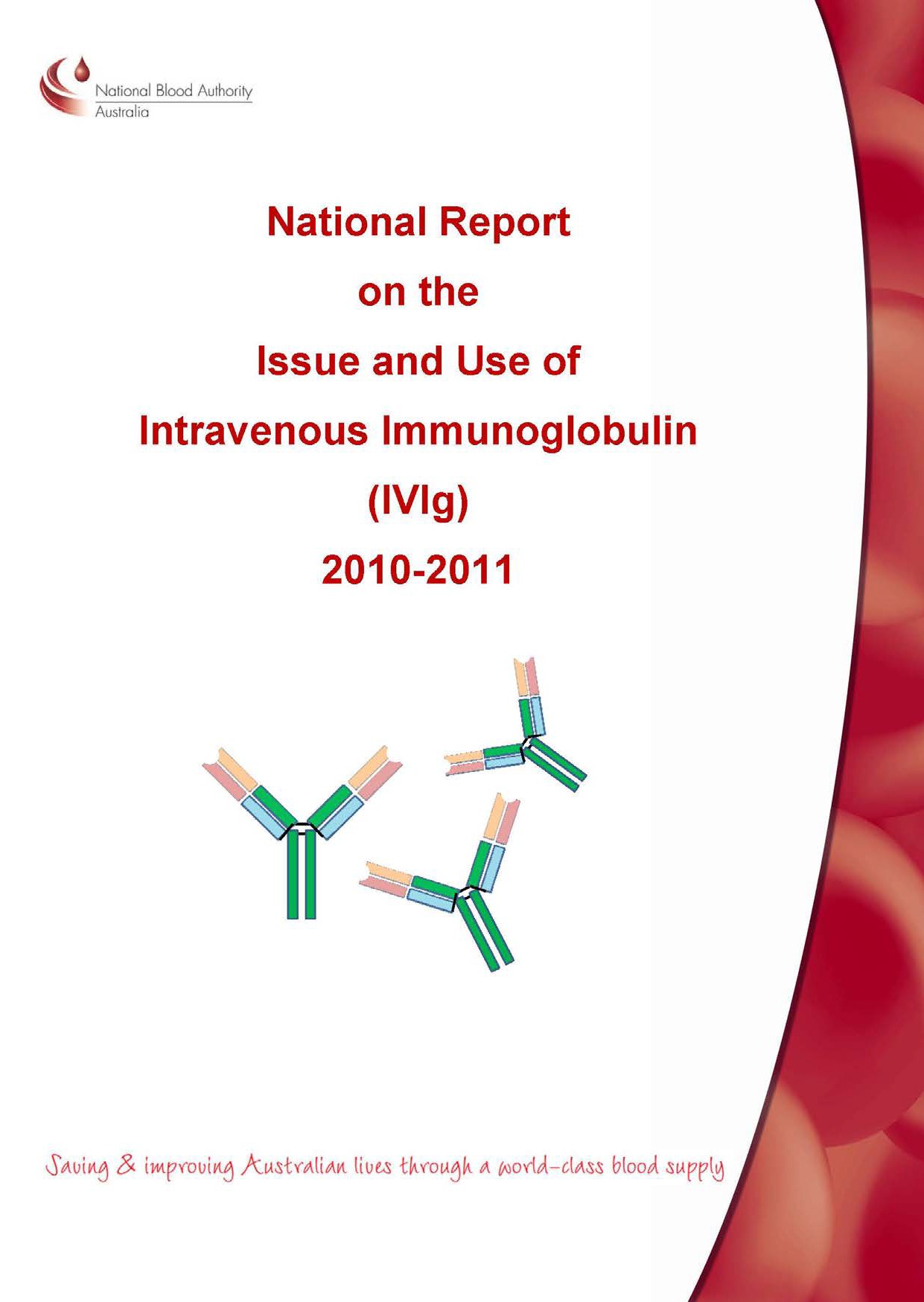














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**1. EXE CU TI V E SUMM ARY**

Demand for Intravenous Immunoglobulin (IVIg) continues to increase, although the rate of increase appears to be slowing. The average annual growth from 2003/04 to 2010/11 was 11.6% per annum and the growth from 2009/10 to 2010/11 was 11.1%. Product issued (grams per 1000 head of population) grew by 10.3% in 2010/11 compared to 10.5% in 2009/10

In 2010/11 2,950,371g (total) of IVIg was issued representing a cost of $149.4 million nationally (excluding cost of plasma collections). Of this total, 86% was domestically produced and 14% was imported. This equates to 2,533,698g of domestic IVIg and 416,673g of imported IVIg. A total of

11,457 patients were issued IVIg nationally under the national blood arrangements and there were

93,887 associated patient episodes 1.

While there is guidance in the Criteria for the Use of Intravenous Immunoglobulin in Australia2 (*the Criteria)* considerable variation remains in the grams issued per treatment episode across the jurisdictions for some conditions. The criteria are due to be updated by mid-2012.

Neurology remains as the discipline using the greatest amount of IVIg and demand in this discipline grew by 14.1% in 2010/11. Haematology is the next largest user of IVIg. Growth had declined in Immunology as the third largest user of IVIg in 2009/10 but increased again in 2010/11 from 1.7% to

6.8%.

In 2010/11 the top three indications for which most IVIg was issued are;

• acquired hypogammaglobulinaemia secondary to haematological malignancies (21.2%)

• chronic inflammatory demyelinating polyneuropathy (CIDP, 20.1%)

• primary immunodeficiency diseases (PID, 15.6%).

1 A treatment episode is a treatment involving the infusion of IVIg on a particular day. An approval may authorise a series of treatment episodes spanning some months.

2 Jurisdictional Blood Committee, for and on behalf of the Australian Health Minister’s Conference. Criteria for the Use of

Intravenous Immunoglobulin in Australia. Canberra, Commonwealth of Australia, 2007. Available at <<http://www.nba.gov.au/ivig/index.html>>

**2. PUR PO SE**

The purpose of this report is to document the trends in the demand for, and cost of, IVIg in 2010/11 and provide insights into the drivers of demand. The report draws on data held by the National Blood Authority (NBA) on the volumes of IVIg issued (issues) and the recorded purchases. Information is also sourced from the Australian Red Cross Blood Service (Blood Service) STARS database which is maintained by the Blood Service on behalf of all Australian governments in their role as contracted gatekeeper and distributer of IVIg products. The report aims to provide stakeholders with meaningful detail on IVIg demand to assist in informed decision making. Major stakeholders include patients,

clinicians, other health professionals and administrators, and governments.

**3. I NTRO DU C TI O N AN D C AV E ATS**

This report provides an overview of volume of IVIg issued in Australia. The report summarises product issued over time and provides detail on issues within the 2010/11 financial year. The report focuses

on IVIg which has been funded by the National Blood Authority under the National Blood Agreement,

but also provides limited data on IVIg supplied under Direct Orders (DOs) which are paid for directly by state or hospital arrangements.

The report provides information at the national, and where appropriate, jurisdictional levels.

Information is provided on patient volumes, the grams per 1000 head of population, average dose and number of treatment episodes by condition.

It should be noted that *the Criteria* was introduced in March 2008 with a transition period extending to the end of September 2008, or in some particular cases, longer. Diagnoses and indications captured prior to the implementation of *the Criteria* were mapped to ensure that they were meaningfully represented, however information from previous years may not be directly comparable from 2008/09 forward.

Care should be taken when interpreting the data relating to the smaller jurisdictions as these can be overly influenced by one or two patients.

The reporting period covers Quarter One 2008/09 to Quarter Four of the 2010/11 financial years. The information for this report is gathered from the national Blood Service Supply Tracking Analysis

Recording System (STARS) database, which is then reconciled by the NBA against the Integrated

Data Management System (IDMS) system for contract management, blood and blood product invoice validation and supply management and planning, and Big Red (the data warehouse and reporting solution for all NBA systems, with end users in the NBA and in jurisdictions).

**4. TRE NDS I N I S SUE S OF IVIG - 2003/ 04 TO 2010/ 11**

The total volume of IVIg issued under the National Blood Arrangements continued to increase during

2010/11 (Figure 1). A total of 2,950,371g were issued nationally in 2010/11 - an increase of 295,186g over 2009/10. Of this total, 14% was imported product.

**Figure 1 IVIg issued (grams) nationally 2003/04 to 2010/11**

3,500,000

3,000,000

2,500,000

2,000,000

**Grams of IVIg issued to AHPs**

1,500,000

1,000,000

500,000

0

2003-04 2004-05 2005-06 2006-07 2007-08 2008-09 2009-10 2010-11

**Financial year**

Domestic Imported

Source: IDMS database of issues via Big Red

However, the increase in growth nationally is lower than in previous years, suggesting the rate is slowing (Table 1 below).

**Table 1 Growth in total IVIg issues from 2003/04**

Growth from previous year

Average growth from

2004/05 2005/06 2006/07 2007/08 2008/09 2009/10 2010/11

4.7% 16.2% 13.9% 13.5% 10.5% 11.6% 11.1%

2003/04 4.7% 10.3% 11.5% 12.0% 11.7% 11.7% 11.6%

Source: IDMS database of issues via Big Red

Average growth is the fixed rate of growth each year that would accumulate from 2003/04 to give the year’s value. It is obtained by the formula ; where *Vn* = volume in year *n*



Figure 2 and Table 2 show issues of total IVIg and growth presented by 1000 head of population, with the rate growing from 119.86g per 1000 head of population in 2009/10 to 132.21g in 2010/11. The increase in issues per head of population continues to be higher than population growth.

It is likely that some of the growth (in per capita terms) of IVIg use relates to the ageing of the Australian population and the strong correlation between ageing and conditions that are treated with IVIg.

**Figure 2 Grams of IVIg issued per 1000 head of population nationally**

140.00

120.00

100.00

80.00

**Grams per 1000 population**

60.00

40.00

20.00

0.00

2003-04 2004-05 2005-06 2006-07 2007-08 2008-09 2009-10 2010-11

**Financial year**

Source: IDMS database of issues via Big Red and ABS Estimated resident population (ABS 3101.0)

**Table 2 IVIg issues (grams per 1000 head of population) nationally and percentage change from previous year**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Year of issue | 2003/04 | 2004/05 | 2005/06 | 2006/07 | 2007/08 | 2008/09 | 2009/10 | 2010/11 |
| Issue of IVIg  (g/1000 pop) | 68.06 | 70.34 | 80.54 | 90.11 | 100.21 | 108.42 | 119.86 | 132.21 |
| Increase by year |  | 3.3% | 14.5% | 11.9% | 11.2% | 8.2% | 10.5% | 10.3% |

Source: IDMS database of issues via Big Red

When compared to other international benchmarking, Australia’s use of IVIg per capita continues to be high (Figure 3).

**Figure 3 International IVIg use (grams per 1000 population) selected countries 2005 to 2010**

140

120

100

**Grams per 1000 population**

2005

80 2006

2007

60 2008

2009

2010

40

20

0

Australia Canada Finland Italy New Zealand

Source: Data prepared for presented at National Plasma Product Supply Planners (NPPSpa), 2010

**5. TRE NDS I N CO S TS 2 003 - 2011**

Figure 4 shows the increased cost of the provision of IVIg under the National Blood Arrangements over time. Total issue costs of IVIg in 2010/11 was, $185 million, an increase of $113 million from

2003/04. On average IVIg issue costs have grown around 15% while average demand growth was

11.6% since 2003/04. The NBA has over the past eight years achieved savings on prices for both imported and domestic IVIg. In 2010/11 the cost increase over 2009-10 was only 5% while demand volume increase was 11%

With the introduction of the new CSL Ltd. contract arrangements on 1 January 2009 the direct price per gram of domestic IVIg fell. The lighter bars indicate the total cost of plasma collection. Plasma collection costs have increased from 2003/04 at $52 million to $111 million in 2010/11, this is an average growth of 11.5% during this time. The average increase of plasma collection volumes during the same time was 7%.

**Figure 4 Cost of IVIg from 2003/04 to 2010/11**

200,000,000

180,000,000

160,000,000

140,000,000

120,000,000

100,000,000

**Dollars**

80,000,000

60,000,000

40,000,000

20,000,000

-

2003-04 2004-05 2005-06 2006-07 2007-08 2008-09 2009-10 2010-11

**Financial Year**

Total direct IVIg costs Plasma Costs

Source: IDMS database of purchases via Big Red

5. 1. PLAS MA CO ST S

The Blood Service collected 472 tonnes of plasma for fractionation; 95% of this was used to produce domestic IVIg (Intragam P) and the remaining 5% was used for other hyperimmune products.

The fractionation process is a serial extraction process, and after each production step further products may also be produced from the residual plasma. Factor VIII is obtained from cryoprecipitate. Factor IX and Prothrombin complex are next precipitated from residual plasma after the removal of

the cryoprecipitate. The next group of products precipitated are the immunoglobulins (IVIg and

hyperimmunes). Finally albumin is extracted from the residual plasma. This means that not all the above plasma collection costs can be allocated to IVIg.

The cost of plasma is paid separately by jurisdictions based on their use of domestic IVIg.

5. 2. SHA RES O F T O T AL BLO OD PRO DU CT BUDG ET

Figure 5 illustrates the proportional cost of IVIg within the blood budget overall. IVIg is the third largest budget contributor and represents almost 20% of the total budget for blood and blood products.

**Figure 5 Share of total expense 2010/11**

Hyperimmunes

1.3%

Albumin

2.4%

Fresh Blood Products & Plasma Collection

53.3%

IVIG

19.9%

Clotting Factor

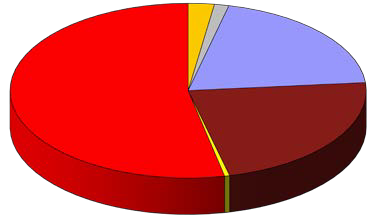
Products

22.7%

Diagnostics

0.5%

Source: NBA Reporting systems 2010/11



**6. TRE NDS I N U SE**

Since the introduction of *the Criteria*, IVIg data is often summarised by the chapter of *the Criteria* in which IVIg use is controlled for various conditions. The chapters described in *the Criteria* are:

• chapter 5, conditions for which IVIg has an established therapeutic role

• chapter 6, conditions for which IVIg has an emerging therapeutic role

• chapter 7, conditions for which IVIg has application in exceptional circumstances only

• chapter 8, conditions for which IVIg use is not indicated.

