NATIONAL BLOOD AUTHORITY
AUSTRALIA

NATIONAL REPORT ON THE ISSUE AND USE OF IMMUNOGLOBULIN (Ig)

ANNUAL REPORT 2018-19

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Introduction

Immunoglobulin (Ig) products, derived from pooled human plasma, are a precious and high-cost resource. Strengthening Ig governance is a priority for the National Blood Authority (NBA), and several measures are being developed and implemented to ensure the sustainability of these products into the future.

Immunoglobulin products analysed in this report include intravenous Ig (IVIg), subcutaneous Ig (SCIg) and normal human Ig (NHIg). Aggregated data for IVIg and SCIg are referred to as Ig unless specifically stated. Normal human Ig is reported separately. Immunoglobulin products are used to treat a broad range of conditions, with applications in replacement and immune modulation therapy. This report provides an analysis of national data on national Ig supply in Australia in 2018-19. It also considers trends in supply over the last 10 years.

In Australia it is estimated that over 99 per cent of all Ig is supplied under national blood arrangements through contracts administered by the NBA. The NBA's role is to coordinate national supply and demand planning for blood and blood products including supply risk management; purchasing blood and blood products on behalf of all Australian governments; developing and implementing national strategies to encourage better governance; promoting appropriate use of blood and blood products; and providing expert advice to support government policy development. Further background is at **Appendix A.**

The national Ig Governance Program was introduced in 2014 to pursue governments' objectives for Ig products funded and supplied under the national blood arrangements, namely to:

- ensure Ig product use and management reflects appropriate clinical practice and represents efficient, effective and ethical expenditure of government funds, in accordance with relevant national safety and quality standards for health care,
- ensure that access to Ig products is consistent with the criteria for access determined by governments, and
- improve the capture of information of the need for, use of, and outcomes of treatment with Ig products to inform future decisions.

The NBA is responsible for administering the National Ig Governance Program which includes the development and maintenance of a national framework to access government-funded Ig. The current framework comprises a National Policy, the Criteria for access, and BloodSTAR (Blood System for Tracking Authorisations and Reviews), a national online system.

The *National Policy: Access to Government-Funded Immunoglobulin Products in Australia* (National Policy) released in November 2016, sets out the process that must be followed and describes the rules and requirements that must be complied with to access government-funded Ig products in Australia. The National Policy supports all those involved in the prescription, use and management of Ig to understand their roles and responsibilities under the governance arrangements.

The *Criteria for the Clinical Use of Immunoglobulin in Australia* (the Criteria) was developed in collaboration with expert specialist clinicians. It identifies the medical conditions and circumstances for which the use of Ig is clinically appropriate, and where there are no safe, effective and cost-effective alternative treatments. First published in 2007 (Version 1), with the second edition (Version 2) in 2012 and the third edition implemented in October 2018 (Version 3), the Criteria identifies the conditions and circumstances for which the use of Ig is funded under national blood arrangements. In the third edition, eligibility criteria were updated to align with new evidence and best clinical practice, along with other improvements to aid prescribers. Version 3 also reflects earlier updated access arrangements for SCIg and NHIg.

Although Version 3 of the Criteria was introduced in October 2018, not all patients transitioned at this time, with some patients continuing under existing authorisations until their scheduled review. This meant that in 208-19, while most patients accessed treatment under Version 3 of the Criteria, some patients were still authorised to receive treatment under Version 2 until the end of the existing authorisation period. All patients will be transitioned to the new Criteria by October 2019. Therefore, for this 2018-19 report, conditions are a combination of Version 3 and Version 2 Criteria.

Version 3 of the Criteria clearly articulates and standardises the qualifying and continuing Ig access requirements. In 2019-20, 148 specific conditions or 59 medical conditions were classified into 3 categories:

- conditions for which Ig has an established therapeutic role (previously Chapter 5)
- conditions for which Ig has an emerging therapeutic role (previously Chapter 6)
- conditions for which Ig has an application in exceptional circumstances only (previously Chapter 7)
- conditions for which Ig should not be supplied under the national blood arrangements (previously Chapter 8).

Introduced in 2016, BloodSTAR was developed by the NBA on behalf of all Australian Governments to serve the needs of health providers and support users to meet their obligations under the National Policy. Through BloodSTAR, persons in prescriber roles can request patient authorisation for access to government-funded Ig. Under the governance arrangements, persons om dispenser roles may only dispense product to patients with an active authorisation in BloodSTAR. Nurses and Midwives can request product from Dispensers through BloodSTAR. BloodSTAR streamlines the authorisation process, reduces variability, standardises prescribing practices, and increases efficiency and transparency while strengthening decision-making and improving data capture. BloodSTAR implementation commenced across Australia in July 2016 and was completed in October 2018.

In addition to the clinical and diagnostic criteria for access to intravenous products, access to SCIg products is provided through an assurance framework for the appropriate use of the product. Subcutaneous Ig access rules are detailed on the NBA website at https://www.blood.gov.au/SCIg. Participation in the National SCIg program requires hospitals to establish their capability and capacity to manage a hospital based SCIg program, where the hospital provides access to all resources and takes full accountability for the management and use of the product within defined governing requirements.

Normal human Ig may only be supplied for two purposes: (i) for the treatment of susceptible contacts of measles, hepatitis A, poliomyelitis and rubella, as directed by public health officials; or (II) for the treatment of immunodeficiency conditions for which the product is indicated for patients for whom IVIg and SCIg are both contraindicated. Normal human Ig access rules are detailed on the NBA website at https://www.blood.gov.au/NHIg.

Immunoglobulin products should be prescribed and dispensed in accordance with any the relevant state or territory legislative requirements. In-hospital management of Ig products must also be in accordance with the National Safety and Quality Health Service (NSQHS) Standards, in particular Standards 1, 2 and 7, and the Australian and New Zealand Society of Blood Transfusion (ANZSBT) *Guidelines for the Administration of Blood Products and Guidelines for Transfusion and Immunohaematology Laboratory Practice*.

Demand for Ig is met through domestic and imported Ig products. Domestic Ig is manufactured by CSL Behring (Australia) Pty Ltd (CSL Behring) using plasma collected from voluntary, non-remunerated Australian donations. Both domestic and imported Ig are distributed by the Australian Red Cross Lifeblood (Lifeblood).

Australia is in a unique position to provide analysis and commentary on the use of Ig due to its national supply arrangements. This report begins with an analysis of Ig supply over the last 10 years, then considers patient demographics, expenditure on Ig, clinical indications for which Ig was supplied and finally analyses the dose prescribed for various conditions. The top 10 medical conditions account for 88 per cent of all Ig supplied in 2018-19, and for this reason specific analysis focuses on these groups.

Issues of immunoglobulin

Immunoglobulin comprises approximately 50 per cent of total blood expenditure each year. Demand for Ig was growing at a consistent annual rate of more than 10 per cent up to and including 2017-18. This rate of growth decreased to 7.2 per cent in 2018-19, which is the lowest annual rate of increase since 2004-05 when Australia first secured supply sufficiency through national importation of Ig by the NBA.

The National Fractionation Agreement for Australia (NaFAA) with CSL Behring commenced on 1 January 2018, for the continued manufacture and supply of fractionated blood plasma products. The NaFAA will continue until 31 December 2026, subject to a review in 2022.

Table 1: Ig growth for the last 5 years

2014-15	2015-16	2016-17	2017-18	2018-19
10.2%	12.4%	11.2%	10.6%	7.2%

Many of the plasma derived products used in Australia are manufactured under the NaFAA by CSL Behring from plasma collected by the Blood Service. CSL Behring is the sole manufacturer of plasma derived blood products in Australia and the NBA is responsible for negotiating and managing the NaFAA.

In 2018-19, 736.4 tonnes of Australian plasma were pooled for fractionation under the agreements, and expenditure totalled $263.0 million.

Immunoglobulin is imported to meet the shortfall in domestic Ig production against clinical demand in Australia. In addition to supply under the national blood arrangements, the NBA also supports the purchase of small amounts of obtained imported Ig when necessary, through direct orders by individual states and territories.

Two contracts were in place for the supply of imported Ig under the national blood arrangements. The contracts commenced in September 2015 and the base term expired on 31 December 2018. The NBA exercised the available extension options, and the contracts will expire on 31 December 2020. The suppliers are CSL Behring and Grifols Australia Pty Ltd.