6. 1. USE B Y CH APT ER

Table 3 and Table 4 outline the volume of IVIg issued (grams) per chapter. It should be noted that prior to 2008, data has been mapped to the current chapters, therefore may not be directly comparable. As would be expected, the highest amount of IVIg issued is for indications within chapter

5, those for which IVIg has an established therapeutic role.

**Table 3 IVIg issued (grams) by chapters in the Criteria**

|  |
| --- |
| 2004/05 2005/06 2006/07 2007/08 2008/09 2009/10 2010/11 |
| Chapter 5 1,005,594 1,172,728 1,363,847 1,625,246 1,990,586 2,212,914 2,505,332 |
| Chapter 6 402,416 400,682 368,458 417,939 345,176 371,832 397,231 |
| Chapter 7 17,820 19,518 33,970 45,130 47,275 61,924 76,033 |
| Chapter 8 13,110 16,259 15,351 8,888 3,326 2,550 2,574 |
| Direct orders 0 0 0 280 0 243 215 |
| Not in current  classification 43,056 47,730 76,426 37,743 0 0 0 |

Source: IVIg Stars database maintained by the Blood Service.

**Table 4 IVIg issued (% total) by chapters in the Criteria**

|  |
| --- |
| 2004/05 2005/06 2006/07 2007/08 2008/09 2009/10 2010/11 |
| Chapter 5 68% 71% 73% 76% 83% 84% 84% |
| Chapter 6 27% 24% 20% 20% 14% 14% 13% |
| Chapter 7 1% 1% 2% 2% 2% 2% 3% |
| Chapter 8 1% 1% 1% 0% 0% 0% 0% |
| Direct orders 0% 0% 0% 0% 0% 0% 0% |
| Not in current  classification 3% 3% 4% 2% 0% 0% 0% |

Source: IVIg Stars database maintained by the Blood Service.

6. 2. USE B Y DI S CI PLI NE

In 2010/11, in line with previous years, volumes of IVIg ordered were greatest for the disciplines of neurology, haematology and immunology (Figure 6 and Table 5). Neurology demand grew by 14.1% in 2010/11. Haematology demand grew by 13.4%. Rate of growth in Immunology slowed to an increase of 1.7% between 2008/09 and 2009/10, but the rate of growth increased again in 2010/11 to

6.8%. The category of “mixed” discipline represents conditions that may be treated by clinicians from more than one medical discipline.

**Figure 6 IVIg issued (grams) by discipline over time**

1,400,000

1,200,000

1,000,000

800,000

**Grams issued**

600,000

400,000

2004-05

2005-06

2006-07

2007-08

2008-09

2009-10

2010-11

200,000

0

Neurology Haematology Immunology Mixed Transplant - solid Dermatology

Source: IVIg Stars database maintained by the Blood Service.

Note: Mixed indicates where a treatment has commenced in one discipline before being re categorised as a further discipline.

**Table 5 IVIg issued (grams) by discipline by year**

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
| Discipline | 2004/05 | 2005/06 | 2006/07 | 2007/08 | 2008/09 | 2009/10 | 2010/11 |
| Neurology | 515,403 | 597,393 | 672,045 | 819,505 | 981,372 | 1,124,604 | 1,283,190 |
| Haematology | 433,247 | 468,756 | 554,499 | 625,304 | 716,767 | 794,098 | 900,826 |
| Immunology | 308,999 | 361,821 | 426,687 | 481,177 | 520,264 | 529,132 | 565,064 |
| Mixed | 211,459 | 214,221 | 178,124 | 166,942 | 102,937 | 106,884 | 126,619 |
| Transplant - solid | 8,031 | 10,793 | 23,788 | 38,524 | 51,940 | 69,561 | 72,149 |
| Dermatology | 4,857 | 3,933 | 2,909 | 3,774 | 13,083 | 24,943 | 33,324 |

Source: IVIg Stars database maintained by the Blood Service.

6. 3. USE P ER 10 00 HE AD O F PO PULAT I O N

National and jurisdictional IVIg issues per 1000 head of population for the last eight years are presented in Figure 7. Tasmania, Queensland, New South Wales and the ACT continue to have issues per head of population above the national rate, while the other jurisdictions are below the national rate. It should be noted that rates for the smaller population jurisdictions must be viewed with some caution. WA and the NT have remained reasonably stable in terms of the issues per 1000 population, SA has had significant variability and all other jurisdictions have seen a continued strong increase in the issues per 1000 population.

**Figure 7 IVIg issues by state by head of 1000 population over time**

180.00

160.00

140.00

120.00

**Grams per 1000 population**

100.00

80.00

60.00

2003-04

2004-05

2005-06

2006-07

2007-08

2008-09

2009-10

2010-11

40.00

20.00

0.00

NSW VIC QLD WA SA TAS ACT NT Aust

Source: NBA IDMS issues data.

6. 4. USE B Y DI AG NO SI S

The Blood Service is required to collect information on diagnosis and indication for use. The largest group of primary diagnoses for which IVIg was issued has changed over time and is presented in Figure 8.

Acquired hypogammaglobulinaemia secondary to haematological malignancies are the primary diagnoses for which the greatest percentage of IVIg was issued in 2010/11 (21.2%) closely followed by CIDP (20.1%). PID accounted for 15.6% of total IVIg use.

**Figure 8 Disease grouping to which the highest percentages of IVIg was issued nationally**

25.0%

20.0%

15.0%

10.0%

2004-05

2005-06

2006-07

2007-08

2008-09

2009-10

2010-11

5.0%

0.0%

Acquired hypogammaglobulinaemia

secondary to haematological malignancies

Chronic inflammatory demyelinating

polyneuropathy

Primary immunodeficiency diseases

Myasthenia gravis

Multifocal motor neuropathy

ITP in adults

Inflammatory myopathies

Guillain-Barre syndrome

Specific antibody deficiency

Secondary hypogammaglobulinaemia

Source: IVIg Stars database maintained by the Blood Service. These disease groups are all in Chapter 5.

**7. 2010/ 11 I N R EVI EW**

The following sections in the report provide more detailed information on IVIg demand in 2010/11.

7. 1. SU MMA RY INFOR MA T ION

In 2010/11, STARS recorded 2,981,170g of IVIg while the NBA’s Integrated Data Management System (IDMS) recorded 2,950,371g of IVIg issued nationally. The latter represented a cost of $149.4 million. Of these 2,533,698g were domestic IVIg (86%) and 416,673g (14%) imported IVIg. A total of

11,457 patients were issued IVIg under the National Blood Arrangements for 93,887 patient episodes.

This excludes patients who received IVIg by DOs.

**Table 6 Annual numbers of patients, treatments and grams recorded in STARS**

|  |  |  |  |
| --- | --- | --- | --- |
| Year | Number of patients | Number of treatment episodes | Total grams issued |
| 2008/09 | 9,832 | 77,212 | 2,386,361 |
| 2009/10 | 10,502 | 85,291 | 2,649,220 |
| 2010/11 | 11,457 | 93,887 | 2,981,170 |

Source: IVIg Stars database maintained by the Blood Service.

7. 2. TOTAL I SSUES A ND EX PENDI T UR E

Table 7 shows the total grams of IVIg issued in 2010/11 by jurisdiction, while Figure 9 depicts the jurisdictional issues in a graphical form. Nationally in IDMS, the total amount was 2,950,371g, with issues increasing with population size of the jurisdiction, as expected. The amounts captured in STARS are presented in Table 8.

**Table 7 Grams IVIg issued by jurisdiction 2003/04 to 2010/11**

|  |  |
| --- | --- |
| **NSW Vic. Qld. WA SA Tas. ACT NT** | |
| 2003/04 | Domestic 410,505 318,762 306,639 125,094 110,031 40,353 23,895 6,321 |
| Imported 0 22,200 3,000 144 2,856 0 0 0 |
| 2004/05 | Domestic 420,858 326,130 284,043 148,200 95,403 46,065 24,615 7,806 |
| Imported 41,376 13,860 19,992 144 5,922 0 0 0 |
| 2005/06 | Domestic 452,565 361,665 219,633 152,127 109,515 33,837 21,774 8,004 |
| Imported 76,368 52,097 134,475 7,765 15,300 13,608 8,165 0 |
| 2006/07 | Domestic 493,172 407,244 337,301 155,821 92,958 50,583 26,470 6,732 |
| Imported 103,270 88,398 79,393 20,577 18,375 11,065 7,170 0 |
| 2007/08 | Domestic 599,126 423,170 400,144 148,986 108,596 52,755 27,393 6,825 |
| Imported 105,633 111,010 85,055 38,445 18,416 11,740 16,875 0 |
| 2008/09 | Domestic 562,320 417,574 383,865 143,628 128,511 53,745 22,841 10,503 |
| Imported 249,905 131,228 171,367 42,895 27,604 19,965 14,200 0 |
| 2009/10 | Domestic 668,526 507,038 439,089 162,963 143,285 61,686 33,225 8,610 |
| Imported 252,416 101,930 200,264 16,248 31,244 17,110 11,550 0 |
| 2010/11 | Domestic 887,016 577,260 631,545 167,745 139,296 76,197 45,540 9,099 |
| Imported 136,728 93,835 107,798 30,108 27,383 8,843 11,900 80 |

Source: IDMS database of issues via Big Red.

**Figure 9 Total grams of IVIg issued by jurisdiction 2010/11**

1,000,000

900,000

800,000

700,000

600,000

500,000

Domestic

Imported

400,000

300,000

200,000

100,000

0

NSW VIC QLD WA SA TAS ACT NT

Source: IDMS database of issues via Big Red.

**Table 8 IVIg issued as recorded in STARS for 2010/11**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| State | Grams issued | Proportion of total issues | Proportion of Australian population | Grams per 1000 population |
| NSW | 1,037,032 | 34.8% | 32.3% | 144.00 |
| Vic. | 688,031 | 23.1% | 24.7% | 124.74 |
| Qld. | 731,215 | 24.5% | 20.4% | 160.28 |
| WA | 197,117 | 6.6% | 10.3% | 86.00 |
| SA | 175,128 | 5.9% | 7.4% | 106.18 |
| Tas. | 86,971 | 2.9% | 2.3% | 170.98 |
| ACT | 56,871 | 1.9% | 1.6% | 159.65 |
| NT | 9,021 | 0.3% | 1.0% | 39.10 |
| Total | 2,981,385 | 100.0% | 100.0% | 133.59 |

Source: IVIg Stars database maintained by the Blood Service. ABS population statistics.

The 2010/11national average of IVIg issued (grams per 1000 head of population) is 133.59g

according to the data recorded in the STARS database. Figure 10 presents the STARS information by jurisdiction. New South Wales, Queensland, Tasmania and the ACT received issues per 1,000 population greater than the national average. Clearly, different patient populations within the jurisdictions will impact these figures significantly. Factors affecting the patient load include the age distribution and the incidence of particular diseases. SA and Tasmania have older populations, however, their rates of use of IVIg are markedly different. We note that the smaller patient numbers mean that specific patient needs will strongly impact these figures. ACT may also be affected by providing services to New South Wales residents (cross border issues).

**Figure 10 IVIg issued (grams per 1000 population) by jurisdiction by year**

180.00

160.00

140.00

120.00

100.00

80.00

60.00

2004-05

2005-06

2006-07

2007-08

2008-09

2009-10

2010-11

40.00

20.00

0.00

NSW VIC QLD WA SA TAS ACT NT National

Source: IVIg Stars database maintained by the Blood Service.

**Figure 11 2010/11 year costs of IVIg by jurisdiction**

45

40

35

30

25

**$ million**

Domestic

20 Imported

15

10

5

0

NSW VIC QLD WA SA TAS ACT NT

Source: IDMS database of purchases via Big Red

**Table 9 Annual growth from previous year -Total issues of IVIg by jurisdiction between 2004/05 to 2010/11**

|  |
| --- |
| NSW Vic. Qld. WA SA Tas. ACT NT |
| 2004/05 12.6% -0.3% -1.8% 18.4% -10.2% 14.2% 3.0% 23.5% |
| 2005/06 14.4% 21.7% 16.5% 7.8% 23.2% 3.0% 21.6% 2.5% |
| 2006/07 12.8% 19.8% 17.7% 10.3% -10.8% 29.9% 12.4% -15.9% |
| 2007/08 18.2% 7.8% 16.4% 6.3% 14.1% 4.6% 31.6% 1.4% |
| 2008/09 15.2% 2.7% 14.4% -0.5% 22.9% 14.3% -16.3% 53.9% |
| 2009/10 13.4% 11.0% 15.2% -3.9% 11.8% 6.9% 20.9% -18.0% |
| 2010/11 11.2% 10.2% 15.6% 10.4% -4.5% 7.9% 28.3% 6.6% |

Source: IDMS database of issues via Big Red.

Despite the introduction and promulgation of *the Criteria* in 2008, setting uniform access criteria for IVIg, the growth in its use varies significantly across jurisdictions. This, together with the strong growth in total use of IVIg, has generated interest in a better understanding of the clinical demand, treatment, and management arrangements for IVIg in each jurisdiction.

In response to these issues, in March 2011, a joint meeting of the Clinical, Technical and Ethical Principal Committee (CTEPC) and the Jurisdictional Blood Committee (JBC) agreed to a review of the authorisation process and clinical governance framework for IVIg as a priority task. A tender to undertake a review into the administrative and clinical governance options for IVIg has been released.

7. 3. IVIG I SSUED BY T O P 10 PRI MAR Y DI AG NO SI S BY ST AT E

The top 10 primary diagnoses nationally and by jurisdiction for the four quarters in 2010/11 are presented in Figure 12. Top 10 diagnoses differ between jurisdictions. As shown in Figure 8 nationally, acquired hypogammaglobulinaemia secondary to haematological malignancies (21.2%), CIDP (20.1%) and PID (15.6%) were the indications for which the greatest proportion of IVIg was issued in 2010/11.

**Figure 12 Proportion of IVIg issued by top 10 diagnoses by jurisdiction for 2010/11**

40.0%

35.0%

30.0%

25.0%

ITP in adults

20.0%

15.0%

10.0%

5.0%

0.0%

NSW VIC QLD WA SA TAS ACT NT

National

Source: IVIg Stars database maintained by the Blood Service.

Acquired hypogammaglobulinaemia

secondary to haematological malignancies

Chronic inflammatory demyelinating

polyneuropathy

Primary immunodeficiency diseases

Myasthenia gravis

Multifocal motor neuropathy

Inflammatory myopathies

Guillain-Barre syndrome

Specific antibody deficiency

Secondary hypogammaglobulinaemia

7. 4. I VI G I SSUED (GRA MS PER 1 000 PO P ULA T I O N) BY JURI S DI CT I O N

The grams issued per 1000 head of population for each indication varies between jurisdictions and complete data for each jurisdiction can be found at *Appendix A*

IVIg by grams per 1000 head of population - 2010/11 by jurisdiction and . Some of the more notable differences in average dose per patient by indication are shown in Table 10.

**Table 10 IVIg issued (grams per 1000 head of population) by indication and by jurisdiction**

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Disease Group | NSW | Vic. | Qld. | WA | SA | Tas. | ACT | NT | Australia |
| Chapter 5 | | | | | | | | | |
| Acquired hypogamma-  globulinaemia secondary to haematological malignancies | 29.23 | 21.33 | 47.77 | 6.41 | 16.02 | 54.47 | 45.36 | 2.69 | 28.31 |
| Chronic inflammatory demyelinating  polyneuropathy | 27.43 | 29.79 | 25.36 | 27.80 | 18.16 | 39.00 | 20.77 | 3.11 | 26.85 |
| Primary immunodeficiency  diseases | 27.35 | 17.75 | 19.70 | 10.24 | 20.26 | 11.77 | 45.82 | 6.25 | 20.85 |
| Myasthenia gravis | 8.31 | 8.78 | 11.21 | 7.78 | 2.76 | 11.57 | 5.79 | 0.00 | 8.50 |
| Multifocal motor neuropathy | 7.69 | 7.42 | 6.07 | 12.56 | 10.92 | 1.70 | 1.18 | 13.52 | 7.85 |
| ITP in adults | 8.66 | 5.06 | 9.40 | 3.89 | 8.70 | 3.87 | 11.02 | 6.68 | 7.34 |
| Inflammatory myopathies | 8.79 | 5.27 | 5.36 | 1.07 | 7.98 | 10.37 | 4.24 | 0.00 | 6.24 |
| Guillain-Barre syndrome | 4.64 | 5.79 | 4.24 | 2.87 | 4.08 | 3.36 | 3.64 | 0.00 | 4.53 |
| **Chapter 5 Total** | **123.87** | **102.76** | **132.43** | **72.91** | **89.84** | **137.70** | **138.42** | **33.17** | **112.26** |
| Chapter 6 | | | | | | | | | |
| Specific antibody deficiency | 6.87 | 2.76 | 2.90 | 3.92 | 4.22 | 4.90 | 7.73 | 0.78 | 4.45 |
| Secondary hypogammaglobuli naemia | 2.98 | 2.41 | 6.98 | 1.33 | 1.27 | 13.15 | 1.45 | 1.09 | 3.55 |
| Kidney transplantation | 1.34 | 7.70 | 1.31 | 1.08 | 0.56 | 3.10 | 1.23 | 0.00 | 2.84 |
| HSCT (for prevention of GvHD in high risk Allogeneic HSCT) | 0.17 | 2.00 | 6.26 | 0.02 | 3.14 | 0.00 | 0.00 | 0.00 | 2.06 |
| **Chapter 6 Total** | **16.29** | **19.09** | **23.96** | **10.18** | **13.41** | **25.73** | **16.10** | **4.45** | **17.80** |
| Chapter 7 Total | 3.84 | 2.48 | 3.88 | 2.71 | 2.92 | 7.56 | 5.12 | 1.48 | 3.41 |
| Total | 144.00 | 124.74 | 160.28 | 86.00 | 106.18 | 170.98 | 159.65 | 39.10 | 133.59 |

Source: IVIg Stars database maintained by the Blood Service.

Note: Caution should be used when interpreting these figures for the small jurisdictions.

Understanding the differences in the amount of IVIg issued per 1000 head of population between jurisdictions for the more common indications would be beneficial. For example, the amount of IVIg issued per 1000 head of population for CIDP varies from 39g to 3g, with the national average being

26.8g.

7. 5. PAT I ENT CO UNT S

Excluding IVIg issued under DOs, a total of 11,457 unique patients were issued IVIg nationally over

2010/11 and there were 93,887 patient episodes. Patient numbers by quarter are shown in Table 11. Note these are numbers of the unique patients for whom IVIg was issued in the quarter. A particular patient may appear in a number of quarters.

**Table 11 Number of unique patients for whom IVIg was issued by jurisdiction by Quarter**

2008/09

|  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Year Quarter | NSW | Vic. | Qld. | WA | SA | Tas. | ACT | NT | Australia |
| Sep | 2216 | 1296 | 1448 | 402 | 331 | 145 | 105 | 13 | 5956 |
| Dec | 2255 | 1327 | 1466 | 399 | 364 | 151 | 105 | 19 | 6086 |
| Mar | 2261 | 1313 | 1470 | 357 | 362 | 170 | 99 | 17 | 6049 |
| Jun | 2383 | 1356 | 1544 | 373 | 395 | 177 | 98 | 31 | 6357 |
| Sep | 2447 | 1377 | 1652 | 385 | 400 | 184 | 112 | 24 | 6581 |
| Dec | 2499 | 1388 | 1670 | 357 | 440 | 177 | 109 | 20 | 6660 |
| Mar | 2556 | 1394 | 1682 | 354 | 395 | 183 | 102 | 15 | 6681 |
| Jun | 2607 | 1460 | 1755 | 373 | 413 | 189 | 121 | 22 | 6940 |
| Sep | 2707 | 1506 | 1839 | 376 | 420 | 197 | 144 | 22 | 7211 |
| Dec | 2784 | 1545 | 1887 | 395 | 394 | 205 | 132 | 21 | 7363 |
| Mar | 2761 | 1544 | 1888 | 379 | 397 | 214 | 130 | 15 | 7328 |
| Jun | 2800 | 1628 | 1947 | 385 | 419 | 200 | 142 | 23 | 7544 |

Source: IVIg Stars database maintained by the Blood Service.

2010/11

2009/10

From Table 11, note that the growth between 2009/10 and 2010/11 of the average number of unique patients over the quarters for all Australia is 9.6%. This growth is, however, not the same in each state. The ACT with 23.4%, Queensland with 11.9%, Tasmania with 11.3% and Victoria with 10.7%

have above average growth. New South Wales is just below the average with 9.3%. WA has less than half the growth at 4.5% and NT has no growth. SA has a decline in the average number of unique patients of 1.1%.

**Figure 13 Jurisdiction share of unique patients receiving IVIg in June quarter 2011 compared with the jurisdiction share of population in Jun quarter 2011**

40%

35%

30%

**Proportion of Australian total**

25%

20%

15%

10%

5%

0%

NSW VIC QLD WA SA TAS ACT NT

Share of number of unique patients June 2011 Share of population

Source: IVIg Stars database maintained by the Blood Service.

Figure 13 shows the jurisdictional share of patient numbers and compares them with the jurisdictions population share. New South Wales and Queensland number shares are significantly above their population.

**Figure 14 Numbers of unique patients by state for 2008/09 to 2010/11**

0.7

0.6

**Number of unique patients per 1000 population**

0.5

0.4

0.3

0.2

0.1

0

NSW VIC QLD SA WA TAS ACT NT Australia

2008-09 2009-10 2010-11

Source: IVIg Stars database maintained by the Blood Service and ABS population statistics.

**Figure 15 Treatment episodes per 1000 population by state for 2008/09 to 2010/11**

6

5

**Number of unique patients per 1000 population**

4

3

2

1

0

NSW VIC QLD SA WA TAS ACT NT Australia

2008-09 2009-10 2010-11

Source: IVIg Stars database maintained by the Blood Service and ABS population statistics.

Figure 14 shows the variability between the states in the numbers of unique patients and Figure 15 shows the number of treatment episodes. Moreover, the figures show that most states have strong growth in numbers and treatment episodes underpinning their growth in use of IVIg.

7. 6. VARI A BI LI T Y BETW EEN JU RISDICT IONS

Variability between jurisdictions in the way IVIg is used may by measured in a number of ways. Table

12 shows the average grams issued to patients with selected conditions. Appendix A shows the grams IVIg per 1000 population the grams issued per episode for the different indications is shown at Appendix B. Clearly, any of these measures for the jurisdictions with smaller populations should be viewed with caution.

Table 12 presents the differences for twenty disease groups using the largest amounts of IVIg. In general, such variance in average grams per patient from national average and between jurisdictions warrants further consideration. In particular, it would be informative to understand the reasons for the variation in the doses issued for some of the more common indications such as CIDP, multifocal motor neuropathy with persistent conduction block, polymyositis, and severe combined

immunodeficiency. For example, in severe combined immunodeficiency, there is more than a two-fold variation in dose issued per patient between even the large patient population jurisdictions.

**Table 12 Average grams IVIg issued per unique patient by disease group and by jurisdiction 2010/11**

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Disease group | Chapter | NSW | Vic. | Qld. | WA | SA | Tas. | NT | ACT | Australia |
| Acquired hypogammaglobulinaemia secondary to haematological malignancies | 5 | 186.13 | 197.40 | 229.15 | 174.99 | 174.95 | 221.64 | 237.62 | 124.20 | 203.05 |
| Chronic inflammatory demyelinating polyneuropathy | 5 | 366.54 | 484.64 | 370.78 | 708.08 | 427.96 | 601.21 | 528.43 | 358.50 | 428.29 |
| Primary immunodeficiency diseases | 5 | 303.01 | 312.80 | 296.55 | 300.82 | 276.21 | 299.40 | 302.24 | 180.38 | 300.81 |
| Myasthenia gravis | 5 | 334.47 | 396.92 | 360.13 | 445.74 | 189.92 | 392.40 | 412.80 |  | 360.10 |
| Multifocal motor neuropathy | 5 | 390.04 | 560.52 | 364.11 | 822.64 | 782.78 | 288.00 | 420.00 | 780.00 | 490.69 |
| ITP in adults | 5 | 174.28 | 122.52 | 158.23 | 120.55 | 143.44 | 140.57 | 196.25 | 128.50 | 152.19 |
| Inflammatory myopathies | 5 | 307.18 | 409.06 | 394.65 | 245.60 | 424.68 | 586.11 | 377.25 |  | 354.18 |
| Guillain-Barre syndrome | 5 | 176.97 | 174.52 | 163.80 | 146.01 | 181.74 | 213.56 | 117.82 |  | 170.92 |
| Specific antibody deficiency | 6 | 276.42 | 287.15 | 210.29 | 209.19 | 248.57 | 356.14 | 275.40 | 90.00 | 257.99 |
| Secondary hypogammaglobulinaemia | 6 | 140.09 | 156.08 | 205.55 | 112.81 | 189.82 | 371.50 | 258.00 | 126.00 | 174.73 |
| Kidney transplantation | 6 | 122.19 | 248.27 | 175.59 | 164.43 | 115.38 | 315.00 | 219.00 |  | 202.17 |
| HSCT (prevention of GvHD in high risk Allogeneic HSCT) | 6 | 51.23 | 289.76 | 257.38 | 28.50 | 370.50 |  |  |  | 243.67 |
| Stiff person syndrome | 5 | 400.00 | 496.20 | 1127.14 |  | 504.00 | 608.00 |  | 210.00 | 603.32 |
| Foeto-maternal /neonatal alloimmune thrombocytopenia | 6 | 154.80 | 199.37 | 690.43 | 683.40 | 615.00 |  | 6.00 | 6.00 | 368.24 |
| Pemphigoid | 6 | 668.00 | 518.00 | 1133.25 |  | 255.00 |  | 981.00 |  | 732.50 |
| Autoimmune haemolytic anaemia | 6 | 119.46 | 100.02 | 161.72 | 88.33 | 152.50 | 83.00 | 96.00 |  | 123.68 |
| Pemphigus | 6 | 695.00 | 354.00 | 583.20 | 345.00 | 1647.00 |  |  |  | 599.19 |
| Kawasaki disease | 5 | 42.22 | 40.87 | 39.13 | 36.25 | 43.35 | 49.50 | 109.50 |  | 41.63 |
| Ig para-proteinaemic neuropathy | 6 | 296.73 | 238.50 | 204.60 | 754.00 | 180.00 |  |  |  | 282.12 |
| Toxic shock syndrome | 6 | 149.35 | 119.92 | 101.46 | 118.75 | 69.00 | 30.00 | 119.00 | 150.00 | 121.73 |

Source: IVIg Stars database maintained by the Blood Service.

7. 7. I SSUE D AN D RE PO R T ED AS ‘C RI T ERI A N O T MET’

The Blood Service was asked to indicate circumstances where IVIg was issued to patients who did not meet *the Criteria* in Chapters 5, 6 or 7. IVIg is sometimes issued in emergency life threatening situations prior to diagnosis or in situations where the Clarification Process has not published a

‘resolution’ and the Jurisdictional Blood Committee (JBC) has decided to allow continued access to

IVIg until such time as a resolution is published.

Table 13 lists the requests that did not meet *the Criteria* but for which product was issued by the Blood Service. A total of 69,120g were issued to 880 unique patients, representing 2,307 treatment episodes.

**Table 13 Issues of IVIg under the National Blood Arrangements which did not meet the Criteria**

|  |  |  |  |
| --- | --- | --- | --- |
| 2008/09 2009/10 2010/11 | | | |
|  | Patients Episodes Issued  (grams) | Patients Episodes Issued  (grams) | Patients Episodes Issued  (grams) |
| Criteria  Not Met | 852 2325 69,093 | 60 139 4,569 | 37 43 1,644 |
| Indefinite | 1 2 48 |  |  |
| DO Advised |  | 13 0 0 | 20 0 0 |
| DO Issued | 2 1 140 | 7 9 377 | 5 6 215 |
| Pending | 28 94 2,603 | 9 17 474 | 39 85 2,996 |
| Single | 1 1 27 | 1 13 507 | 1 1 30 |
| Not approved | 39 0 0 | 61 0 0 | 65 0 0 |
| Grand  Total | 923 2423 71,911 | 151 178 5,927 | 167 135 4,885 |

Source: IVIg Stars database maintained by the Blood Service.