Report Snapshot

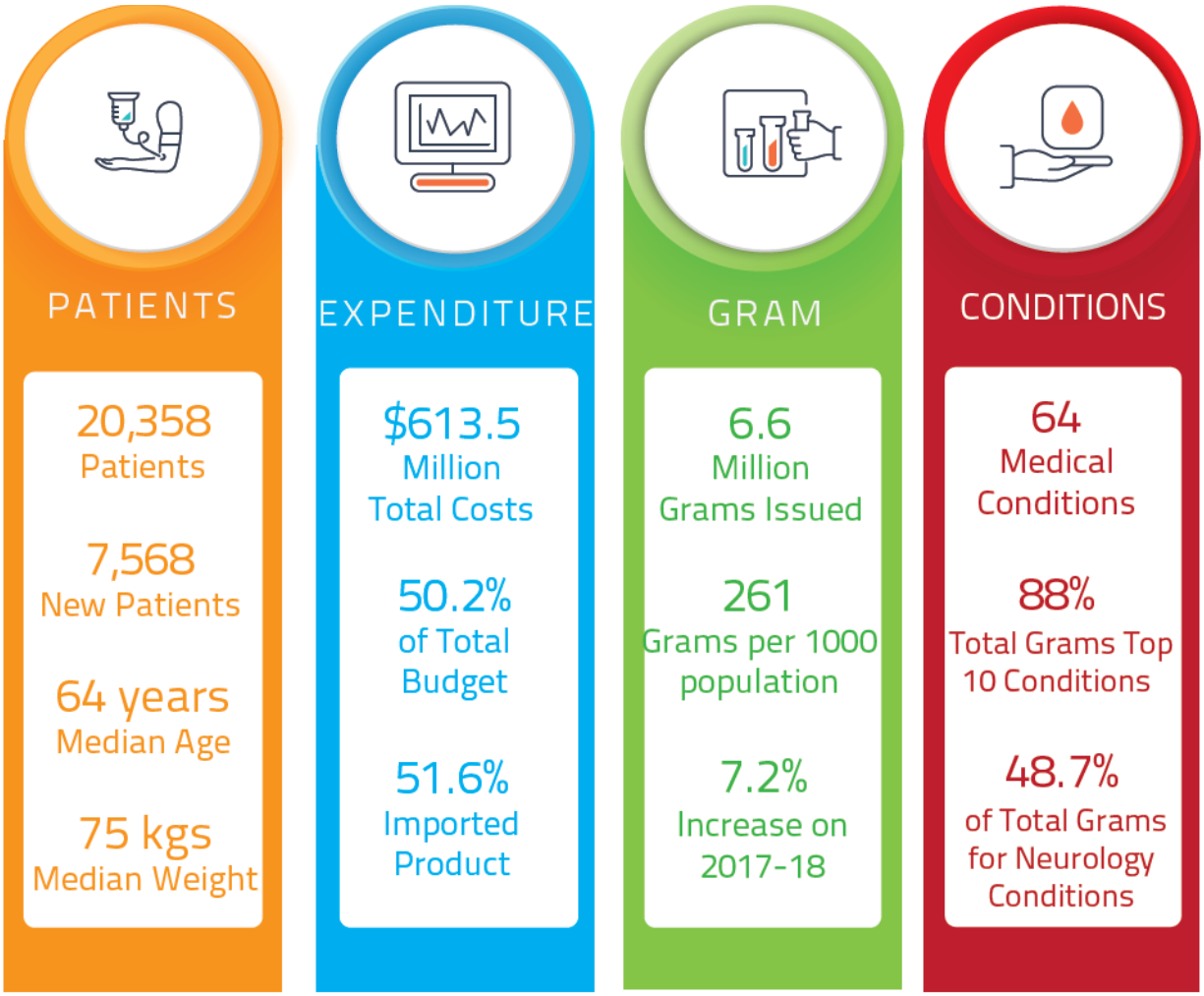

Figure 1: Snapshot

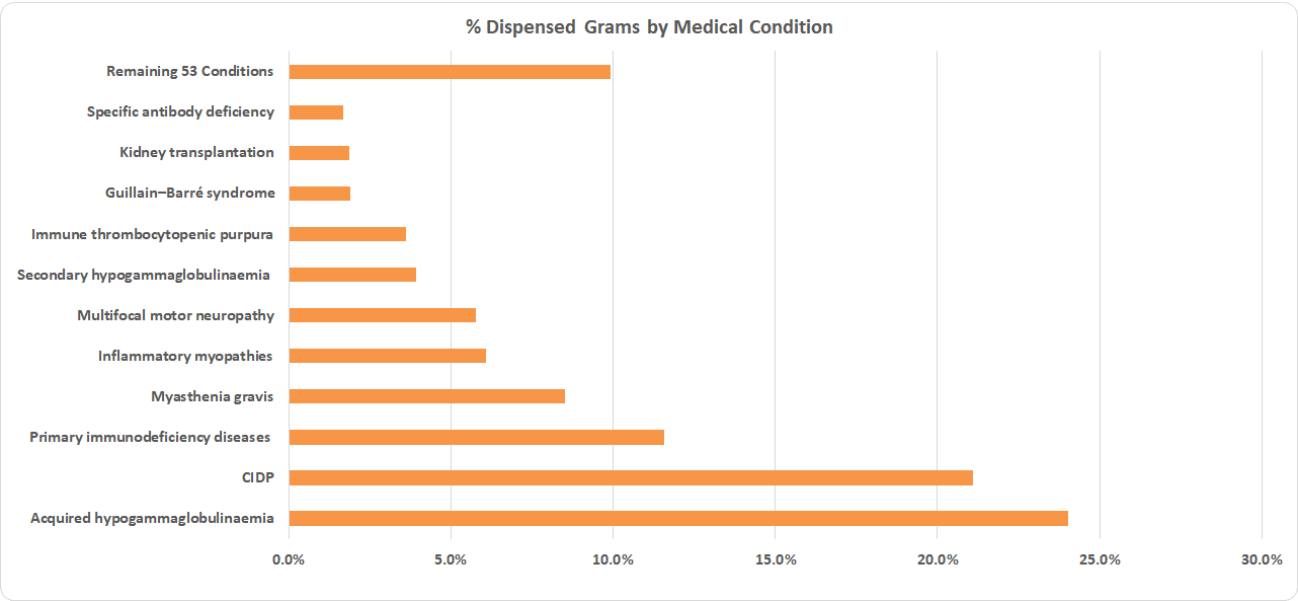

Figure 2: Per cent dispensed grams by medical condition

Methodology

Prior to 2016-17 authorisation and dispense data were collected by Lifeblood. In 2016, states and territories commenced transition to using BloodSTAR as per Table 2. Lifeblood entered information on current patients and authorisations into BloodSTAR using information from the Supply Tracking Analysis Recording System (STARS). These data are known as l*egacy* data. When comparing data across time there are limitations to some data that may not be directly comparable due to changes in Criteria versions, or whether the data has come from BloodSTAR or STARS. More information about these differences can be found in the data quality section below.

Table 2: Go live dates for BloodSTAR

State and Territory	Go Live Date
Northern Territory	14 July 2016
South Australia	1 August 2016
Queensland	22 August 2016
Tasmania	14 September 2016
Victoria	26 September 2016
Australian Capital Territory	24 October 2016
Western Australia	5 December 2016
New South Wales	22 October 2018

The report includes some language that may be unique to the Australian environment. A list of acronyms and definitions used in this report is at **Appendix B**.

The Criteria groups together several specific conditions into one medical condition. For example, Primary Immunodeficiency Diseases (PID) is a medical condition in the Criteria, with this group incorporating the numerous separate specific conditions. In some cases, the analysis will focus on the medical condition, while in other areas it will focus on the specific condition.

Each specific condition has been classified according to its allocated clinical speciality. For some specific conditions this classification could fit into more than one clinical speciality. For example, there are immunological conditions affecting the blood that could potentially be mapped to either immunology or haematology. Where there appears to be significant overlap between clinical specialities, the specific condition is mapped as agreed by the National Immunoglobulin Governance Advisory Committee (NIGAC). In most cases, the specific condition is mapped to the speciality most likely to be responsible for patients with that specific condition, noting that this can vary. **Appendix C** provides the mapping of specific condition to clinical speciality.

The summary of key items from the data file is provided for each specific condition at the state and territory level. The summary includes patient numbers, average age, average weight, grams of Ig used for the specific condition, grams per treatment episode and grams per 1,000 population (**Appendix D**). The source used for each figure and table is provided at **Appendix E**.

Note that the grams per 1,000 population measure shown in earlier reports has been a poor indicator for benchmarking. Raw population figures do not consider the underlying population age structure, hospital usage patterns, and cross-border referrals; nor do total issues take account of varying product wastage rates across time, and states and territories. A study done in South Australia (SA) in 2010 (Australian Health Review article - "Red alert - a new perspective on patterns of blood use in the South Australian public sector") shows this and can be found at https://www.publish.csiro.au/AH/AH10957.

DATA QUALITY

There are some factors relating to data quality, which need to be considered when reading this report. These factors are:

- The reconciliation of data held in STARS, BloodSTAR/BloodNet and Integrated Data Management System (IDMS) indicates minor variances at a national level. In some cases, these differences can be explained by product being ordered and recorded in IDMS the month prior to product being dispensed to a patient.
- Patient and authorisation data for some records are incomplete. For example, data from STARS and BloodSTAR may not always include patient weight. Legacy data entered in BloodSTAR did not include patient weight.
- The Australian Bureau of Statistics (ABS) Australian Demographic Statistics (cat. No 3101.0) was used from 2011-12.
- Care should be taken when interpreting the data relating to the smaller states and territories as one or 2 patients can overly influence the use as compared to larger states.
- There has been no adjustment for Ig dispensed in one state or territory for patients residing in a different state or territory.
- States and territories are based on the state or territory of the facility which dispensed the product.
- The STARS data have age and weight data recorded at treatment dates (first reported in 2009-10). This data changes over time. Weight data is complete in 2018-19 based on the transition to BloodSTAR.
- Age data are based on the patient's age on 1 January each year for both STARS and BloodSTAR.
- Episodes in STARS were known as Treatment Episodes. In BloodSTAR these are known as Dispense Events. In this document we have used Treatment Episodes for consistency.
- Patient Counts are distinct counts and will not sum for National or Total rows and columns, as patients may have:
  - more than one specific condition,
  - product dispensed in more than one state or territory,
  - treatment episodes recorded both at a private facility and at a public facility,
  - received IVIg and SCIg, or
  - received both domestic and imported product.
- In some cases, grams issued or dispensed may not total as the aggregate may be round to the nearest integer.
- Earlier versions of the Criteria classified medical conditions into 4 Chapters based on the level of evidence supporting the use of Ig. In BloodSTAR, these are known as Categories.
- Previous annual reporting for Ig, named conditions as Primary Diagnosis or grouped conditions as Disease Category. In BloodSTAR, these are known as Specific Conditions or Medical Conditions respectively. Conditions were also grouped to Disciplines previously and these are now known as Specialities in BloodSTAR.
- For 2018-19 Specific and Medical Conditions are based on the *Criteria* version 2, as per the mapping at **Appendix C**.

- Dispensed data can be entered into BloodSTAR at any time, if there is a valid and active authorisation. This means that a treatment episode may be recorded in one month and the actual treatment episode was in another month which means data for 2017-18 could be recorded in 2018-19.

- In order to maintain the anonymity of individual patients and health providers, data showing less than 5 may be suppressed or aggregated if there is a potential to re-identify or exceptions are agreed between national and state/territory data custodians.

This report uses data from three primary sources, as follows:

1. Data collected by the NBA on the units of Ig issued to Australian Health Providers (AHPs). These data are held in the NBAs IDMS,
2. Data previously collected by Lifeblood under contractual arrangements with the NBA on behalf of all Australian governments. These data were collected either when an order was placed for Ig or was collected following the treatment where product was issued as imprest stock. The data were collected in Lifeblood's STARS database, and
3. Data collected by the NBA on the units dispensed by AHPs to be administered to the patient. The data are collected into the NBAs BloodNet and BloodSTAR systems.

Table 3 shows the reconciliation between the 3 systems used for this report. A variance of 1.9 per cent represents about one week of issues. This difference relates to timing of data entry or product held as imprest stock.