The application of *the Criteria* means that the number of patients receiving IVIg who do not meet *the*

*Criteria* has fallen from 852 on 2008/09 to 37 patients in 2010/11.

7. 8. RECON CILIAT ION

A reconciliation of STARS quarterly data with the Blood Service clinical issue reports that the NBA receives on a monthly basis indicates small variances (Table 14). Nationally reconciliation indicated that, the Blood Service issues were within half a per cent of the data recorded in STARS. In the Northern Territory, approximately 14% more IVIg was issued than is recorded in STARS, whilst in South Australia and the ACT there were more issues recorded in STARS than actual issues during that time period (approximately 5% and 4% respectively). In some cases these differences can be explained by product being ordered and recorded in STARS the month prior to product actually being issued.

**Table 14 Reconciliation of STARS (STARS minus NBA issues, in grams) quarterly data with the Blood Service monthly clinical issue reports by jurisdiction and nationally**

|  |  |
| --- | --- |
| 2004/05 2005/06 2006/07 2007/08 2008/09 2009/10 2010/11 | |
| NSW | 3.6% -0.1% -0.5% 0.0% -1.0% -1.3% -1.5% |
| Vic. -6.1% -4.3% -2.9% 0.4% 2.2% 1.7% -2.7% | |
| Qld. | 11.7% 6.7% -4.3% -3.8% -1.2% -0.6% 1.1% |
| SA 0.6% -5.4% 4.6% 3.3% 5.1% -1.0% 0.3% | |
| WA | -4.4% -2.3% -1.2% -0.1% -0.6% 0.0% -5.2% |
| Tas. -1.8% 1.3% -11.7% -2.2% 2.6% 0.6% -2.3% | |
| NT | -6.4% -4.0% -7.9% -5.5% -13.7% -5.2% 0.3% |
| ACT -3.7% -17.0% -1.1% -9.2% 4.5% 3.0% 1.7% | |
| Total 1.5% -0.6% -2.1% -0.8% 0.3% -0.2% -1.2% | |

Source: NBA IDMS issues data and IVIg Stars database maintained by the Blood Service.

Note: The proportion the STARS data is in excess of the NBA issues data for the same period.

**8. DEMOGR AP HI CS OF IVIG PATI EN TS**

This section provides demographic information on patients to whom IVIg was issued based on the entries in the STARS database between the September quarter 2008 and June quarter 2011. It is assumed that the Patient IDs are unique and sequential or increasing over time. Table 15 shows the basic count information.

**Table 15 Basic numbers**

|  |  |
| --- | --- |
| Number | |
| Total unique patient Ids | 20,091 |
| Total unique patient Ids with some weight data | 14,795 |
| Total unique patient Ids with an age recorded | 15,938 |
| Total unique patient Ids with a weight change | 2,522 |
| Total unique patient Ids with more than one jurisdiction | 382 |
| Total unique patient Ids with two jurisdictions | 352 |
| Total unique patient Ids with three jurisdictions | 25 |
| Total unique patient Ids with more than one diagnosis | 1,547 |
| Total unique patient Ids with two diagnoses | 1403 |
| Total unique patient Ids with three diagnoses | 135 |
| Total unique patient Ids with four diagnoses | 8 |
| Total unique patient Ids born 1920 or earlier | 147 |

Source: IVIg Stars database maintained by the Blood Service.

**Table 16 Additions to the database - number of Patient IDs added in quarter**

|  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| Sep  Q08 | Dec  Q08 | Mar  Q09 | Jun  Q09 | Sep  Q09 | Dec  Q09 | Mar  Q10 | Jun  Q10 | Sep  Q10 | Dec  Q10 | Mar  Q11 | Jun  Q11 |
| 7306 | 1110 | 1046 | 1096 | 1390 | 1277 | 986 | 929 | 1423 | 1131 | 1256 | 1141 |

Source: IVIg Stars database maintained by the Blood Service.

Table 16 shows that the average number of new patients each quarter is approximately 1,000. The September quarter 2008 has a larger number of patients because of the existing patients (approximately 6,000), who were issued their first IVIg prior to 2008/09 and received some IVIg in that quarter. Under the assumption that Patient IDs are almost sequential, new patients in a quarter will have a Patient ID greater than any patients in the previous quarter and less than any new patients in the next quarter.

The STARS data has age and weight data recorded at treatment dates. These data will change over time. The year of birth is calculated from age data and applied that to all of the patient’s treatments. The distribution of estimated birth years is shown in Figure 16 where it is compared with the age distribution of the Australian Population from the Australian Bureau of Statistics (ABS).

**Figure 16 Proportion of IVIg Patient IDs by estimated birth year**

2.5%

2.0%

1.5%

**Proportion of total**

1.0%

0.5%

0.0%

2011

2008

2005

2002

1999

1996

1993

1990

1987

1984

1981

1978

1975

1972

1969

1966

1963

1960

1957

1954

1951

1948

1945

1942

1939

1936

1933

1930

1927

1924

1921

1918

1915

1912

**Estimated birth year**

No IDs Aus pop

Source: IVIg Stars database maintained by the Blood Service.

ABS 3201.0 Population by Age and Sex, Australian States and Territories

Figure 16 shows that there is a spike of IVIg issued for the very young and those over 70 years. The median birth year of patients for whom IVIg is issued is 1952, compared to the median birth year for the Australian population which is 1973 (i.e. age 37), indicating that half the IVIg issued is for patients over 60.

The age profiles (from ABS data) of the different jurisdictions are shown in Figure 17 and Table 17. It can be seen that the Northern Territory has a very young profile with a higher population in the early working age period. The ACT also has a higher population in the working years. South Australia and Tasmania have older populations and lower than average proportion in working ages.

**Figure 17 Proportion of population 2010 by approximate birth year**

2.0%

1.8%

1.6%

1.4%

1.2%

**Proportion of total**

1.0%

0.8%

0.6%

0.4%

NSW VIC QLD SA WA TAS NT ACT

Australia

0.2%

0.0%

2010

2006

2002

1998

1994

1990

1986

1982

1978

1974

1970

1966

1962

1958

1954

1950

1946

1942

1938

1934

1930

1926

1922

1918

1914

1910-

**Approximate birth year**

Source: ABS 3201.0 Population by Age and Sex, Australian States and Territories

**Table 17 Median estimated year of birth for IVIg patients**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
| NSW | Vic. | Qld. | WA | SA | Tas. | ACT | NT | Australia |
| 1951 | 1953 | 1950 | 1958 | 1951 | 1948 | 1958 | 1977 | 1952 |

Source: IVIg Stars database maintained by the Blood Service.

Figure 18 shows the cumulative distribution of estimated birth years. Jurisdictions with lines to the left have generally younger age profiles than jurisdictions with lines to the right.

**Figure 18 Cumulative distribution of estimated birth year of IVIg patients by jurisdiction**

100%

90%

**Proportion of total with estimated birth year after horizontal axis value**

80%

70%

60%

50%

40%

30%

20%

NSW VIC QLD WA SA TAS ACT NT Aus

10%

0%

2011

2008

2005

2002

1999

1996

1993

1990

1987

1984

1981

1978

1975

1972

1969

1966

1963

1960

1957

1954

1951

1948

1945

1942

1939

1936

1933

1930

1927

1924

1921

1918

1915

1912

**Estimated birth year**

Source: IVIg Stars database maintained by the Blood Service.

**Table 18 Median estimated year of birth for IVIg patients for the top 40 primary diagnoses by grams used**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Primary Diagnosis | Patients | Patients with known age | Patients with known age (%) | Median estimated birth year | Total  (grams)  2008/09  – 2010/11 |
| Chronic inflammatory demyelinating polyneuropathy | 2004 | 1723 | 86% | 1946.0 | 1,620,355 |
| Common variable immunodeficiency disease | 1487 | 1364 | 92% | 1957.0 | 1,060,980 |
| Chronic lymphocytic leukaemia | 1547 | 1305 | 84% | 1938.0 | 634,366 |
| Myasthenia gravis | 799 | 675 | 84% | 1947.0 | 486,371 |
| Multifocal motor neuropathy with persistent conduction block | 478 | 421 | 88% | 1952.0 | 465,093 |
| Multiple myeloma | 1365 | 1121 | 82% | 1941.0 | 457,263 |
| Non-Hodgkins lymphoma | 997 | 863 | 87% | 1944.0 | 376,528 |
| Guillain-Barré syndrome | 1592 | 1085 | 68% | 1958.0 | 272,362 |
| ITP refractory | 1310 | 893 | 68% | 1949.0 | 217,625 |
| Secondary hypogammaglobulinaemia  (excludes haematological malignancies) | 787 | 618 | 79% | 1958.0 | 203,871 |
| Polymyositis | 325 | 275 | 85% | 1949.0 | 199,036 |
| IgG subclass deficiency EXISTING  patients only | 334 | 252 | 75% | 1949.0 | 192,768 |
| Other relevant haematological malignancies | 882 | 666 | 76% | 1957.0 | 190,127 |
| ITP in specific circumstances  (surgery, corticosteroids contraindicated, chronic ITP) | 1036 | 745 | 72% | 1949.0 | 162,801 |
| Kidney transplantation post-transplant | 540 | 407 | 75% | 1962.0 | 145,079 |
| Specific antibody deficiency | 635 | 219 | 34% | 1956.0 | 128,140 |
| HSCT (for prevention of GvHD in high risk  Allogeneic HSCT). | 444 | 334 | 75% | 1962.0 | 121,984 |
| Other primary immunodeficiency | 283 | 175 | 62% | 1959.0 | 119,008 |
| X linked agammaglobulinaemia | 133 | 107 | 80% | 1989.0 | 89,222 |
| Inclusion body myositis | 123 | 98 | 80% | 1938.0 | 73,420 |
| Dermatomyositis | 125 | 102 | 82% | 1961.0 | 68,022 |
| ITP with life-threatening haemorrhage | 319 | 232 | 73% | 1950.0 | 48,444 |
| Stiff person syndrome | 40 | 35 | 88% | 1958.0 | 47,966 |
| Foeto-maternal /neonatal alloimmune thrombocytopenia (Antenatal) | 46 | 34 | 74% | 1978.0 | 44,624 |
| Autoimmune haemolytic anaemia | 274 | 194 | 71% | 1946.0 | 39,926 |
| Kawasaki disease | 825 | 547 | 66% | 2007.0 | 33,034 |
| ITP in pregnancy | 186 | 138 | 74% | 1980.0 | 32,050 |
| Ig para-proteinaemic neuropathy | 64 | 50 | 78% | 1937.5 | 29,440 |
| TSS - streptococcal | 180 | 122 | 68% | 1965.5 | 23,289 |
| Solid organ - lung | 143 | 118 | 83% | 1959.0 | 22,216 |
| Epilepsy (rare childhood cases) | 43 | 37 | 86% | 2002.0 | 21,240 |
| Kidney transplantation pre-transplant | 210 | 147 | 70% | 1962.0 | 20,954 |
| Pemphigus vulgaris | 25 | 24 | 96% | 1958.0 | 20,721 |
| Toxic epidermal necrolysis/Steven  Johnson syndrome | 146 | 104 | 71% | 1970.0 | 19,779 |
| Severe combined Immunodeficiency | 41 | 39 | 95% | 1963.0 | 18,957 |

|  |
| --- |
| Primary Diagnosis Patients Patients Patients Median Total with with estimated (grams)  known known birth year 2008/09  age age (%) – 2010/11 |
| ITP in children 375 256 68% 2006.0 18,886 |
| Paraneoplastic syndromes 78 60 77% 1953.0 16,838 |
| Potassium channel antibody-associated 57 49 86% 1965.0 16,776 encephalopathy |
| Acute disseminated encephalomyelitis 91 68 75% 1990.0 16,385 |
| Neonatal haemochromatosis 15 11 73% 1984.0 16,248 |

Source: IVIg Stars database maintained by the Blood Service.

Table 18 shows the median estimated year of birth for patients with the top 40 diagnoses who were issued IVIg. For a number of indications the proportion of patients with some age data recorded is lower than for other indications.

**Figure 19 Distribution of reported weight of IVIg patients**

3500

3000

2500

2000

**Number of patients**

1500

1000

500

0

10 20 30 40 50 60 70 80 90 100 110 120 130 140 150 160 170 180 190 200+

**Weight in kilograms**

Source: IVIg Stars database maintained by the Blood Service.

Although weight data is not recorded for all IVIg patients, Figure 19 shows the weight distribution of patients receiving IVIg. In Figure 20 we make a comparison with ABS survey data from 1995. As the ABS data is for adults only we did not include IVIg patients with weight 20kg or less in the distribution. More current data only reports on body mass index which is calculated from body weight and height.

The data downloads did not include height data so we have made comparison with the older 1995 data. The STARS data does not have gender so the comparison is crude. It appears that IVIg have slightly more obese people proportionally than the Australia population, although average weights would appear to be slightly lower than the general Australian population.

**Figure 20 The weight distribution of IVIg patients compared with adult Australia population**

30%

25%

20%

15%

**Proportion of total**

IVIg patients

Average Australian Adults

10%

5%

0%

Less than 50 50 to less

60 to less

70 to less

80 to less

90 to less

100 to less Greater than

than 60

than 70

than 80

than 90

than 100

than 110

110

**Weight in kilograms**

Source: IVIg Stars database maintained by the Blood Service.

ABS 4359.0 - How Australians Measure Up, 1995: Average of male and female as no total average published.

8. 1. DOSING - NEW PATIENT S CO MP ARE D W IT H EX IST ING PAT I ENT S FO R SELE CT ED DI A G NO SES

For all indications, understanding dosing, both initial and maintenance, assists with understanding clinical demand and informed decision making. Data recorded in both STARS and the NBA data systems allows us to investigate dosing practices and the NBA chose to analyse a random selection of patients within the top 5 indications to identify if:

• there any clear differences in how new patients are dosed in relation to existing patients

• patient doses increase or decrease after initial doses

• the pattern of dosing over time for patients with chronic conditions.