Table 3: Grams recorded in the different systems held by the NBA

	Total Issued Grams	BloodSTAR Dispensed Grams	STARS Dispensed Grams	Total Dispensed Grams	Difference Grams	Difference %
NSW	**2,374,587**	1,588,429	736,603	**2,325,032**	49,555	2.1%
VIC	**1,460,269**	1,420,048	125	**1,420,173**	40,096	2.7%
QLD	**1,679,227**	1,664,540	1,802	**1,666,341**	12,886	0.8%
SA	**333,821**	324,321	92	**324,413**	9,408	2.8%
WA	**421,196**	411,365	80	**411,445**	9,751	2.3%
TAS	**137,670**	136,059	-	**136,059**	1,611	1.2%
NT	**31,378**	30,026	92.5	**30,118**	1,260	4.0%
ACT	**134,327**	132,420	100	**132,520**	1,807	1.3%
Sub Total	**6,572,475**	**5,707,208**	**738,894**	**6,446,102**	**126,373**	**1.9%**
OTHER	**95**					
Total	**6,572,570**					

Note 1: Includes NHIg
Note 2: Other includes Norfolk Island

Trends

DEMAND TRENDS

In 2018-19 a total of 6,572,570 grams of Ig was issued, representing an increase of 443,758 grams (7.2 per cent) from 2017-18. Prior to 2017-18 the increase in Ig use averaged about 11 per cent, with the greatest proportion of that increase comprising imported products (**Figure 3**).

While a proportion of this increase may be attributable to population increases, there has also been a steady increase in the use of Ig per 1,000 population since the introduction of the Criteria in 2008.

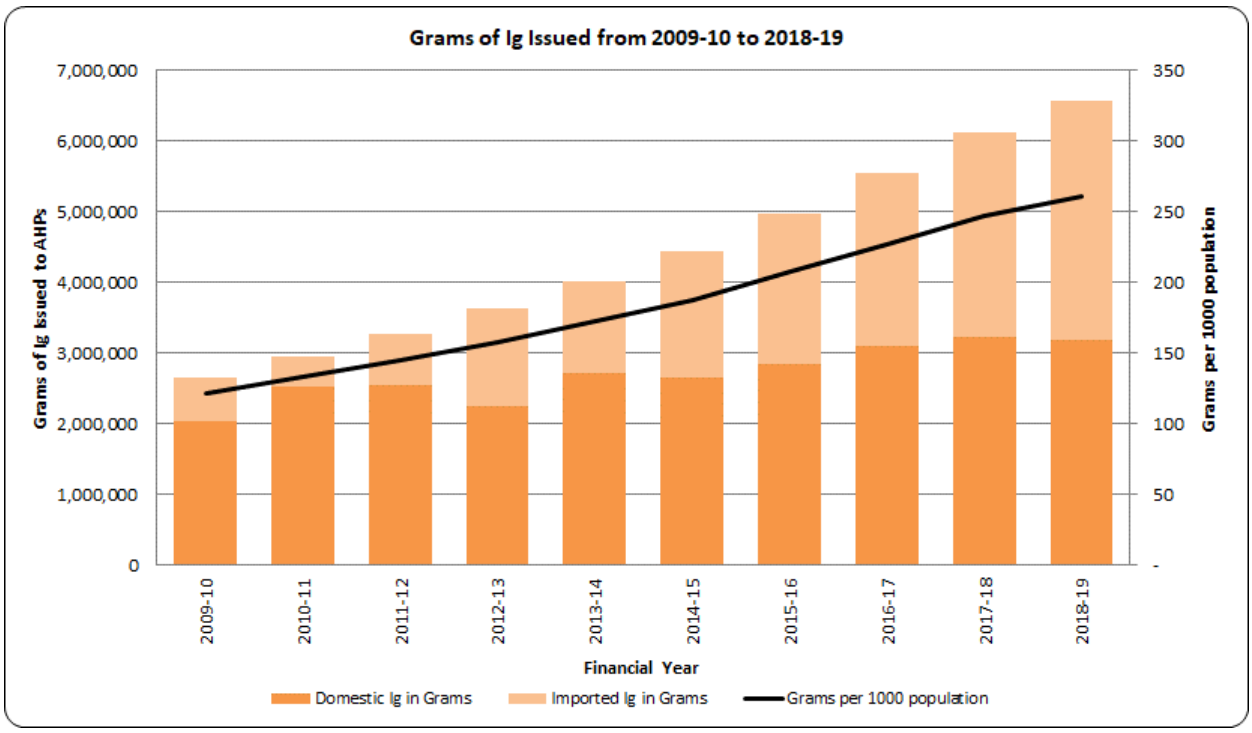

Figure 3: Ten-year trend in issues of Ig

A breakdown of the change per year in grams issued by state and territory has been provided in **Table 4**.

Over the past 10 years the Australian Capital Territory (ACT) has been growing at an average of 14 per cent, followed by the Northern Territory (NT) at 13 per cent.

Table 4: Percentage change in grams issued compared to previous year over time by state and territory

	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
2009-10	13%	11%	15%	12%	-4%	7%	-18%	20%	**12%**
2010-11	11%	10%	16%	-4%	10%	8%	7%	28%	**11%**
2011-12	11%	7%	16%	9%	6%	1%	47%	17%	**11%**
2012-13	11%	13%	11%	9%	7%	-6%	21%	12%	**11%**
2013-14	10%	11%	12%	15%	6%	14%	1%	12%	**11%**
2014-15	9%	11%	12%	7%	12%	8%	8%	8%	**10%**
2015-16	14%	10%	14%	11%	17%	2%	36%	3%	**12%**
2016-17	14%	11%	8%	10%	18%	4%	6%	7%	**11%**
2017-18	11%	12%	10%	5%	9%	21%	23%	13%	**11%**
2018-19	9%	8%	4%	7%	5%	8%	0%	19%	**7%**
Average last 10 years	**11%**	**10%**	**12%**	**8%**	**9%**	**7%**	**13%**	**14%**	11%

FINANCIAL TRENDS

Total expenditure on Ig (excluding plasma for fractionation) in 2018-19 was $341.5 million, an increase of $14.0 million (4.6 per cent) over 2017-18 (**Figure 4**). The increased expenditure predominately represents increases in demand.

There also continues to be an increase in the price of plasma for fractionation due to the increased ratio of apheresis to whole blood plasma for fractionation being supplied, resulting in an increase in the cost of domestic Ig.

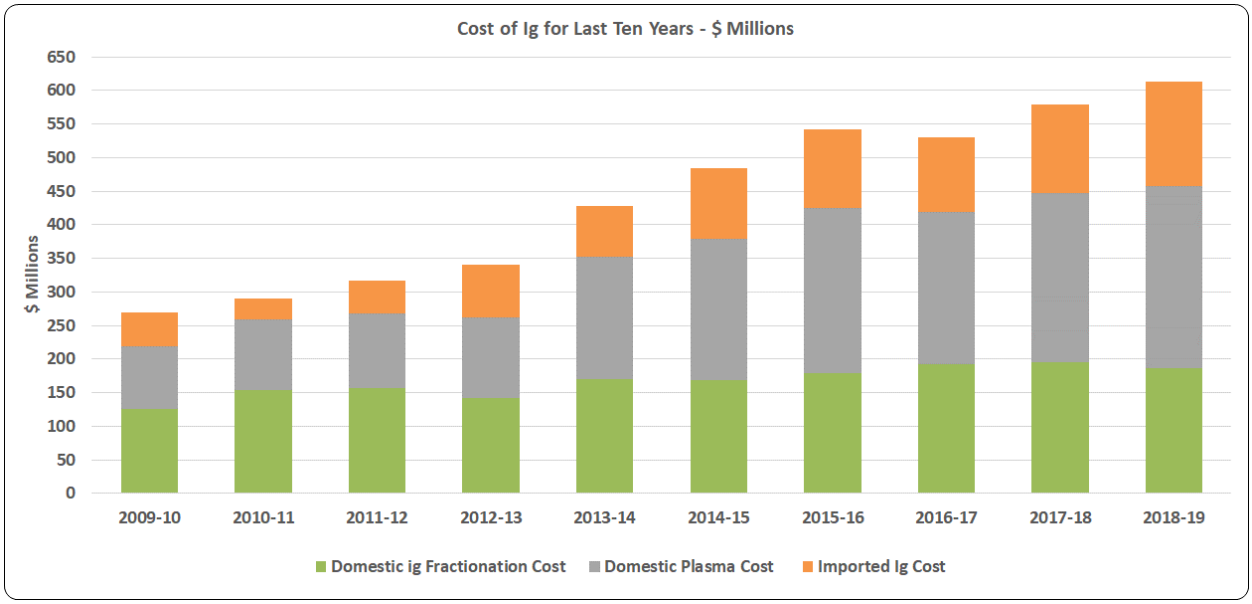

Figure 4: Ten-year trend in expenditure on Ig

In Australia, the total cost of domestic Ig supply comprises the cost of the plasma collected by Lifeblood, plus the cost of purchase of the finished Ig product from the supplier (CSL Behring). Imported Ig product is purchased at a total product cost only.

The cost of Ig as a proportion of the national blood budget is shown at **Figure 5**. Immunoglobulin is the second largest budget item, representing 28 per cent of the total budget for blood and blood products. Combined with expenditure for plasma for fractionation, Ig accounts for 50 per cent of the total blood budget, at a total expenditure of $613.5 million (excluding specific hyperimmune plasma for fractionation).

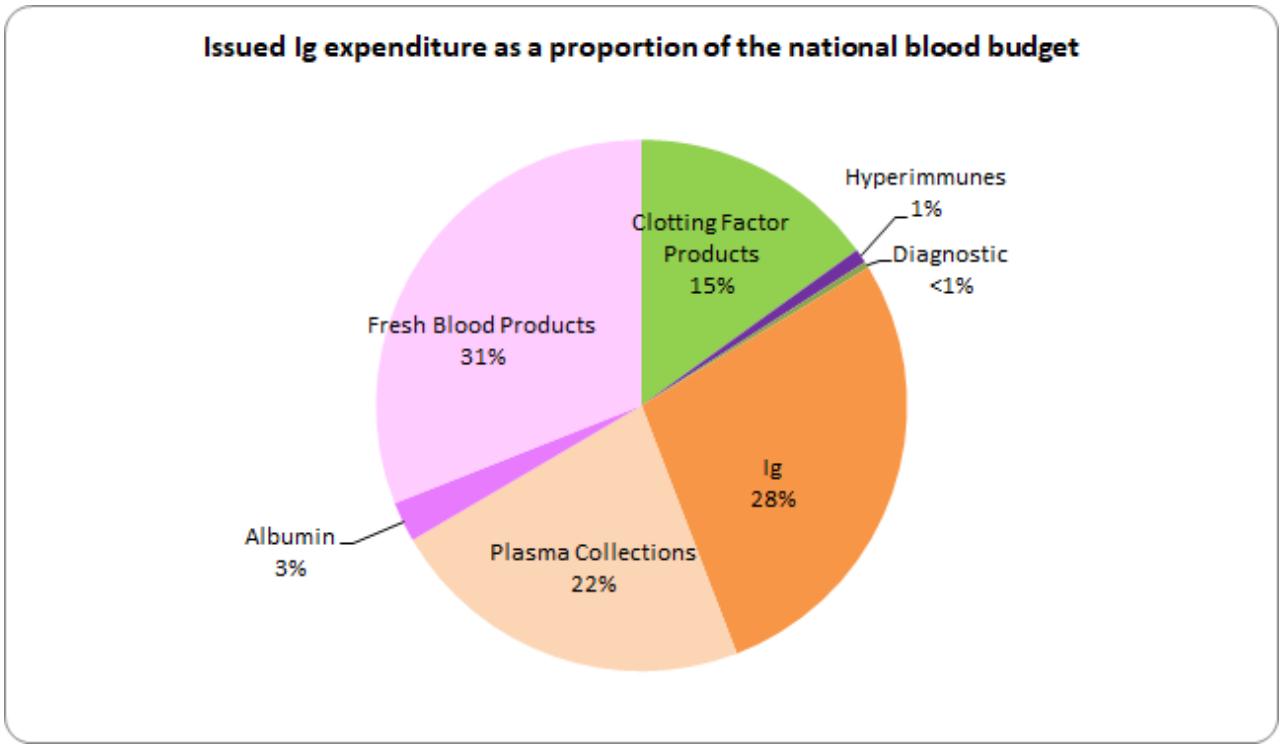

Figure 5: Ig expenditure as a proportion of the national blood budget

Of the Ig supplied under national blood arrangements in Australia in 2018-19, 48 per cent was manufactured domestically and 52 per cent was imported from overseas (see **Table 5**: Issues of domestic Ig compared with imported Ig

This represents a 15.41 per cent increase in product importation from 2017-18. Domestic supply is driven by the amount of plasma for fractionation collected in Australia and this increased by 9 per cent in 2018-19 over 2017-18. Intragam 10 (IVIg) and Evogam (SCIg) were Ig products manufactured domestically in 2018-19.

The imported products available were Privigen (IVIg), Flebogamma (IVIg) and Hizentra (SCIg). When a patient is allocated to receive one of the imported products, the clinician may choose a product different to that allocated by BloodSTAR if there is a valid clinical reason. Supply of Privigen constituted 66.2 per cent of the supply of imported Ig.

Table 6 shows the split between Ig issues for domestic and imported products, by public and private AHPs for 2018-19.

Table 5: Issues of domestic Ig compared with imported Ig

			NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Domestic Ig	Intragam P	g	447	360	-	-	-	-	-	-	807
		$(m)	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0	$0.0
	Intragam 10	g	1,126,733	667,513	828,273	154,815	209,985	61,090	8,588	55,333	3,112,328
		$(m)	$65.9	$39.0	$48.4	$9.0	$12.3	$3.6	$0.5	$3.2	$181.9
	Evogam	g	22,138	11,962	18,651	9,006	4,559	767	909	1,426	69,419
		$(m)	$1.3	$0.7	$1.1	$0.5	$0.3	$0.0	$0.1	$0.1	$4.1
	Total Domestic	g	**1,149,318**	**679,834**	**846,924**	**163,821**	**214,544**	**61,857**	**9,496**	**56,759**	**3,182,554**
		$(m)	**$67.2**	**$39.7**	**$49.5**	**$9.6**	**$12.5**	**$3.6**	**$0.6**	**$3.3**	**$186.0**
Imported Ig	Flebogamma	g	335,278	205,756	250,212	45,971	59,253	23,915	1,893	6,609	928,886
		$(m)	$15.1	$9.3	$11.3	$2.1	$2.7	$1.1	$0.1	$0.3	$41.8
	Privigen	g	806,350	520,460	543,030	103,855	139,375	46,555	19,475	63,605	2,242,705
		$(m)	$36.3	$23.4	$24.4	$4.7	$6.3	$2.1	$0.9	$2.9	$100.9
	Hizentra	g	83,641	54,219	39,062	20,174	8,024	5,343	514	7,354	218,331
		$(m)	$4.9	$3.2	$2.3	$1.2	$0.5	$0.3	$0.0	$0.4	$12.7
	Total Imported	g	**1,225,269**	**780,435**	**832,304**	**170,000**	**206,652**	**75,813**	**21,882**	**77,568**	**3,389,922**
		$(m)	**$56.3**	**$35.8**	**$38.0**	**$7.9**	**$9.4**	**$3.5**	**$1.0**	**$3.6**	**$155.5**
Proportion of domestic to imported Ig		g %	48%	47%	50%	49%	51%	45%	30%	42%	**48%**
		$(m) %	54%	53%	57%	55%	57%	51%	36%	48%	**54%**

Note: $(m) excludes the costs for plasma for fractionation.
Note: Excludes Norfolk Island

Table 6: Issues of domestic Ig compared with imported Ig and public versus private Australian Health Providers

			NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Domestic Ig	Public	g	815,590	407,410	305,263	133,959	142,557	47,020	9,496	56,759	**1,918,148**
	Private	g	333,728	272,425	541,661	29,863	71,987	14,838	-	-	**1,264,501**
	Total Domestic	g	**1,149,318**	**679,834**	**846,924**	**163,821**	**214,544**	**61,857**	**9,496**	**56,759**	**3,182,649**
Imported Ig	Public	g	1,000,437	519,201	395,906	146,950	158,610	60,326	21,882	77,568	**2,380,878**
	Private	g	224,833	261,235	436,398	23,050	48,043	15,487	-	-	**1,009,044**
	Total Imported	g	**1,225,269**	**780,435**	**832,304**	**170,000**	**206,652**	**75,813**	**21,882**	**77,568**	**3,389,922**
Total Ig	Public	g	1,816,026	926,610	701,169	280,908	301,167	107,346	31,378	134,327	**4,299,025**
	Private	g	558,561	533,659	978,058	52,913	120,030	30,325	-	-	**2,273,545**
	Total Ig	g	**2,374,587**	**1,460,269**	**1,679,227**	**333,821**	**421,196**	**137,670**	**31,378**	**134,327**	**6,572,570**
Ig as portion of National	Public	g%	42%	22%	16%	7%	7%	2%	1%	3%	**100.0%**
	Private	g%	25%	23%	43%	2%	5%	1%	0%	0%	**100.0%**
	Total Ig	g%	**36%**	**22%**	**26%**	**5%**	**6%**	**2%**	**0%**	**2%**	**100.0%**
	Population %		32%	26%	20%	7%	10%	2%	1%	2%	**100.0%**
Grams Per 1,000 Population	Public		225.9	141.9	138.8	161.1	115.6	201.8	127.7	317.4	**170.8**
	Private		69.5	81.7	193.6	30.3	46.1	57.0	-	-	**90.3**
	Total Ig		**295.4**	**223.7**	**332.5**	**191.5**	**161.6**	**258.9**	**127.7**	**317.4**	**261.1**

Note: Excludes Norfolk Island

Patient demographics

PATIENT NUMBERS

Immunoglobulin was dispensed to 20,358 patients under the national blood arrangements during 2018-19, including 7,568 new patients. This represents a 4.9 per cent increase in the number of patients since 2017-18. A summary of new and total patient numbers is provided in **Figure 6**.

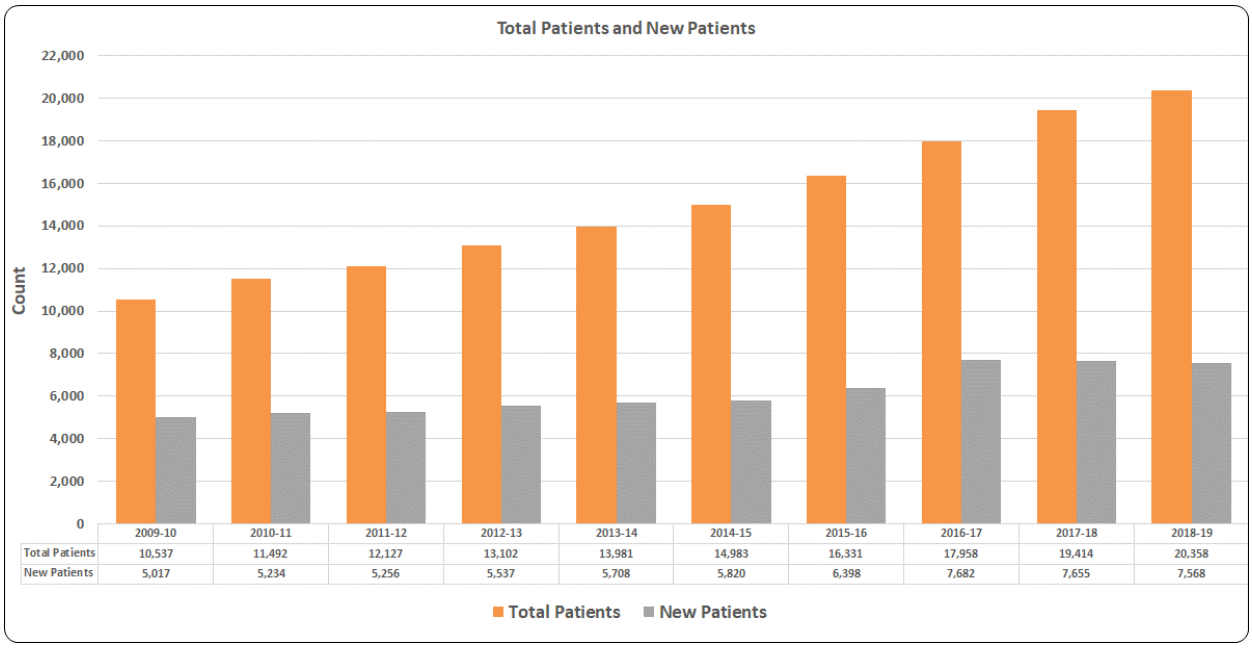

Figure 6: New and total patients since 2009-10

The number of patients per 1,000 population dispensed Ig varies between state and territory. Complete data for specific conditions by state and territory can be found at **Appendix D**.

Table 7 shows a breakdown of the proportion of patients in each state and territory with a comparison to the proportion of the population in each state and territory.