We have classified patients as new in a quarter if they appear for the first time in that quarter for a diagnosis. The following analysis is for the five primary diagnoses that have the highest use of IVIg.

8. 1. 1. CHRO NI C I NFLA MMAT O RY DE MYELIN A T ING PO LYNE URO P AT HY (CI DP)

The following series of charts (Figure 21, Figure 22, Figure 23 and Figure 24) show numbers and amounts of IVIg for patients with CIDP. Figure 21 and Figure 22 show that the numbers of patients and total grams are increasing at a reasonably steady rate. The increase over the twelve quarters is

34% for numbers of patients and 43% for total grams. In Figure 23 the reasonably stable grams per patient shows that the growth in total grams is driven mainly by the increase in numbers of patients. On a per patient basis new patients are receiving between 20-30% more than existing patients. When the data are considered in terms of the amount per episode in Figure 24, the trend appears to be reasonably stable and new patient episodes doses are 10 to 15% lower than those of existing patients. This would indicate that the loading doses are given by increased frequency of dosing rather larger individual doses.

**Figure 21 CIDP - new and existing - number of patients**

1200

**Number of patients – Chronic inflammatory demyelinating polyneuropathy**

1000

800

600

**Number**

400

200

0

**Quarter**

New Existing Total

Source: IVIg Stars database maintained by the Blood Service.

























**Figure 22 CIDP - new and existing - total grams**

180,000

**Total grams – Chronic inflammatory demyelinating polyneuropathy**

160,000

140,000

120,000

100,000

**Grams used**

80,000

60,000

40,000

20,000

0

**Quarter**

New Existing Total

Source: IVIg Stars database maintained by the Blood Service.























**Figure 23 CIDP - new and existing - grams per patient**

200

**Grams per patient – Chronic inflammatory demyelinating polyneuropathy**

2.0

180

1.8

**Ratio of grams perpatient new and existing**

160

1.6

140

1.4

120

**Grams per patient**

1.2

100

1.0

80 0.8

60 0.6

40 0.4

20 0.2

0 0.0

**Quarter**

New Existing Ratio (RHS)

Source: IVIg Stars database maintained by the Blood Service.



















**Figure 24 CIDP - new and existing - grams per episode**

**Grams per episode – Chronic inflammatory demyelinating polyneuropathy**

40

1.6

35 1.4

**Ratio of new and existing gram per episode**

30 1.2

25 1.0

**Grams per episode**

20 0.8

15 0.6

10 0.4

5 0.2

0 0.0

**Quarter**

New Existing Ratio (RHS)

Source: IVIg Stars database maintained by the Blood Service.



















8. 1. 2. CO MMO N V ARI A BLE I MMU NO DEFI CI ENC Y DI SEA SE (C VI D)

The following charts (Figure 25 and Figure 26) show the numbers and grams per episode for CVID.

**Figure 25 CVID - new and existing - number of patients**

1400

**Number of patients – Common variable immunodeficiency disease**

1200

1000

800

**Number**

600

400

200

0

























**Quarter**

New Existing Total

Source: IVIg Stars database maintained by the Blood Service.

Growth in the number of patients is proportionally smaller than with CIDP. The largest numbers of

new patients appear in the June quarter in both years. The increase over the twelve quarters for CVID is 23% for numbers and 35% for total grams. The grams per episode are generally stable for existing patients. The grams per episode for new patients are more varied reflecting their low absolute numbers.

**Figure 26CVID - new and existing - grams per episode**

**Grams per episode – Common variable immunodeficiency disease**

40

1.6

35 1.4

**Ratio of new and existing gram per episode**

30 1.2

25 1.0

**Grams per episode**

20 0.8

15 0.6

10 0.4

5 0.2

0



















**Quarter**

0.0

New Existing Ratio (RHS)

Source: IVIg Stars database maintained by the Blood Service.

8. 1. 3. CHRO NI C LY MPHO C YT I C LEUKA E MI A (CLL)

The increase over the twelve quarters is 22% for numbers of patients and 26% for total grams. There is a very slight increase in the dosage per episode for chronic lymphocytic leukaemia.

**Figure 27 Chronic lymphocytic leukaemia - new and existing - number of patients**

900

**Number of patients – Chronic lymphocytic leukaemia**

800

700

600

500

**Number**

400

300

200

100

0

**Quarter**

New Existing Total

Source: IVIg Stars database maintained by the Blood Service.

























**Figure 28 Chronic lymphocytic leukaemia - new and existing - grams per episode**

**Grams per episode – Chronic lymphocytic leukaemia**

40

1.6

35 1.4

**Ratio of new and existing gram per episode**

30 1.2

25 1.0

**Grams per episode**

20 0.8

15 0.6

10 0.4

5 0.2

0 0.0

**Quarter**

New Existing Ratio (RHS)

Source: IVIg Stars database maintained by the Blood Service.



















8. 1. 4. MYA ST HENI A G R AVI S

The increase over the twelve quarters is 61% for numbers of patients and 78% for total grams for this condition. The latter reflects a slight increase in the dose per episode interacting with the strong growth in numbers.

**Figure 29 Myasthenia gravis - new and existing - number of patients**

450

**Number of patients – Myasthenia gravis**

400

350

300

250

**Number**

200

150

100

50

0

**Quarter**

New Existing Total

Source: IVIg Stars database maintained by the Blood Service.

























**Figure 30 Myasthenia gravis - new and existing - grams per episode**

**Grams per episode – Myasthenia gravis**

40

1.6

35 1.4

**Ratio of new and existing gram per episode**

30 1.2

25 1.0

**Grams per episode**

20 0.8

15 0.6

10 0.4

5 0.2

0 0.0

**Quarter**

New Existing Ratio (RHS)

Source: IVIg Stars database maintained by the Blood Service.



















8. 1. 5. MULT I PLE MYE LO MA

The increase over the twelve quarters is 39% for numbers of patients and 43% for total grams for this condition. The latter reflects a slight increase in the dose per episode.

**Figure 31 Multiple myeloma - new and existing - number of patients**

700

**Number of patients – Multiple myeloma**

600

500

400

**Number**

300

200

100

0

**Quarter**

New Existing Total

Source: IVIg Stars database maintained by the Blood Service.

























**Figure 32 Multiple myeloma - new and existing - grams per episode**

**Grams per episode – Multiple myeloma**

40

1.6

35 1.4

**Ratio of new and existing gram per episode**

30 1.2

25 1.0

**Grams per episode**

20 0.8

15 0.6

10 0.4

5 0.2

0 0.0

**Quarter**

New Existing Ratio (RHS)

Source: IVIg Stars database maintained by the Blood Service.



















8. 2. DI FFE REN CE I N U SE BETW EEN JURI SDI CT I O NS - SELECT ED I NDI CAT I O NS

In this section we compare the grams issued per treatment episode for some selected indications between jurisdictions. The five indications for which the greatest amount of IVIg was issued over the last two financial years are presented.

8. 2. 1. CHRO NI C I NFLA MMAT O RY DE MYELIN A T ING PO LYNE URO P AT HY (CI DP)

Figure 33 shows the grams issued per treatment episode for the different jurisdictions for chronic inflammatory demyelinating polyneuropathy. The small jurisdictions have very small numbers of patients so results should be regarded cautiously. There are differences between the apparent dosing of the different jurisdictions. New South Wales and Queensland have ‘grams per episode’ about 10% below the Australian average whereas South Australia and Western Australia have ‘grams per episode’ about 20% above.

**Table 19 Total national numbers chronic inflammatory demyelinating polyneuropathy**

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | Sep  Q08 | Dec  Q08 | Mar  Q09 | Jun  Q09 | Sep  Q09 | Dec  Q09 | Mar  Q10 | Jun  Q10 | Sep  Q10 | Dec  Q10 | Mar  Q11 | Jun  Q11 |
| NSW | 315 | 332 | 353 | 376 | 390 | 386 | 408 | 418 | 421 | 432 | 443 | 442 |
| Vic. | 226 | 240 | 243 | 237 | 245 | 254 | 249 | 253 | 253 | 252 | 266 | 273 |
| Qld. | 162 | 167 | 167 | 195 | 189 | 200 | 219 | 210 | 208 | 225 | 222 | 241 |
| WA | 59 | 60 | 64 | 71 | 73 | 66 | 65 | 74 | 75 | 71 | 70 | 73 |
| SA | 35 | 38 | 42 | 41 | 44 | 49 | 49 | 50 | 49 | 46 | 49 | 52 |
| Tas. | 29 | 30 | 31 | 32 | 32 | 32 | 33 | 31 | 29 | 32 | 30 | 24 |
| ACT | 11 | 11 | 14 | 12 | 12 | 11 | 11 | 13 | 12 | 12 | 13 | 11 |
| NT | 1 | 1 | 1 | 2 | 1 | 0 | 2 | 2 | 2 | 1 | 0 | 0 |
| Australia | 838 | 879 | 915 | 966 | 986 | 998 | 1036 | 1051 | 1049 | 1071 | 1093 | 1116 |

Source: IVIg Stars database maintained by the Blood Service.

**Figure 33Chronic inflammatory demyelinating polyneuropathy - grams per episode**

120

**Grams per episode – Chronic inflammatory demyelinating polyneuropathy**

100

80 NSW VIC

**Grams per episode**

60 QLD WA

SA

40 TAS ACT

20 NT Aus

0

Sep Q 08

Dec Q 08

Mar Q 09

Jun Q 09

Sep Q 09

Dec Q 09

Mar Q 10

Jun Q 10

Sep Q 10

Dec Q 10

Mar Q 11

Jun Q 11

**Quarter**

Source: IVIg Stars database maintained by the Blood Service.

8. 2. 2. CO MMO N V ARI A BLE I MMU NODEFI CI ENC Y DI SEA SE (C VI D)

For CVID Figure 34 shows most of the larger jurisdictions are clustered around the Australian average. Western Australia is below the average starting at -13% of the average at the beginning of the period and ending at -8% of the average at the end of the period.

**Figure 34 Common variable immunodeficiency disease - grams per episode**

**Grams per episode – Common variable immunodeficiency disease**

40

35

30

25 NSW VIC

**Grams per episode**

20 QLD WA

15 SA TAS

10 ACT NT

5 Aus

0

Sep Q 08

Dec Q 08

Mar Q 09

Jun Q 09

Sep Q 09

Dec Q 09

Mar Q 10

Jun Q 10

Sep Q 10

Dec Q 10

Mar Q 11

Jun Q 11

**Quarter**

Source: IVIg Stars database maintained by the Blood Service.

**Table 20 Total national numbers common variable immunodeficiency disease**

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | Sep  Q08 | Dec  Q08 | Mar  Q09 | Jun  Q09 | Sep  Q09 | Dec  Q09 | Mar  Q10 | Jun  Q10 | Sep  Q10 | Dec  Q10 | Mar  Q11 | Jun  Q11 |
| NSW | 431 | 443 | 437 | 449 | 450 | 456 | 469 | 484 | 498 | 502 | 500 | 510 |
| Vic. | 155 | 170 | 178 | 178 | 181 | 179 | 181 | 186 | 193 | 192 | 195 | 200 |
| Qld. | 197 | 199 | 204 | 210 | 219 | 220 | 220 | 218 | 223 | 223 | 225 | 232 |
| WA | 63 | 65 | 60 | 63 | 66 | 60 | 55 | 54 | 53 | 53 | 55 | 54 |
| SA | 64 | 66 | 79 | 79 | 84 | 87 | 89 | 91 | 94 | 92 | 96 | 97 |
| Tas. | 6 | 11 | 12 | 15 | 14 | 15 | 15 | 15 | 15 | 16 | 16 | 17 |
| ACT | 28 | 28 | 26 | 28 | 31 | 31 | 33 | 36 | 36 | 40 | 43 | 46 |
| NT | 2 | 2 | 0 | 3 | 2 | 3 | 2 | 2 | 4 | 3 | 1 | 1 |
| Australia | 946 | 984 | 996 | 1025 | 1047 | 1051 | 1064 | 1086 | 1116 | 1121 | 1131 | 1157 |

Source: IVIg Stars database maintained by the Blood Service.

8. 2. 3. CHRO NI C LY MPHO C YT I C LEUKA E MI A (CLL)

For CCL Figure 35 shows most of the larger jurisdictions are clustered around the Australian average.

**Table 21 Total national numbers chronic lymphocytic leukaemia**

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | Sep  Q08 | Dec  Q08 | Mar  Q09 | Jun  Q09 | Sep  Q09 | Dec  Q09 | Mar  Q10 | Jun  Q10 | Sep  Q10 | Dec  Q10 | Mar  Q11 | Jun  Q11 |
| NSW | 236 | 244 | 242 | 256 | 260 | 257 | 259 | 254 | 271 | 284 | 280 | 285 |
| Vic. | 142 | 151 | 148 | 157 | 150 | 156 | 167 | 161 | 168 | 168 | 165 | 167 |
| Qld. | 170 | 176 | 181 | 183 | 205 | 200 | 199 | 212 | 205 | 207 | 212 | 222 |
| WA | 20 | 19 | 20 | 24 | 23 | 24 | 22 | 23 | 27 | 29 | 25 | 23 |
| SA | 48 | 58 | 60 | 60 | 61 | 64 | 59 | 61 | 62 | 56 | 50 | 55 |
| Tas. | 26 | 25 | 21 | 22 | 21 | 19 | 19 | 23 | 25 | 25 | 26 | 25 |
| ACT | 9 | 8 | 7 | 10 | 10 | 13 | 14 | 16 | 19 | 17 | 15 | 14 |
| NT | 1 | 2 | 1 | 4 | 3 | 2 | 2 | 2 | 2 | 2 | 1 | 2 |
| Australia | 652 | 683 | 680 | 716 | 733 | 735 | 741 | 752 | 779 | 788 | 774 | 793 |

Source: IVIg Stars database maintained by the Blood Service.

**Figure 35 Chronic lymphocytic leukaemia - grams per episode**

**Grams per episode – Chronic lymphocytic leukaemia**

60

50

40 NSW VIC

**Grams per episode**

30 QLD WA

SA

20 TAS ACT

10 NT Aus

0

Sep Q 08

Dec Q 08

Mar Q 09

Jun Q 09

Sep Q 09

Dec Q 09

Mar Q 10

Jun Q 10

Sep Q 10

Dec Q 10

Mar Q 11

Jun Q 11

**Quarter**

Source: IVIg Stars database maintained by the Blood Service.