Table 7: Patient numbers by state and territory

2017-18	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Patient Counts	7,230	4,447	4,833	1,114	1,126	392	112	363	19,414
New Patients	2,634	2,040	1,606	516	507	167	64	150	7,655
Population	**7,919,815**	**6,387,081**	**4,963,072**	**1,728,494**	**2,582,563**	**524,969**	**246,858**	**415,874**	**24,773,350**
Proportion of Population	32.0%	25.8%	20.0%	7.0%	10.4%	2.1%	1.0%	1.7%	**100%**
Patients per 1,000 Population	0.91	0.70	0.97	0.64	0.44	0.75	0.45	0.87	0.78
2018-19									
Patient Counts	7,648	4,678	4,953	1,188	1,193	410	115	394	20,358
New Patients	2,905	1,926	1,477	511	471	143	51	145	7,568
Population	**8,038,047**	**6,528,913**	**5,050,660**	**1,743,445**	**2,605,843**	**531,850**	**245,703**	**423,229**	**25,172,336**
Proportion of Population	31.9%	25.9%	20.1%	6.9%	10.4%	2.1%	1.0%	1.7%	**100%**
Patients per 1,000 Population	0.95	0.72	0.98	0.68	0.46	0.77	0.47	0.93	0.81
% Change in Patients	**5.8%**	**5.2%**	**2.5%**	**6.6%**	**6.0%**	**4.6%**	**2.7%**	**8.5%**	**4.9%**
% Change in New Patients	**10.3%**	**-5.6%**	**-8.0%**	**-1.0%**	**-7.1%**	**-14.4%**	**-20.3%**	**-3.3%**	**-1.1%**

AGE AND WEIGHT

The distribution of estimated age is shown in **Figure 7** where it is compared with the age distribution of the Australian population at June 2019[1]. A bimodal peak can be seen in the patient population treated with Ig, with most Ig recipients aged over 55. The ageing population is expected to place a greater burden on Ig demand into the future, with the proportion of the world's population over 60 years expected to more than double between 2015 and 2050[2].

Immunoglobulin dosing is dependent on the weight of the patient. For many conditions, the patient weight determines the initial dosing, with maintenance therapy titrated against IgG levels and the patient's clinical response to therapy.

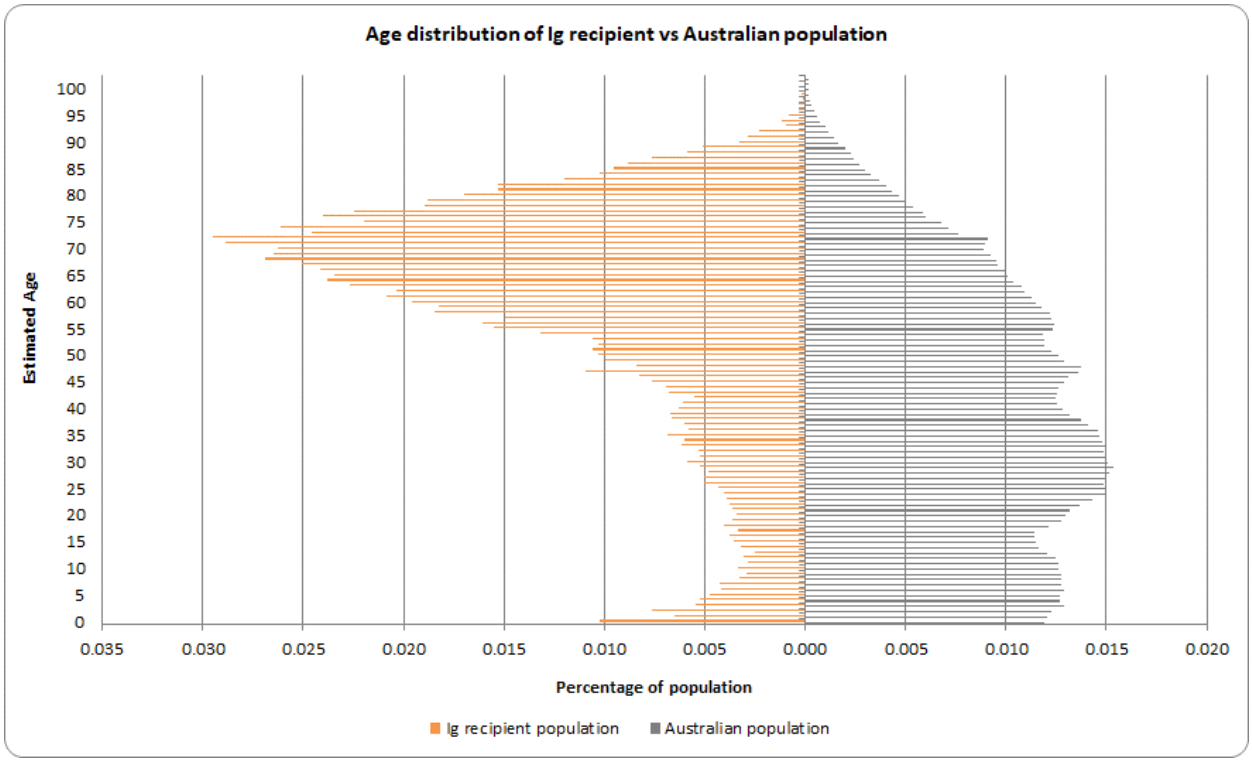

Figure 7: Patient age relative to Australian average

Note: The above figure calculations relate only 2018-19 patients.

Figure 7 compares the age of Ig recipients in Australia in 2018-19 and the Australian population using stats from the ABS 3101.59 published June 2019[3].

The amount of Ig prescribed for a patient may vary depending on the indication as well as a patient's weight and is set out in the Criteria. When prescribing Ig, persons in the prescriber role should aim to use the lowest dose possible that achieves the appropriate clinical outcome for each patient. The dose may be adjusted for Ideal Body Weight (IBW) for some patients. A calculator is available in BloodSTAR to facilitate this where appropriate.

With an increasingly obese population, we may expect increases in demand if total (rather than ideal) body weight dosing is continued. Reviews of the literature relating to lean body mass dosing should be considered for future research.

[1] ABS 3101.59
[2] World Health Organization, Ageing and health (who.int)
[3] ABS 4841.0

Care should be taken when analysing weights, since not all patients have their weight recorded, and for those that do, the weight recorded may not be recent.

Table 8 shows the number of distinct patients and the average weight by age ranges for patients with dispenses in 2018-19.

Table 8: Patient numbers and average weight by age range

Age Range	Patient Counts	Average Weight (kg)	Treatment Episodes	Grams Dispensed
0-4	714	12	2,433	22,482
5-9	393	25	2,844	37,426
10-14	304	44	2,997	61,805
15-17	216	63	2,017	54,455
18-19	156	69	1,376	38,049
20-29	880	74	9,023	257,259
30-39	1,235	77	13,246	405,834
40-49	1,561	81	18,273	592,153
50-59	2,814	81	32,604	1,024,349
60-69	4,748	81	52,867	1,648,145
70-79	4,916	78	53,074	1,610,370
80-89	2,172	73	22,318	638,936
90 or more	249	68	2,182	54,839
Total	**20,358**	**74**	**215,254**	**6,446,102**

Ig Dispenses

IG DISPENSES BY CRITERIA CHAPTER

The Criteria classifies medical conditions into four chapters based on the level of evidence supporting the use of Ig, as follows:

- Chapter 5, conditions for which Ig has an established therapeutic role
- Chapter 6, conditions for which Ig has an emerging therapeutic role
- Chapter 7, conditions for which Ig has application in exceptional circumstances only
- Chapter 8, conditions for which Ig use is not supported.

Immunoglobulin was predominately dispensed for medical conditions within Chapter 5. Refer to **Appendix D** for further information.

Table 9: Ig grams dispensed by criteria chapter

Chapter	2014-15	2015-16	2016-17	2017-18	2018-19
Chapter 5 - has an established therapeutic role	3,785,615	4,223,866	4,620,916	5,081,838	5,406,598
Chapter 6 - has an emerging therapeutic role	494,489	535,596	645,636	721,766	792,821
Chapter 7 - has application in exceptional circumstances only	178,221	216,927	220,122	271,817	246,231
Chapter 8 - use is not supported		5	741	288	453
Other			96	25	
Total	**4,458,326**	**4,976,394**	**5,487,511**	**6,075,733**	**6,446,102**

While Ig may be dispensed without an approved authorisation in life threatening situations (including prior to a confirmed diagnosis or in situations where the diagnosis is unclear at the time of treatment), under the National Policy, an authorisation for access must be submitted retrospectively. The *Conditions for which Ig use is not supported* and *Other* dispenses generally reflect situations where a retrospective authorisation request identified Ig was used in an emergency to treat a condition that is not supported, or not otherwise mentioned in the Criteria. Data to support compliance with all aspects of qualifying criteria for each specific condition were not always collected in STARS.

IG DISPENSES BY SPECIALITY

Medical Conditions are classified under a medical speciality. The key specialities are Neurology, Haemotology and Immunology. Other shows total for Nephrology, Transplant Medicine and Dermatology specialities.

All Prescribers are responsible for registering for access to BloodSTAR at each hospital/health facility where they practice and/or are employed. Medical specialists must have their particular speciality field of practice registered with the Australian Health Practitioner Regulation Agency (AHPRA) for the specialty field to be recognised for the purposes of meeting eligibility requirements as specified in the Criteria.

Since 2014-15, there has been a 1.48 fold increase in Ig issues for neurological conditions, compared with a 1.52 fold increase for both haematological conditions and 1.42 fold increase for immunological conditions.

The variation across states and territories in number of new and total patients and the amount of Ig dispensed per clinical speciality is illustrated in **Tables 10 to 12** for 2018-19.