8. 2. 4. MYA ST HENI A G R AVI S

The picture for myasthenia gravis shown in Figure 36 shows a higher level of variability. The numbers of patients for this condition are quite small and this may explain the divergence.

**Table 22 Total national numbers Myasthenia gravis**

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | Sep  Q08 | Dec  Q08 | Mar  Q09 | Jun  Q09 | Sep  Q09 | Dec  Q09 | Mar  Q10 | Jun  Q10 | Sep  Q10 | Dec  Q10 | Mar  Q11 | Jun  Q11 |
| NSW | 92 | 93 | 99 | 106 | 120 | 129 | 133 | 128 | 126 | 132 | 136 | 141 |
| Vic. | 51 | 50 | 56 | 65 | 65 | 66 | 71 | 73 | 70 | 75 | 82 | 88 |
| Qld. | 54 | 58 | 64 | 78 | 80 | 90 | 79 | 78 | 91 | 94 | 97 | 109 |
| WA | 27 | 25 | 24 | 24 | 23 | 21 | 21 | 21 | 23 | 27 | 28 | 25 |
| SA | 10 | 8 | 15 | 9 | 16 | 11 | 9 | 10 | 10 | 9 | 8 | 16 |
| Tas. | 12 | 10 | 11 | 9 | 10 | 10 | 9 | 9 | 11 | 10 | 10 | 11 |
| ACT | 1 | 1 | 0 | 0 | 0 | 0 | 1 | 1 | 3 | 2 | 2 | 4 |
| NT | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Australia | 247 | 245 | 269 | 291 | 314 | 327 | 323 | 320 | 334 | 349 | 363 | 394 |

Source: IVIg Stars database maintained by the Blood Service.

**Figure 36 Myasthenia gravis - grams per episode**

**Grams per episode – Myasthenia gravis**

70

60

50

NSW

**Grams per episode**

40 VIC QLD

30 WA SA

TAS

20

ACT

NT

10

Aus

0

Sep Q 08

Dec Q 08

Mar Q 09

Jun Q 09

Sep Q 09

Dec Q 09

Mar Q 10

Jun Q 10

Sep Q 10

Dec Q 10

Mar Q 11

Jun Q 11

**Quarter**

Source: IVIg Stars database maintained by the Blood Service.

8. 2. 5. MULT I PLE MYE LO MA

Figure 37 shows a quite dispersed picture. Western Australia and South Australia are more than 30%

above and New South Wales and Queensland more than 10% below the national average.

**Table 23 Total national numbers Multiple myeloma**

|  |  |  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | Sep  Q08 | Dec  Q08 | Mar  Q09 | Jun  Q09 | Sep  Q09 | Dec  Q09 | Mar  Q10 | Jun  Q10 | Sep  Q10 | Dec  Q10 | Mar  Q11 | Jun  Q11 |
| NSW | 146 | 142 | 136 | 153 | 157 | 176 | 173 | 177 | 192 | 194 | 174 | 190 |
| Vic. | 73 | 75 | 66 | 73 | 71 | 67 | 81 | 81 | 103 | 106 | 107 | 95 |
| Qld. | 188 | 197 | 191 | 201 | 213 | 217 | 215 | 230 | 244 | 250 | 245 | 252 |
| WA | 5 | 6 | 5 | 6 | 9 | 8 | 13 | 10 | 12 | 8 | 8 | 10 |
| SA | 12 | 14 | 13 | 10 | 10 | 15 | 15 | 13 | 12 | 9 | 6 | 7 |
| Tas. | 11 | 21 | 31 | 35 | 37 | 35 | 37 | 40 | 44 | 42 | 44 | 42 |
| ACT | 5 | 3 | 5 | 5 | 7 | 10 | 10 | 10 | 17 | 14 | 14 | 12 |
| NT | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 |
| Australia | 440 | 458 | 448 | 483 | 504 | 528 | 544 | 561 | 624 | 623 | 598 | 609 |

Source: IVIg Stars database maintained by the Blood Service.

**Figure 37 Multiple myeloma - grams per episode**

**Grams per episode – Multiple myeloma**

90

80

70

60 NSW

**Grams per episode**

50 VIC QLD

40 WA SA

30 TAS

20 ACT NT

10 Aus

0

Sep Q 08

Dec Q 08

Mar Q 09

Jun Q 09

Sep Q 09

Dec Q 09

Mar Q 10

Jun Q 10

Sep Q 10

Dec Q 10

Mar Q 11

Jun Q 11

**Quarter**

Source: IVIg Stars database maintained by the Blood Service.

8. 3. T I ME I N T REAT ME N T

Patients requiring IVIg may have a condition requiring only very short term IVIg treatments (e.g. Kawasaki’s disease) or may suffer from a condition requiring chronic IVIg treatment and where it may be necessary to have IVIg for the rest of their life. For each unique patient and diagnosis we have estimated the time in treatment as the number of days between the recorded first date when IVIg was issued and last date it was issued for that patient. A patient first recorded in the last quarter will have

a maximum possible difference of about 90 days. In this calculation, a patient who has a chronic condition receiving IVIg since the first quarter of 2008/09 could have days in treatment of up to 730 days.

We have looked at the five conditions for which the largest amount of IVIg is issued for each those conditions classified as short term and long term.

**Figure 38 Days in treatment selected long term conditions**

600

Chronic inflammatory demyelinating polyneuropathy Common variable immunodeficiency disease

Chronic lymphocytic leukaemia Myasthenia gravis

Multiple myeloma

500

400

**Number of patients**

300

200

100

0

000 040 080 120 160 200 240 280 320 360 400 440 480 520 560 600 640 680 720 760 800 840 880 920 960 10001040

to to to

to to

to to

to to

to to

to to to to

to to

to to to

to to

to to to

to to

040 080 120 160 200 240 280 320 360 400 440 480 520 560 600 640 680 720 760 800 840 880 920 960 100010401080

**Days between first and last treatment**

Source: IVIg Stars database maintained by the Blood Service.

Note: The groups of days “n to m” is greater than n and less than or equal to m.

The distributions shown in Figure 38 reflect a large number of patients that had IVIg throughout the period, the new patients joining in each quarter (most of whom continue to receive IVIg) and some patients that receive IVIg for a short period only despite their condition being of a longer term nature. The data also reflect the poor prognoses of some of the patients with chronic lymphocytic leukaemia (CLL). No data exists to classify the ceased patients by outcome of treatment.

**Figure 39 Days in treatment selected short term conditions**

100%

Guillain-Barré syndrome ITP refractory Polymyositis

ITP in specific circumstances (surgery, corticosteroids contraindicated, chronic ITP) Kidney transplantation post-transplant

90%

80%

70%

**Proportion of total**

60%

50%

40%

30%

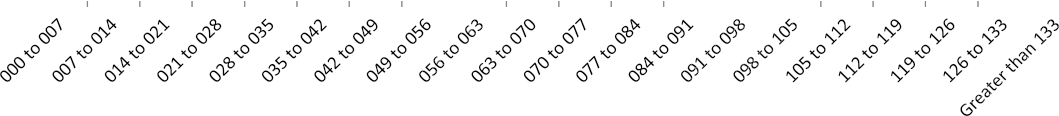
20%

10%

0%

**Days between the first and last treatment**

Source: IVIg Stars database maintained by the Blood Service.



Note: Polymyositis, while it is treated in short term bursts, is subject to relapses. Which is reflected in the large numbers in the Greater than 133 days category.

The groups of days “n to m” is greater than n and less than or equal to m.

For conditions considered short term, most patients receive treatment with IVIg for less than a week. However, it is of interest to note that 55% of patients who received IVIg for kidney transplants post- transplant received IVIg long term and less than 20% of patients receiving IVIg for polymyositis had treatment courses less than a week. Figure 40 shows the treatment periods for Kawasaki disease.

The vast majority receive treatment with IVIg for only one day and a few receive additional treatments.

**Figure 40 Days in treatment for Kawasaki disease by quarter of first joining**

**Number**

90

Sep Q 08 Dec Q 08 Mar Q 09 Jun Q 09 Sep Q 09 Dec Q 09

Mar Q 10 Jun Q 10 Sep Q 10 Dec Q 10 Mar Q 11 Jun Q 11

80

70

60

50

40

30

20

10

0

000 to

001

001 to

002

002 to

003

003 to

004

004 to

005

005 to

006

006 to

007

007 to

008

008 to

009

009 to

010

010 to

014

014 to

018

018 to

022

022 to

026

026 to

030

Greater than 30

**Days between first and last treatment**

Source: IVIg Stars database maintained by the Blood Service.

Note: The groups of days “n to m” is greater than n and less than or equal to m.

**9. CO NCL USI O NS**

The data that are available raise a number of questions regarding the use of IVIg in Australia. Most significantly are:

• Why is Australia’s demand for IVIg per 1000 population higher than many other countries with similar, well developed health care systems?

• Are patient outcomes in the different countries equivalent? Is Australia seeing patient benefits from the higher use?

• What are the clinical factors influencing the continued increase in the rate of ordering within neurology?

• What are the known causes for the variability in per head of population use of IVIg between conditions and between jurisdictions?

Gaps in the data that need to be addressed to better understand drivers of demand include:

• recording of each IVIg use event, as this would provide a basis for better analysis of IVIg use

• inclusion of high quality demographic (such as height, weight and age) data for all patients

• IVIg efficacy and patient outcomes.

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **APPEN DI X A**  **IVIG BY G R AMS P ER 1000 HE AD OF POP UL ATION - 2010/ 11 BY JU RISDIC TION AND PRIM AR Y DI AGN OSIS** | | | | | | | | | | |
| **Disease**  **Category** | **Primary Diagnosis** | **NSW** | **Vic.** | **Qld.** | **WA** | **SA** | **Tas.** | **ACT** | **NT** | **Grand**  **Total** |
| Chapter 5 | Chronic inflammatory demyelinating polyneuropathy | 26.99 | 29.20 | 25.07 | 27.19 | 18.04 | 38.82 | 20.37 | 3.07 | 26.42 |
|  | Chronic lymphocytic leukaemia | 11.41 | 8.60 | 13.19 | 2.96 | 9.70 | 13.36 | 15.36 | 2.06 | 10.09 |
|  | Common variable immunodeficiency disease | 24.05 | 12.14 | 16.17 | 7.64 | 17.77 | 10.74 | 43.82 | 3.91 | 17.14 |
|  | Dermatomyositis | 1.68 | 1.36 | 0.38 | 0.60 | 1.91 | 3.94 | 2.24 | 0.00 | 1.28 |
|  | Guillain-Barré syndrome | 4.57 | 5.68 | 4.19 | 2.80 | 4.05 | 3.34 | 3.57 | 0.00 | 4.45 |
|  | Hypogammaglobulinaemia Unclassified | 0.00 | 0.01 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 |
|  | Inclusion body myositis | 1.77 | 0.69 | 0.94 | 0.00 | 1.17 | 4.22 | 0.00 | 0.00 | 1.11 |
|  | ITP associated with HIV | 0.04 | 0.07 | 0.18 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.07 |
|  | ITP in pregnancy | 0.73 | 0.21 | 0.37 | 0.25 | 0.43 | 0.30 | 1.16 | 1.30 | 0.46 |
|  | ITP in specific circumstances (surgery, corticosteroids contraindicated, chronic ITP) | 2.76 | 2.30 | 3.89 | 1.10 | 3.28 | 0.74 | 2.05 | 1.94 | 2.68 |
|  | ITP refractory | 3.16 | 2.33 | 4.45 | 2.40 | 2.25 | 2.61 | 7.20 | 3.06 | 3.12 |
|  | ITP with life-threatening haemorrhage | 1.83 | 0.06 | 0.39 | 0.06 | 2.68 | 0.20 | 0.40 | 0.31 | 0.90 |
|  | Kawasaki disease | 0.70 | 0.57 | 0.40 | 0.28 | 0.52 | 0.39 | 0.60 | 0.00 | 0.53 |
|  | Lambert-Eaton myasthenic syndrome | 0.32 | 0.10 | 0.17 | 0.00 | 0.14 | 0.00 | 0.00 | 0.00 | 0.17 |

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| **Disease**  **Category** | **Primary Diagnosis** | **NSW** | **Vic.** | **Qld.** | **WA** | **SA** | **Tas.** | **ACT** | **NT** | **Grand**  **Total** |
|  | Multifocal motor neuropathy with persistent conduction block | 7.57 | 7.27 | 6.00 | 12.29 | 10.84 | 1.69 | 1.16 | 13.38 | 7.73 |
|  | Multiple myeloma | 6.94 | 5.02 | 16.24 | 0.99 | 1.33 | 26.80 | 12.90 | 0.31 | 7.80 |
|  | Myasthenia gravis | 8.18 | 8.61 | 11.08 | 7.61 | 2.74 | 11.52 | 5.68 | 0.00 | 8.37 |
|  | Neonatal haemochromatosis | 0.00 | 0.42 | 1.02 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.31 |
|  | Non-Hodgkins lymphoma | 5.92 | 4.57 | 14.54 | 1.13 | 4.41 | 10.43 | 14.82 | 0.00 | 6.92 |
|  | Other primary immunodeficiency | 2.11 | 2.10 | 0.43 | 1.30 | 1.07 | 0.66 | 0.03 | 2.28 | 1.54 |
|  | Other relevant haematological malignancies | 4.49 | 2.72 | 3.26 | 1.20 | 0.46 | 3.63 | 1.42 | 0.30 | 3.05 |
|  | Polymyositis | 5.19 | 3.11 | 3.99 | 0.45 | 4.84 | 2.16 | 1.92 | 0.00 | 3.74 |
|  | Severe combined Immunodeficiency | 0.01 | 0.33 | 1.66 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.42 |
|  | Stiff person syndrome | 0.71 | 0.44 | 1.71 | 0.00 | 0.30 | 1.19 | 0.00 | 0.90 | 0.74 |
|  | Wiskott-Aldrich syndrome | 0.03 | 0.01 | 0.08 | 0.17 | 0.09 | 0.32 | 0.00 | 0.00 | 0.06 |
|  | X linked agammaglobulinaemia | 0.70 | 2.83 | 1.14 | 0.90 | 1.20 | 0.00 | 1.09 | 0.00 | 1.36 |
| Chapter 5 Total | | 121.85 | 100.75 | 130.93 | 71.30 | 89.22 | 137.05 | 135.78 | 32.81 | 110.49 |
| Chapter 6 | Acute disseminated encephalomyelitis | 0.59 | 0.04 | 0.17 | 0.05 | 0.07 | 0.29 | 0.00 | 0.00 | 0.25 |
|  | ANCA (PR3 or MPO)-positive idiopathic rapidly progressive glomerulonephritis | 0.03 | 0.05 | 0.09 | 0.05 | 0.00 | 0.00 | 0.00 | 0.00 | 0.04 |
|  | Autoimmune haemolytic anaemia | 0.41 | 0.59 | 1.02 | 0.23 | 0.55 | 0.49 | 0.53 | 0.00 | 0.57 |

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| **Disease**  **Category** | **Primary Diagnosis** | **NSW** | **Vic.** | **Qld.** | **WA** | **SA** | **Tas.** | **ACT** | **NT** | **Grand**  **Total** |
|  | Bullous pemphigoid | 0.44 | 0.16 | 0.13 | 0.00 | 0.15 | 0.00 | 0.00 | 0.00 | 0.22 |
|  | Cicatricial pemphigoid | 0.29 | 0.21 | 0.85 | 0.00 | 0.00 | 0.00 | 2.70 | 0.00 | 0.36 |
|  | Evans syndrome | 0.08 | 0.00 | 0.04 | 0.06 | 0.12 | 0.00 | 0.00 | 0.00 | 0.05 |
|  | Foeto-maternal /neonatal alloimmune thrombocytopenia (Antenatal) | 0.07 | 0.52 | 1.04 | 1.45 | 0.22 | 0.00 | 0.02 | 0.00 | 0.53 |
|  | Foeto-maternal /neonatal alloimmune thrombocytopenia (Neonatal) | 0.04 | 0.01 | 0.00 | 0.01 | 0.52 | 0.00 | 0.00 | 0.03 | 0.05 |
|  | Haemophagocytic syndrome | 0.19 | 0.27 | 0.39 | 0.00 | 0.02 | 0.21 | 0.00 | 0.00 | 0.21 |
|  | HSCT (for prevention of GvHD in high risk Allogeneic  HSCT). | 0.17 | 1.96 | 6.19 | 0.02 | 3.12 | 0.00 | 0.00 | 0.00 | 2.03 |
|  | IgG subclass deficiency EXISTING patients only | 5.24 | 1.84 | 1.13 | 0.71 | 2.49 | 4.56 | 2.69 | 0.00 | 2.78 |
|  | Ig para-proteinaemic neuropathy | 0.61 | 0.34 | 0.44 | 0.97 | 0.54 | 0.00 | 0.00 | 0.00 | 0.51 |
|  | ITP in children | 0.21 | 0.38 | 0.41 | 0.04 | 0.47 | 0.12 | 0.06 | 1.41 | 0.30 |
|  | Kidney transplantation post-transplant | 0.94 | 6.65 | 1.27 | 1.04 | 0.49 | 3.08 | 1.21 | 0.00 | 2.44 |
|  | Kidney transplantation pre-transplant | 0.38 | 0.90 | 0.02 | 0.02 | 0.07 | 0.00 | 0.00 | 0.00 | 0.36 |
|  | Microscopic polyangiitis | 0.00 | 0.00 | 0.03 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.01 |
|  | Multiple sclerosis - severe relapse with no response to high dose methylprednisolone | 0.07 | 0.11 | 0.35 | 0.00 | 0.00 | 1.50 | 0.00 | 0.00 | 0.16 |
|  | Multiple sclerosis in pregnancy | 0.04 | 0.00 | 0.05 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.02 |

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| **Disease**  **Category** | **Primary Diagnosis** | **NSW** | **Vic.** | **Qld.** | **WA** | **SA** | **Tas.** | **ACT** | **NT** | **Grand**  **Total** |
|  | Multiple sclerosis in young patients severe/relapsing/remitting in whom other therapies have failed | 0.01 | 0.00 | 0.16 | 0.00 | 0.00 | 0.72 | 0.00 | 0.00 | 0.05 |
|  | Opsoclonus myoclonus ataxia | 0.08 | 0.10 | 0.01 | 0.20 | 0.13 | 0.00 | 0.00 | 0.00 | 0.08 |
|  | Pemphigus foliaceus | 0.20 | 0.06 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.08 |
|  | Pemphigus vulgaris | 0.56 | 0.26 | 0.63 | 0.29 | 0.99 | 0.00 | 0.00 | 0.00 | 0.48 |
|  | Post transfusion purpura | 0.01 | 0.04 | 0.00 | 0.06 | 0.00 | 0.00 | 0.00 | 0.00 | 0.02 |
|  | Secondary hypogammaglobulinaemia (excludes haematological malignancies) | 2.93 | 2.36 | 6.90 | 1.30 | 1.26 | 13.08 | 1.42 | 1.08 | 3.49 |
|  | Specific antibody deficiency | 1.52 | 0.86 | 1.74 | 3.13 | 1.71 | 0.32 | 4.89 | 0.77 | 1.60 |
|  | Toxic epidermal necrolysis/Steven Johnson syndrome | 0.36 | 0.44 | 0.06 | 0.13 | 0.17 | 1.18 | 0.31 | 0.46 | 0.30 |
|  | TSS - staphylococcal | 0.23 | 0.11 | 0.08 | 0.09 | 0.04 | 0.00 | 1.09 | 0.00 | 0.15 |
|  | TSS - streptococcal | 0.30 | 0.45 | 0.49 | 0.11 | 0.00 | 0.06 | 0.88 | 0.64 | 0.34 |
|  | Wegener’s granulomatosis | 0.04 | 0.04 | 0.00 | 0.00 | 0.19 | 0.00 | 0.00 | 0.00 | 0.04 |
| Chapter 6 Total | | 16.03 | 18.71 | 23.69 | 9.96 | 13.32 | 25.61 | 15.79 | 4.40 | 17.52 |
| Chapter 7 | Acute leukaemia in children | 0.00 | 0.00 | 0.00 | 0.00 | 0.01 | 0.00 | 0.00 | 0.00 | 0.00 |
|  | Autoimmune congenital heart block | 0.00 | 0.00 | 0.04 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.01 |
|  | Autoimmune diabetic neuropathy | 0.11 | 0.04 | 0.00 | 0.00 | 0.00 | 3.00 | 0.00 | 0.00 | 0.11 |

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| **Disease**  **Category** | **Primary Diagnosis** | **NSW** | **Vic.** | **Qld.** | **WA** | **SA** | **Tas.** | **ACT** | **NT** | **Grand**  **Total** |
|  | Autoimmune neutropenia | 0.26 | 0.01 | 0.12 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.11 |
|  | Catastrophic antiphospholipid syndrome | 0.13 | 0.03 | 0.24 | 0.14 | 0.24 | 0.00 | 0.00 | 0.00 | 0.13 |
|  | Coagulation factor inhibitors | 0.12 | 0.02 | 0.35 | 0.00 | 0.29 | 0.00 | 0.00 | 0.94 | 0.15 |
|  | Devic disease (neuromyelitis optica) | 0.31 | 0.01 | 0.13 | 0.03 | 0.00 | 0.65 | 0.00 | 0.00 | 0.15 |
|  | Epidermolysis bullosa acquisita | 0.00 | 0.00 | 0.00 | 0.34 | 0.00 | 0.00 | 0.00 | 0.00 | 0.03 |
|  | Epilepsy (rare childhood cases) | 0.15 | 0.68 | 0.58 | 0.58 | 0.00 | 0.00 | 0.00 | 0.00 | 0.39 |
|  | Graves ophthalmopathy | 0.00 | 0.03 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.01 |
|  | Haemolytic disease of the newborn | 0.42 | 0.23 | 0.92 | 0.02 | 0.04 | 0.01 | 0.06 | 0.00 | 0.38 |
|  | Haemolytic transfusion reaction | 0.00 | 0.00 | 0.00 | 0.04 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 |
|  | Myocarditis in children | 0.01 | 0.03 | 0.07 | 0.09 | 0.00 | 0.00 | 0.00 | 0.00 | 0.04 |
|  | Paraneoplastic syndromes | 0.29 | 0.38 | 0.10 | 0.54 | 0.10 | 0.28 | 1.73 | 0.00 | 0.31 |
|  | Potassium channel antibody-associated encephalopathy | 0.45 | 0.38 | 0.15 | 0.13 | 0.80 | 0.21 | 0.93 | 0.00 | 0.36 |
|  | Pure red cell aplasia | 0.09 | 0.20 | 0.32 | 0.12 | 0.09 | 2.76 | 0.00 | 0.00 | 0.22 |
|  | Pure white cell aplasia | 0.00 | 0.00 | 0.03 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.01 |
|  | Scleromyxedema | 0.23 | 0.15 | 0.00 | 0.31 | 0.00 | 0.00 | 0.00 | 0.00 | 0.14 |
|  | Sepsis - neonatal | 0.01 | 0.02 | 0.01 | 0.00 | 0.00 | 0.01 | 0.00 | 0.01 | 0.01 |

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| **Disease**  **Category** | **Primary Diagnosis** | **NSW** | **Vic.** | **Qld.** | **WA** | **SA** | **Tas.** | **ACT** | **NT** | **Grand**  **Total** |
|  | Sjogren's Syndrome | 0.20 | 0.00 | 0.19 | 0.33 | 0.90 | 0.00 | 2.30 | 0.00 | 0.24 |
|  | Solid organ - heart | 0.05 | 0.01 | 0.02 | 0.00 | 0.03 | 0.00 | 0.00 | 0.00 | 0.03 |
|  | Solid organ - heart/lung | 0.02 | 0.01 | 0.07 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.02 |
|  | Solid organ - liver | 0.00 | 0.01 | 0.01 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.01 |
|  | Solid organ - lung | 0.60 | 0.18 | 0.17 | 0.00 | 0.40 | 0.61 | 0.00 | 0.51 | 0.32 |
|  | Solid organ - other | 0.00 | 0.01 | 0.03 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.01 |
|  | Susac syndrome | 0.32 | 0.00 | 0.29 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.16 |
| Chapter 7 Total | | 3.78 | 2.43 | 3.83 | 2.65 | 2.90 | 7.52 | 5.03 | 1.47 | 3.35 |
| Chapter 8 | Asthma | 0.00 | 0.37 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.09 |
|  | Atopic dermatitis/eczema | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 |
|  | Recurrent foetal loss (with or without antiphospholipid syndrome) | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 |
|  | Systemic lupus erythematosus | 0.00 | 0.00 | 0.00 | 0.20 | 0.00 | 0.00 | 0.00 | 0.00 | 0.02 |
| Chapter 8 Total | | 0.00 | 0.37 | 0.00 | 0.20 | 0.00 | 0.00 | 0.00 | 0.00 | 0.11 |
| DO | DO issue | 0.00 | 0.03 | 0.01 | 0.00 | 0.00 | 0.00 | 0.00 | 0.00 | 0.01 |
| Grand Total | | 141.66 | 122.30 | 158.46 | 84.11 | 105.44 | 170.17 | 156.60 | 38.68 | 131.48 |

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| **APPEN DI X B**  **IVIG AVE R AG E G R AM PER EPI SO D E I SS UED FO R 20 10/ 11 B Y JURI S DI C TI O N AN D PRI M AR Y DI AG NO SI S** | | | | | | | | | | |
| **Disease**  **Category** | **Primary Diagnosis** | **ACT** | **NSW** | **NT** | **Qld.** | **SA** | **Tas.** | **Vic.** | **WA** | **Grand**  **Total** |
| Chapter 5 | Chronic inflammatory demyelinating polyneuropathy | 46.98 | 32.78 | 40.53 | 32.36 | 43.48 | 51.03 | 35.78 | 46.37 | 35.79 |
|  | Chronic lymphocytic leukaemia | 29.83 | 28.39 | 23.90 | 26.55 | 26.46 | 22.99 | 27.11 | 25.77 | 27.22 |
|  | Common variable immunodeficiency disease | 27.79 | 28.68 | 34.97 | 26.89 | 26.41 | 27.78 | 27.54 | 24.63 | 27.67 |
|  | Dermatomyositis | 46.91 | 29.24 |  | 28.85 | 42.72 | 83.15 | 40.75 | 51.07 | 35.73 |
|  | Guillain-Barré syndrome | 33.18 | 31.69 | 81.38 | 29.92 | 41.25 | 39.52 | 32.38 | 59.41 | 33.47 |
|  | Hypogammaglobulinaemia Unclassified |  |  |  |  |  |  | 70.00 |  | 70.00 |
|  | Idiopathic thrombocytopenic purpura - Adult |  |  |  | 25.00 |  |  |  |  | 25.00 |
|  | Inclusion body myositis | 72.00 | 32.75 |  | 35.93 | 39.74 | 38.44 | 33.71 | 60.00 | 34.71 |
|  | ITP associated with HIV | 96.14 | 29.04 |  | 36.94 |  |  | 55.56 | 80.00 | 39.14 |
|  | ITP in pregnancy | 70.00 | 39.79 | 50.14 | 30.37 | 48.47 | 44.40 | 49.24 | 66.36 | 41.68 |
|  | ITP in specific circumstances (surgery, corticosteroids contraindicated, chronic ITP) | 76.60 | 36.20 | 74.53 | 31.52 | 59.74 | 62.89 | 50.88 | 61.26 | 40.26 |
|  | ITP refractory | 69.51 | 37.36 | 79.59 | 31.82 | 59.91 | 51.21 | 51.97 | 61.85 | 41.07 |
|  | ITP with life-threatening haemorrhage | 80.11 | 37.63 | 52.00 | 34.83 | 61.23 | 71.25 | 65.38 | 74.88 | 41.87 |
|  | Kawasaki disease | 37.88 | 32.49 | 21.86 | 33.91 | 32.89 | 26.31 | 31.22 | 29.46 | 32.04 |