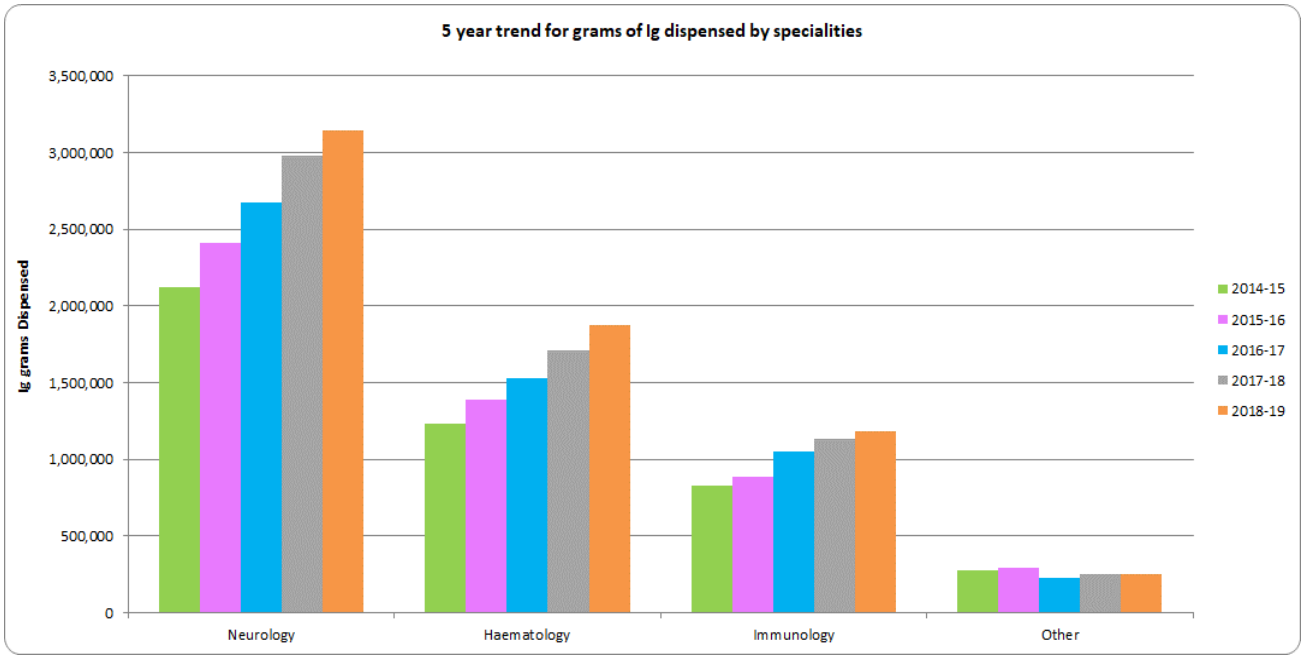

Figure 8: Grams of Ig dispensed by speciality

The data also illustrate the variation between states and territories in the relative amount of Ig used per patient for the same speciality. For example, 31.1 per cent of Western Australia's (WA) Ig patients were haematology patients, using 16.6 per cent of the state's total Ig issue in 2018-19. By comparison, nationally, 39.4 per cent of patients were haematology patients, using 29.1 per cent of the national Ig issue – a significantly different ratio of patients to Ig use, as comparted to WA. The reason for this inter-state and territory variation is unknown, but it may represent differences in clinical practice, differing disease profiles in the patient populations, variable access to alternative therapies, or differences due to the availability of specialist services across Australia.

Table 10: Ig grams dispensed by speciality and state and territory for 2018-19

Specialities	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Dermatology*	27,090	28,150	29,115	3,510	7,763	2,370	295	4,540	**102,832**
Haematology	656,810	387,951	550,722	130,285	68,493	48,153	6,095	27,406	**1,875,913**
Immunology	513,314	229,921	246,491	53,643	76,913	22,126	4,389	32,701	**1,179,498**
Nephrology*	18,295	71,725	11,305	2,583	5,275	10,210	730	738	**120,860**
Neurology	1,103,594	684,632	826,278	133,688	252,792	52,365	18,575	67,135	**3,139,058**
Transplant Medicine*	5,930	17,795	2,432	705	210	835	35	-	**27,942**
Total	**2,325,032**	**1,420,173**	**1,666,341**	**324,413**	**411,445**	**136,059**	**30,118**	**132,520**	**6,446,102**

**Included as other in Figure 8*

Table 11: Patients dispensed Ig by speciality and state and territory for 2018-19

Specialities	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Dermatology*	54	67	39	8	9	<5	<5	8	**<200**
Haematology	2,864	1,800	2,131	602	371	184	35	108	**8,026**
Immunology	1,830	938	858	217	316	85	27	106	**4,330**
Nephrology*	76	224	43	17	32	20	5	<5	**<424**
Neurology	2,747	1,601	1,901	339	464	115	47	170	**7,285**
Transplant Medicine*	102	84	10	7	<5	5	<5	-	**<220**
Total	**7,649**	**4,679**	**4,952**	**1,188**	**<1,198**	**<415**	**<125**	**<399**	**20,358**

**Included as other in Figure 8*

Table 12: New patients dispensed Ig by speciality and state and territory for 2018-19

Specialities	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Dermatology*	29	48	9	5	<5	<5	<5	5	**<117**
Haematology	1,232	799	685	303	164	58	15	46	**3,285**
Immunology	498	324	196	57	101	30	12	23	**1,228**
Nephrology*	76	126	22	14	26	11	5	<5	**<286**
Neurology	1,020	600	563	127	175	40	17	68	**2,584**
Transplant Medicine*	67	42	7	5	<5	<5	<5	-	**<140**
Total	**2,906**	**1,927**	**1,477**	**511**	**<481**	**<153**	**<61**	**<150**	**7,568**

**Included as other in Figure 8*

IG DISPENSES BY MEDICAL CONDITION

The top 10 medical conditions account for 88.4 per cent of all Ig supplied, with the top 3 medical conditions accounting for 56.7 per cent. Acquired hypogammaglobulinaemia — haematological malignancy and post haemopoietic stem cell transplantation (HSCT) is the medical condition for which the greatest percentage of Ig was dispensed in 2018-19 (24.0 per cent), closely followed by chronic inflammatory demyelinating polyneuropathy (CIDP) (21.1 per cent). Primary immunodeficiency diseases (PID) with antibody deficiency accounted for 11.6 per cent of total Ig use.

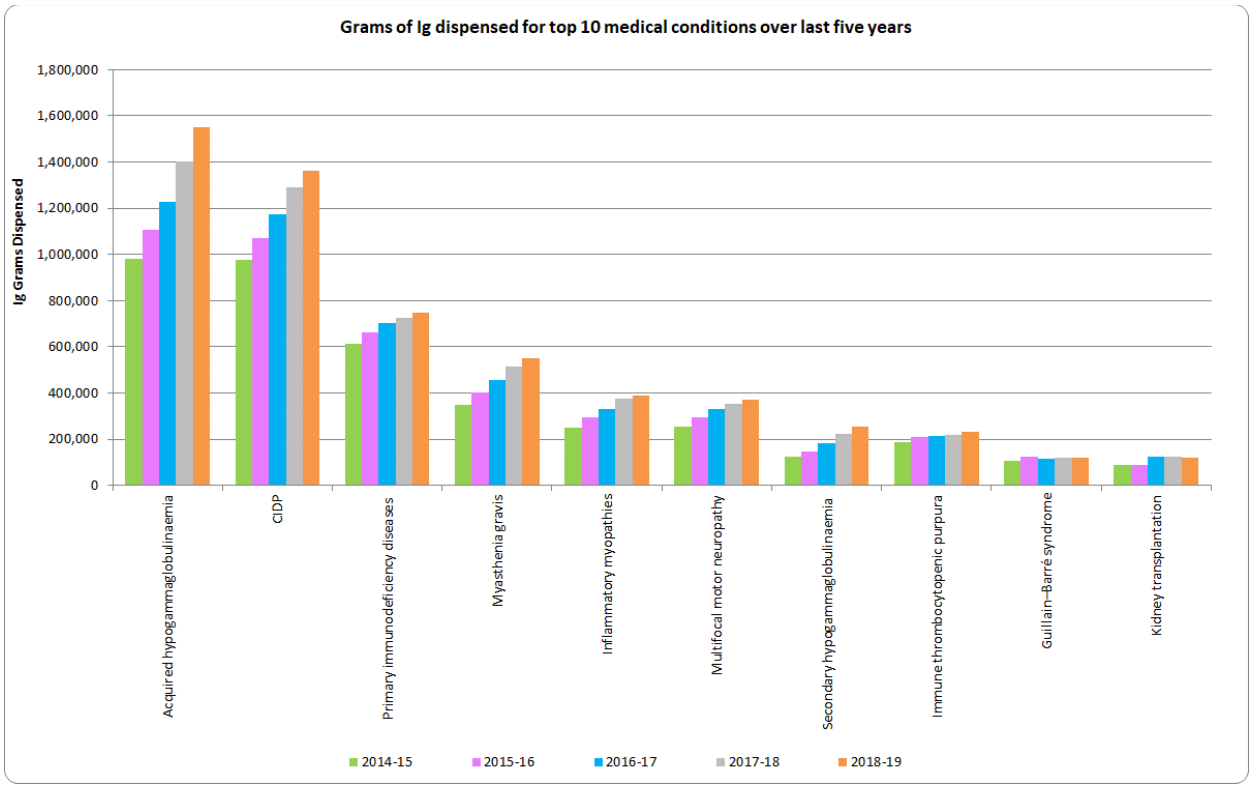

Figure 9: Grams of Ig dispensed by top 10 medical conditions

The top 10 medical conditions by state and territory for 2018-19 is presented in **Table 13**.

Table 13: Grams dispensed by states and territories and medical condition for 2018-19

Specialities	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Acquired hypogammaglobulinaemia	545,093	315,501	471,109	96,440	54,066	41,603	5,132	19,088	**1,548,032**
CIDP	495,909	293,695	352,554	42,433	117,902	27,453	6,808	22,853	**1,359,604**
Primary immunodeficiency diseases	344,677	144,451	139,549	38,875	40,410	11,495	3,789	23,167	**746,412**
Myasthenia gravis	163,720	150,429	163,495	13,743	40,575	4,780	275	12,788	**549,804**
Inflammatory myopathies	130,762	87,879	105,545	28,128	21,780	5,490	1,095	10,423	**391,101**
Multifocal motor neuropathy	119,221	70,127	77,460	35,315	42,390	6,658	7,760	13,945	**372,875**
Secondary hypogammaglobulinaemia	101,188	48,082	78,655	3,747	10,328	7,660	165	3,058	**252,882**
Immune thrombocytopenic purpura	85,834	49,875	54,950	25,370	8,600	4,235	593	3,740	**233,196**
Guillain–Barré syndrome	51,590	27,210	22,009	5,778	10,820	1,590	690	2,375	**122,061**
Kidney transplantation	18,295	71,725	11,305	2,583	5,275	10,210	730	738	**120,860**
Total	**2,056,287**	**1,258,972**	**1,476,631**	**292,409**	**352,145**	**121,173**	**27,036**	**112,173**	**5,696,825**

Ig Dispenses - IVIg and SCIg

In March 2013, the Jurisdictional Blood Committee (JBC) approved the introduction of SCIg under the national blood arrangements. In 2018-19 the SCIg products supplied by the NBA are:

- Evogam 16% 0.8g/5ml and 3.2g/20ml supplied by CSL Behring (domestic)
- Hizentra 5% 1g/5ml, 2g/10ml, 4g/20ml and 10g/50ml supplied by CSL Behring (imported).

In addition to the clinical and diagnostic criteria for access to immunoglobulin products, access to SCIg products is provided through an assurance framework for the appropriate use of the product. The first phase of implementation was through hospital-based management arrangements. Subcutaneous Ig access rules are detailed on the NBA website at https://www.blood.gov.au/SCIg. Participation in the National SCIg program requires hospitals to establish their capability and capacity to manage a hospital based SCIg program, where the hospital provides access to all resources and takes full accountability for the management and use of the product within defined governing requirements. Further work will be undertaken to support supply of SCIg for other pathways of care.

In 2018-19 the medical conditions that SCIg can be used to treat are:

- primary immunodeficiency diseases with antibody deficiency,
- specific antibody deficiency,
- acquired hypogammaglobulinaemia secondary to haematological malignancies, or post-haemopoietic stem cell transplantation (HSCT), and
- secondary hypogammaglobulinaemia unrelated to haematological malignancies, or post-haemopoietic stem cell transplantation (HSCT).

These products are authorised and distributed by Lifeblood in the same manner as IVIg.

Tables 14-17 show the patient numbers, grams dispensed, by medical condition and IVIg and SCIg products or by state and territory for in 2018-19.

Table 14: Patients dispensed by SCIg/IVIg medical conditions and product for 2018-19

	IVIg					SCIg		
Medical Condition	Flebogamma 5%	Flebogamma 10%	Intragam P	Intragam 10	Privigen 10 %	Evogam	Hizentra	Total
Acquired hypogammaglobulinaemia	64	234	5	6,621	1,064	35	233	**6,266**
Primary immunodeficiency diseases	44	23	17	2,252	66	204	382	**2,266**
Secondary hypogammaglobulinaemia	35	48	<5	990	175	31	56	**1,045**
Specific antibody deficiency	5	<5	-	396	19	27	57	**389**

Table 15: Grams dispensed by SCIg/IVIg medical conditions and product for 2018-19

	IVIg					SCIg		
Medical Condition	Flebogamma 5%	Flebogamma 10%	Intragam P	Intragam 10	Privigen 10 %	Evogam	Hizentra	Total
Acquired hypogammaglobulinaemia	14,850	38,395	39	1,223,168	200,145	6,196	65,239	**1,548,032**
Primary immunodeficiency diseases	13,082	5,855	366	546,415	22,710	46,426	111,547	**746,412**
Secondary hypogammaglobulinaemia	8,846	9,575	24	177,333	36,200	6,636	14,269	**252,882**
Specific antibody deficiency	1,726	900	-	82,990	4,445	5,367	13,519	**108,946**

Table 16: Patients dispensed by SCIg medical conditions and state and territory for 2018-19

Products	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Acquired hypogammaglobulinaemia	42	92	55	50	<5	13	<5	10	**261**
Primary immunodeficiency diseases (PID)	203	148	107	45	29	6	<5	26	**560**
Secondary hypogammaglobulinaemia	20	17	37	<5	8	<5	-	-	**84**
Specific antibody deficiency	26	9	14	10	13	<5	-	<5	**<83**

Table 17: Grams dispensed by SCIg medical conditions and state and territory for 2018-19

Products	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Acquired hypogammaglobulinaemia	15,266	22,648	13,964	13,697	743	3,416	72	1,629	**71,435**
Primary immunodeficiency diseases	68,265	34,892	29,283	11,125	6,887	999	1,189	5,333	**157,973**
Secondary hypogammaglobulinaemia	6,179	2,789	9,112	184	1,466	1,175	-	-	**20,905**
Specific antibody deficiency	8,099	1,289	3,564	1,856	2,625	269	-	1,184	**18,886**

Ig Issued – NHIg

In 2013-14, due to the introduction of SCIg as discussed above, demand for NHIg reduced significantly by 18.8 per cent. CSL Behring produces NHIg from hyperimmune plasma specially collected by Lifeblood. The volume of product is limited by the availability of this specialised plasma, and by production scheduling arrangements in CSL Behring's manufacturing facility.

Demand for NHIg further declined in 2014-15 by 78 per cent because of implementation of the NHIg policy outlining the national position on access and use under the national blood arrangements.

Normal human Ig may only be supplied for two purposes; for the treatment of susceptible contacts of measles, hepatitis A, poliomyelitis, and rubella, as directed by public health officials; and for the treatment of immunodeficiency conditions for which the product is indicated for patients for whom IVIg and SCIg are both contraindicated. Normal human Ig access rules are detailed on the NBA website at https://www.blood.gov.au/NHIg.

Figure 10 shows the grams issued and the grams issued per 1,000 population by states and territories for either purpose listed above.

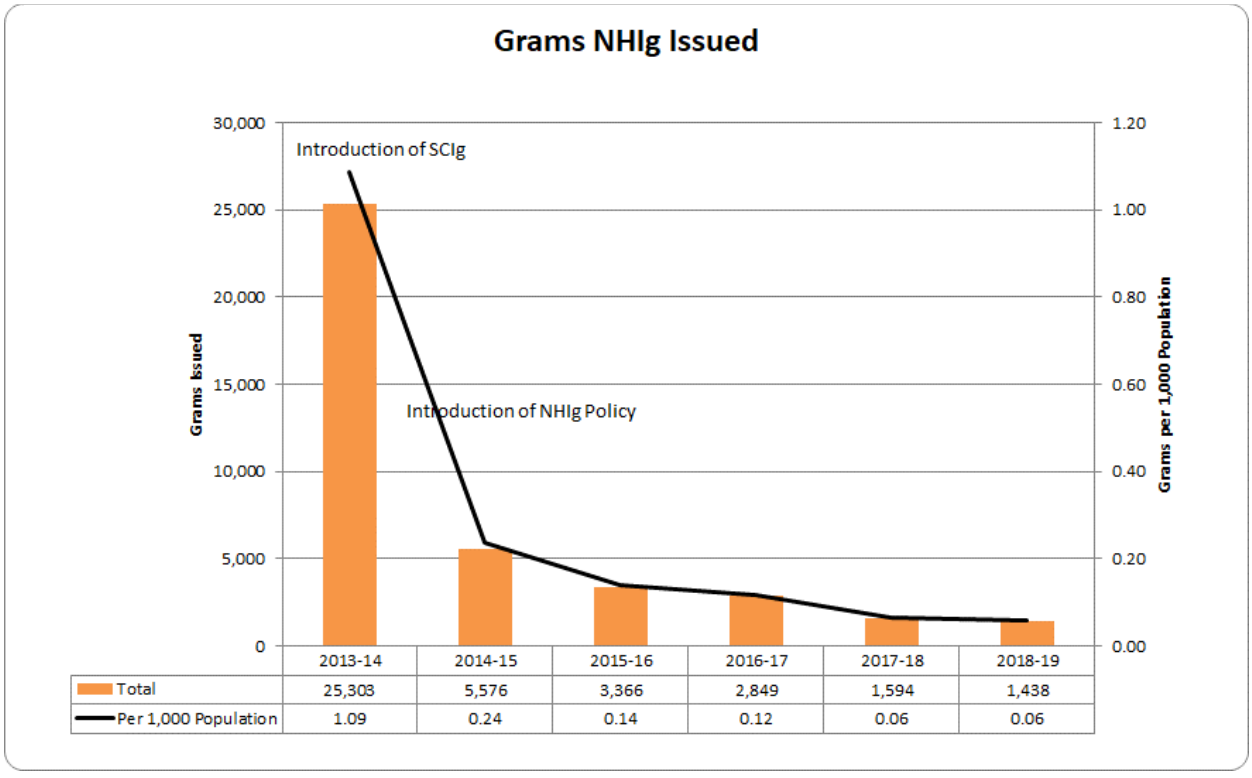

Figure 10: NHIg grams issued and grams issued per 1,000 population

Appendices

APPENDIX A – BACKGROUND

Funding for Ig

The Commonwealth funded 63 per cent of Ig supplied under the national blood arrangements, with the remaining 37 per cent funded by the state or territory to which the product is supplied.

The Criteria

The *Criteria for the Clinical Use of Immunoglobulin in Australia* (the Criteria) is a publication that describes the eligibility criteria that patients must meet to receive Ig that is funded by all Australian governments. Product is provided at no cost to the patient where patients meet the qualifying criteria for access as outlined in the Criteria. The Criteria helps to ensure that Ig is accessed consistently across Australia for the treatment of patients whose health is likely to be improved with Ig therapy. It was developed using the best available scientific evidence and medical expertise.

Version 3 of the Criteria, was published in October 2018, replacing the *Criteria for the Clinical use of Intravenous Immunoglobulin in Australia* – second edition which was introduced in August 2012. Eligibility criteria were updated to align with new evidence and best clinical practice, along with other improvements to aid prescribers. Version 3 of the Criteria also reflects earlier updated access arrangements for SCIg and NHIg.

Although the Version 3 of the Criteria was introduced in October 2018, some patients continued under existing authorisations until their scheduled review for some conditions, while others transitioned on 22 October 2018.

Supply of Product

Immunoglobulin is made from donated human plasma. In Australia Lifeblood is contracted to collect plasma for fractionation, which is then supplied to CSL Behring, who is responsible for the manufacture of Australian plasma derived products. To supplement the supply of Australian Immunoglobulin, the NBA contracts additional suppliers to import Ig products to ensure demand can be met adequately.

There are two main ways Ig is available in Australia:

1. Supply under national blood arrangements

If Ig is ordered to treat a medical condition which is funded under the Criteria, then the product is supplied and funded under national blood arrangements. In this case the cost of the product is shared between the Commonwealth and the relevant state or territory.

Orders for Ig under national blood arrangements are made to Lifeblood, which is contracted by the NBA as the authoriser and distributor of all Ig funded under these arrangements. Clinicians are required to seek authorisation to access government funded Ig for their patients through BloodSTAR. In seeking authorisation, clinicians must provide information to establish that the request in BloodSTAR meets the Criteria. For ongoing conditions, the Criteria may specify review criteria to be applied for reviewing the patient to determine whether access to funded Ig can continue.