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| **Disease**  **Category** | **Primary Diagnosis** | **ACT** | **NSW** | **NT** | **Qld.** | **SA** | **Tas.** | **Vic.** | **WA** | **Grand**  **Total** |
|  | Lambert-Eaton myasthenic syndrome |  | 33.38 | 39.00 | 25.07 | 225.00 |  | 35.36 | 63.00 | 33.59 |
|  | Multifocal motor neuropathy with persistent conduction block | 23.14 | 33.73 | 83.52 | 30.49 | 50.59 | 34.91 | 38.30 | 55.24 | 38.16 |
|  | Multiple myeloma | 33.13 | 28.38 | 38.40 | 25.38 | 24.33 | 28.63 | 27.13 | 26.66 | 26.83 |
|  | Myasthenia gravis | 44.00 | 32.81 |  | 32.32 | 36.80 | 41.10 | 36.99 | 47.89 | 35.19 |
|  | Neonatal haemochromatosis |  | 73.89 |  | 70.84 | 3.00 |  | 57.31 | 68.57 | 67.98 |
|  | Non-Hodgkins lymphoma | 28.50 | 28.34 | 36.00 | 25.29 | 26.18 | 26.21 | 28.97 | 28.71 | 26.94 |
|  | Other primary immunodeficiency | 17.90 | 26.34 | 20.06 | 23.10 | 35.07 | 24.40 | 28.23 | 23.68 | 26.74 |
|  | Other relevant haematological malignancies | 28.72 | 27.77 | 25.80 | 25.14 | 21.72 | 27.08 | 27.60 | 22.17 | 26.73 |
|  | Polymyositis | 38.34 | 31.09 | 40.13 | 33.38 | 47.62 | 55.29 | 43.73 | 42.32 | 35.58 |
|  | Severe combined Immunodeficiency |  | 15.00 |  | 25.39 | 3.00 |  | 20.37 |  | 23.49 |
|  | Stiff person syndrome |  | 41.08 | 21.00 | 60.98 | 46.93 | 35.33 | 40.85 | 66.00 | 47.77 |
|  | Wiskott-Aldrich syndrome |  | 16.29 |  | 23.30 | 14.25 | 33.00 | 7.42 | 26.13 | 21.20 |
|  | X linked agammaglobulinaemia | 13.50 | 22.46 |  | 24.61 | 25.60 | 27.00 | 26.64 | 22.43 | 24.99 |
| Chapter 5 Total | | 32.71 | 30.71 | 47.12 | 28.76 | 35.63 | 35.65 | 32.81 | 40.24 | 31.67 |
| Chapter 6 | Acute disseminated encephalomyelitis | 3.00 | 32.02 |  | 28.47 | 37.23 | 30.94 | 30.42 | 42.24 | 32.32 |
|  | ANCA (PR3 or MPO)-positive idiopathic rapidly progressive glomerulonephritis |  | 36.63 |  | 24.45 |  |  | 25.63 | 38.63 | 29.70 |

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| **Disease**  **Category** | **Primary Diagnosis** | **ACT** | **NSW** | **NT** | **Qld.** | **SA** | **Tas.** | **Vic.** | **WA** | **Grand**  **Total** |
|  | Autoimmune haemolytic anaemia | 75.77 | 34.86 |  | 33.06 | 56.81 | 79.00 | 52.65 | 63.78 | 40.70 |
|  | Bullous pemphigoid |  | 55.63 |  | 27.00 | 255.00 |  | 59.53 | 30.00 | 49.55 |
|  | Churg-Strauss syndrome |  | 21.00 |  |  |  |  |  | 144.00 | 41.50 |
|  | Cicatricial pemphigoid | 65.40 | 65.18 |  | 44.02 |  |  | 116.63 |  | 60.56 |
|  | Evans syndrome | 35.00 | 31.22 |  | 19.88 | 68.50 |  | 51.00 | 55.25 | 31.37 |
|  | Foeto-maternal /neonatal alloimmune thrombocytopenia (Antenatal) | 6.00 | 75.79 |  | 70.24 | 55.68 | 3.39 | 63.95 | 73.20 | 49.64 |
|  | Foeto-maternal /neonatal alloimmune thrombocytopenia (Neonatal) |  | 11.39 | 5.50 | 3.23 | 60.78 | 3.00 | 34.82 | 3.25 | 33.32 |
|  | Haemophagocytic syndrome |  | 37.33 |  | 31.18 | 27.42 | 47.00 | 47.99 | 9.86 | 38.40 |
|  | HSCT (for prevention of GvHD in high risk  Allogeneic HSCT). |  | 26.34 |  | 23.28 | 43.61 |  | 30.17 | 31.50 | 25.65 |
|  | IgG subclass deficiency EXISTING patients only | 22.81 | 26.92 |  | 20.94 | 29.19 | 26.08 | 27.13 | 25.65 | 26.25 |
|  | Ig para-proteinaemic neuropathy |  | 30.84 |  | 30.67 | 25.14 | 120.00 | 35.19 | 52.14 | 34.11 |
|  | ITP in children | 22.60 | 24.16 | 40.09 | 27.23 | 29.93 | 13.50 | 24.08 | 28.39 | 26.27 |
|  | Kidney transplantation post-transplant | 39.14 | 26.88 |  | 15.07 | 25.36 | 42.09 | 32.90 | 66.50 | 30.33 |
|  | Kidney transplantation pre-transplant |  | 40.22 |  | 13.04 | 18.53 |  | 21.94 | 24.90 | 24.74 |
|  | Microscopic polyangiitis |  | 30.00 |  | 23.40 |  |  | 36.67 | 48.90 | 37.72 |

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| **Disease**  **Category** | **Primary Diagnosis** | **ACT** | **NSW** | **NT** | **Qld.** | **SA** | **Tas.** | **Vic.** | **WA** | **Grand**  **Total** |
|  | Multiple sclerosis - severe relapse with no response to high dose methylprednisolone |  | 33.26 |  | 33.13 |  | 40.16 | 22.22 |  | 30.11 |
|  | Multiple sclerosis in pregnancy |  | 29.33 |  | 30.00 |  |  |  |  | 29.57 |
|  | Multiple sclerosis in young patients severe/relapsing/remitting in whom other therapies have failed |  | 17.50 |  | 27.66 | 33.00 | 34.71 | 35.00 |  | 26.19 |
|  | Opsoclonus myoclonus ataxia |  | 29.43 |  | 35.45 | 26.33 | 27.50 | 19.52 | 22.73 | 24.36 |
|  | Pemphigus foliaceus |  | 70.07 |  |  |  |  | 66.00 |  | 69.29 |
|  | Pemphigus vulgaris |  | 52.97 |  | 40.93 | 85.48 |  | 57.84 | 138.00 | 55.85 |
|  | Post transfusion purpura |  | 45.94 |  | 35.00 | 27.60 |  | 64.25 | 75.00 | 46.55 |
|  | Secondary hypogammaglobulinaemia (excludes haematological malignancies) | 32.71 | 25.71 | 34.13 | 23.92 | 22.08 | 35.74 | 26.00 | 19.70 | 24.99 |
|  | Specific antibody deficiency | 20.99 | 23.78 | 8.19 | 20.61 | 25.78 | 26.75 | 26.84 | 23.32 | 23.28 |
|  | Toxic epidermal necrolysis/Steven Johnson syndrome | 22.80 | 43.46 | 54.00 | 36.43 | 85.88 | 70.95 | 63.80 | 93.60 | 55.09 |
|  | TSS - staphylococcal | 66.25 | 65.58 | 88.00 | 47.34 | 80.00 | 70.00 | 52.38 | 81.85 | 60.31 |
|  | TSS - streptococcal | 92.25 | 86.00 | 150.00 | 62.28 | 59.29 | 128.25 | 76.17 | 151.00 | 75.12 |
|  | Wegener’s granulomatosis |  | 31.09 |  | 38.54 | 24.00 | 111.00 | 47.22 | 24.00 | 37.44 |
| Chapter 6 Total | | 28.49 | 29.09 | 21.85 | 24.77 | 32.90 | 28.86 | 32.61 | 30.51 | 28.84 |

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| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Disease**  **Category** | **Primary Diagnosis** | **ACT** | **NSW** | **NT** | **Qld.** | **SA** | **Tas.** | **Vic.** | **WA** | **Grand**  **Total** |
| Chapter 7 | Acute leukaemia in children |  | 12.00 |  | 12.48 | 13.50 | 5.00 | 14.79 | 15.00 | 12.87 |
|  | Autoimmune congenital heart block |  |  |  | 60.00 |  |  | 62.50 |  | 61.07 |
|  | Autoimmune diabetic neuropathy |  | 22.32 |  | 30.00 | 17.40 | 77.24 | 50.49 |  | 44.83 |
|  | Autoimmune neutropenia |  | 58.46 |  | 33.21 |  |  | 37.00 | 34.00 | 43.20 |
|  | Catastrophic antiphospholipid syndrome | 120.00 | 37.48 |  | 32.64 | 66.68 |  | 47.71 | 66.00 | 41.94 |
|  | Coagulation factor inhibitors |  | 40.65 | 73.00 | 36.76 | 47.53 |  | 57.59 | 45.78 | 43.73 |
|  | Devic disease (neuromyelitis optica) |  | 32.02 |  | 22.97 |  | 30.00 | 31.64 | 71.67 | 30.71 |
|  | Epidermolysis bullosa acquisita |  |  |  |  |  |  |  | 64.80 | 64.80 |
|  | Epilepsy (rare childhood cases) |  | 31.34 |  | 27.61 |  | 66.00 | 36.81 | 33.64 | 32.93 |
|  | Graves ophthalmopathy |  | 35.00 |  |  |  |  | 45.00 |  | 36.74 |
|  | Haemolytic disease of the newborn | 2.81 | 17.41 | 3.00 | 76.50 | 3.32 | 3.00 | 14.20 | 3.00 | 22.82 |
|  | Haemolytic transfusion reaction | 3.00 | 30.00 |  |  |  |  | 50.00 | 85.00 | 36.78 |
|  | Myocarditis in children |  | 27.75 |  | 63.46 | 17.50 |  | 15.38 | 52.13 | 32.71 |
|  | PANDAS/tic disorders |  |  |  |  |  |  | 24.00 |  | 24.00 |
|  | Paraneoplastic syndromes | 37.06 | 32.39 |  | 25.07 | 29.27 | 18.00 | 29.97 | 50.41 | 32.95 |
|  | Potassium channel antibody-associated encephalopathy | 30.64 | 29.48 |  | 28.26 | 39.61 | 27.00 | 34.65 | 46.92 | 32.83 |

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| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Disease**  **Category** | **Primary Diagnosis** | **ACT** | **NSW** | **NT** | **Qld.** | **SA** | **Tas.** | **Vic.** | **WA** | **Grand**  **Total** |
|  | Pure red cell aplasia |  | 36.63 |  | 30.50 | 39.33 | 39.74 | 40.18 | 34.70 | 35.44 |
|  | Pure white cell aplasia |  |  |  | 24.96 |  |  |  |  | 24.96 |
|  | Scleromyxedema | 36.00 | 38.92 |  | 35.40 |  |  | 21.35 | 106.13 | 30.24 |
|  | Sepsis - neonatal |  | 3.05 | 3.00 | 4.50 | 3.00 | 3.00 | 3.10 | 3.00 | 3.25 |
|  | Sjogren's Syndrome | 32.54 | 29.69 |  | 25.87 | 121.85 |  | 37.26 | 45.53 | 43.00 |
|  | Solid organ - heart |  | 20.09 |  | 18.00 | 18.00 |  | 38.72 | 150.00 | 25.11 |
|  | Solid organ - heart/lung |  | 37.85 |  | 28.36 | 35.54 |  | 36.00 |  | 32.99 |
|  | Solid organ - liver |  | 21.00 |  | 28.50 |  |  | 21.15 |  | 22.06 |
|  | Solid organ - lung |  | 32.87 | 120.00 | 26.05 | 48.65 | 28.32 | 29.69 | 69.00 | 31.56 |
|  | Solid organ - other |  |  |  | 10.22 |  |  | 25.60 |  | 12.30 |
|  | Solid organ - pancreas |  |  |  |  |  |  | 7.50 |  | 7.50 |
|  | Susac syndrome |  | 32.62 |  | 48.39 |  |  | 41.81 |  | 38.66 |
| Chapter 7 Total | | 28.39 | 29.32 | 49.71 | 32.74 | 45.18 | 46.94 | 29.11 | 42.74 | 32.50 |
| Chapter 8 | Acute optic neuritis |  |  |  |  |  |  |  |  |  |
|  | Amegakaryocytic thrombocytopenia |  |  |  |  |  |  |  |  |  |
|  | Asthma |  |  |  |  |  |  | 38.33 |  | 38.33 |
|  | Atopic dermatitis/eczema |  |  |  | 27.00 |  |  |  |  | 27.00 |

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| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| **Disease**  **Category** | **Primary Diagnosis** | **ACT** | **NSW** | **NT** | **Qld.** | **SA** | **Tas.** | **Vic.** | **WA** | **Grand**  **Total** |
|  | Female infertility |  |  |  |  |  |  | 27.00 |  | 27.00 |
|  | Paraneoplastic cerebellar degeneration (Yo antibodies) |  |  |  |  |  |  |  | 102.50 | 102.50 |
|  | Recurrent foetal loss (with or without antiphospholipid syndrome) |  |  |  |  |  |  |  |  |  |
|  | Sepsis (other than neonatal sepsis) |  |  |  |  |  |  | 56.88 |  | 56.88 |
|  | Systemic lupus erythematosus |  |  |  |  |  |  |  | 39.00 | 39.00 |
| Chapter 8 Total | |  |  |  | 27.00 |  |  | 38.63 | 45.68 | 39.67 |
| Chapter  DO | DO issue |  |  |  | 40.00 |  |  | 33.41 | 25.00 | 32.68 |
| Chapter DO Total | |  |  |  | 40.00 |  |  | 33.41 | 25.00 | 32.68 |
| Grand Total | | 32.12 | 30.48 | 43.74 | 28.14 | 35.43 | 34.79 | 32.71 | 38.54 | 31.27 |

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