Prior to the introduction of BloodSTAR, and in its role as authoriser of requests for Ig, Lifeblood previously maintained a database of requests, and provides data to the NBA for use as a basis for reporting on the annual use of Ig in Australia, known as STARS data. BloodSTAR now holds these data for all states and territories.

2. Direct order and other supply arrangements

For several reasons, medical specialists may sometimes want to prescribe Ig for medical conditions that are not funded under the national blood arrangements as defined in the Criteria. In such cases, IVIg or SCIg may be available either through jurisdictional direct order (JDO) arrangements, or directly from suppliers on a commercial basis, at private expense.

Under JDO arrangements, AHPs can purchase imported product only (IVIg or SCIg) directly from the supplier at an equivalent price to that negotiated by the NBA.

Every state or territory health department is responsible for advising each supplier of imported IVIg and SCIg product of the AHPs in their state or territory. Processes vary, with some state or territory confirming AHP status to the supplier each time a JDO is requested, and others having longer-standing arrangements.

Application and approval arrangements for doctors seeking access to imported Ig products raised through a JDO vary between hospitals and states and territories, but usually involve seeking access through the local hospital therapeutics or Ig committee, or equivalent. Where approval is granted, the cost of the imported Ig product purchased through a JDO is usually borne directly by the AHP.

2018-19 Activities

The history of NBA activities prior to 2019-20 can be found in previous *National Report on the Issues and Use of Immunoglobulin (Ig) – Annual Reports*.

BloodSTAR is now live in all states and territories

During 2016-17, the NBA successfully launched BloodSTAR in all states except NSW. In October 2018 NSW went live in BloodSTAR.

Publication of the third edition of the National Policy

The third edition of the National Policy was released in July 2019 National Policy: Access to Government Funded Immunoglobulin Products in Australia | National Blood Authority.

Publication of Module 2 of the Guidelines for Managing Blood and Blood Product Inventory

The Guidelines for Managing Blood and Blood Product Inventory provides better practice processes that can be used by health providers to ensure risks associated with receipt, storage, collection and transport of blood and blood products are mitigated. It also identifies improvement opportunities for implementation.

In 2016-17, the NBA developed Module 2 to supplement the overarching inventory management principles and support the implementation of BloodSTAR. The module aims to assist health providers in meeting the requirements of the National Policy by:

- describing how to establish and manage stock levels
- outlining the Ig product ordering models
- identifying different methods to determine ordering requirements/triggers
- providing recommendations for good practice.

The document underwent public consultation prior to release. Version 2 of the Guidelines was published in September 2018.

The NBA Ig Governance Program continued its work throughout **2018-19** to improve the Governance and management of publicly funded Ig. This program aims to ensure:

- Ig product use and management reflects appropriate clinical practice and represents efficient, effective, and ethical expenditure of government funds, in accordance with relevant national safety and quality standards for health care
- access to Ig products is consistent with the Criteria for access determined by governments
- improved capture of information on the need for, use of, and outcomes of treatment (including adverse events) with Ig products to inform future changes to the Criteria.

During the **2018-19** period, the program focused on the four key activities listed below:

1. Launched BloodSTAR (*Blood System for Tracking Authorisations and Reviews*) in New South Wales in October 2018
2. Release of Version 3 of the Criteria and commencement of a transition strategy for existing Ig authorisations, including for NSW patients, via BloodSTAR from October 2018
3. Continued implementation of the *National Immunoglobulin Program Performance Improvement Strategy 2019-20 to 2021-22*
4. Continued engagement with the program's network of committees to inform, the work of the national immunoglobulin (Ig) governance program.

For further information on the Ig Governance Program go to the NBA website at https://www.blood.gov.au/Ig-program.

APPENDIX B – ACRONYMS AND GLOSSARY

Acronyms

ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
AHP	Australian Health Provider
AHPRA	Australian Health Practitioner Regulation Agency
ANZSBT	Australia and New Zealand Society of Blood Transfusion
BloodNet	The national online ordering and inventory management system
BloodSTAR	Blood System for Tracking Authorisations and Reviews
CIDP	Chronic Inflammatory Demyelinating Polyneuropathy
HSCT	Hematopoietic stem cell transplantation
HTA	Health Technology Assessment
IDMS	Integrated Data Management System
Ig	Immunoglobulin products including IVIg and SCIg
IVIg	Intravenous immunoglobulin
JBC	Jurisdictional Blood Committee
MSAC	Medical Services Advisory Committee
NBA	National Blood Authority
NHIg	Normal human immunoglobulin
NIGAC	National Immunoglobulin Governance Advisory Committee
NSQHS	National Safety and Quality Health Service
NSW	New South Wales
NT	Northern Territory
PID	Primary Immunodeficiency Diseases
QLD	Queensland
SA	South Australia
SCIg	Subcutaneous Immunoglobulin
STARS	Supply Tracking Analysis Recording System
TAS	Tasmania
VIC	Victoria
WA	Western Australia

Glossary of terms

Term	Description
Blood products	Products manufactured from human blood
Lifeblood	The Australian Red Cross Lifeblood
Condition	Clinical conditions are categorised according to the quality of the available evidence and whether immunoglobulin treatment is considered beneficial Specific conditions (previously known as primary diagnosis) within a medical condition (previous known as disease category). In some instances, the medical condition may be the same as the specific condition, for example – Myasthenia gravis is the specific condition and the medical condition
***Criteria for the clinical use of immunoglobulin in Australia* (the Criteria)**	A document describing the conditions, indications and patient qualifying and review criteria for which Ig is funded under national blood arrangements by all Australian governments
Direct Orders	Previously known as Jurisdictional Direct Orders. Arrangements implemented by the NBA with suppliers to facilitate the purchase of Ig for the treatment of conditions not satisfying the *Criteria for the clinical use of Ig in Australia*
Fractionation	A manufacturing process that separates blood plasma into specific protein fractions
Imprest stock	Health provider orders product for stock that is maintained at a certain level and held at their site
Intravenous immunoglobulin	An immunoglobulin product derived from donated human plasma that is administered intravenously
Jurisdiction	Any of the parties to the Australian National Blood Agreement, being the Australian Government and all state and territory governments
Minimum Product Inventory	The minimum inventory of Ig held by CSL Behring to meet contract obligations
National Blood Agreement	The Agreement signed by all governments in 2003 that sets out the objectives for governments for the management of the Australian blood sector
National blood arrangements	Arrangements, including funding arrangements, established under the National Blood Agreement
National CSL Reserve	The reserve of inventory of Ig that CSL Behring manages on behalf of the NBA for contingency purposes
Normal immunoglobulin	An immunoglobulin product derived from human plasma that is administered by intramuscular injection (as opposed to intravenous or sub-cutaneous injection)
Plasma	The liquid part of the blood containing antibodies and other proteins
Speciality	Classification of the conditions according to the clinical speciality, previously discipline

Term	Description
Subcutaneous immunoglobulin	An immunoglobulin product derived from donated human plasma that is administered subcutaneously
Treatment episode or Dispense Event	One instance or episode of a treatment plan, for example a treatment plan may be made up of 4 episodes over 4 months with an episode occurring every 4 weeks (4 treatment episodes) OR 1 dose of transfused product every two weeks for 6 months would be 13 treatment episodes or dispense event

APPENDIX C – CONDITIONS MAPPING TABLE

Specific Condition Name	Medical Condition Name	Version	Chapter	Speciality
Acute disseminated encephalomyelitis	Acute disseminated encephalomyelitis (ADEM)	2	6	Neurology
Acute leukaemia	Acquired hypogammaglobulinaemia — haematological malignancy and post HSCT	3	5	Haematology
Acute leukaemia in children	Acute leukaemia in children	2	7	Haematology
Autoimmune haemolytic anaemia	Autoimmune haemolytic anaemia (AIHA)	2	6	Haematology
Autoimmune neutropenia	Autoimmune neutropenia	2	7	Immunology
Autoimmune retinopathy	Autoimmune retinopathy (AIR)	3	7	Immunology
Autoimmune uveitis	Autoimmune uveitis	2	7	Immunology
Bullous pemphigoid	Bullous pemphigoid (BP)	2	6	Dermatology
Catastrophic antiphospholipid syndrome	Catastrophic antiphospholipid syndrome	2	7	Immunology
Cerebellar degeneration	Paraneoplastic neurological syndromes	2	7	Neurology
Chronic Immune thrombocytopenic purpura (ITP)	Immune thrombocytopenic purpura (ITP) — adult	3	5	Haematology
Chronic inflammatory demyelinating polyneuropathy	Chronic inflammatory demyelinating polyneuropathy (CIDP)	2	5	Neurology
Chronic lymphocytic leukaemia	Acquired hypogammaglobulinaemia — haematological malignancy and post HSCT	2	5	Haematology
Churg-Strauss syndrome	ANCA-positive systemic necrotising vasculitis	2	6	Immunology
Cicatricial pemphigoid/ mucous membrane pemphigoid	Cicatricial pemphigoid (CP) or Mucous Membrane Pemphigoid (MMP)	2	6	Dermatology

Specific Condition Name	Medical Condition Name	Version	Chapter	Speciality
Coagulation factor inhibitors	Coagulation factor inhibitors	2	7	Haematology
Combined immunodeficiency generally less profound than SCID (e.g. thymoma)	Primary immunodeficiency diseases (PID) with antibody deficiency	3	5	Immunology
Common variable immunodeficiency disease (CVID)	Primary immunodeficiency diseases (PID) with antibody deficiency	2	5	Immunology
Dermatomyositis	Inflammatory myopathies: polymyositis (PM), dermatomyositis (DM) and inclusion body myositis (IBM)	2	5	Neurology
Devic disease (neuromyelitis optica)	Devic disease (neuromyelitis optica)	2	7	Neurology
Diabetic amyotrophy	Diabetic amyotrophy	2	7	Neurology
Encephalitis associated with antibodies to CASPR2	Antibody mediated autoimmune encephalitis (AMAE)	3	6	Neurology
Encephalitis associated with antibodies to GABA (A or B) receptor	Antibody mediated autoimmune encephalitis (AMAE)	3	6	Neurology
Encephalitis associated with antibodies to glycine receptor	Antibody mediated autoimmune encephalitis (AMAE)	3	6	Neurology
Encephalitis associated with antibodies to LGI1	Antibody mediated autoimmune encephalitis (AMAE)	3	6	Neurology
Encephalitis associated with antibodies to NMDA receptor	Antibody mediated autoimmune encephalitis (AMAE)	3	6	Neurology
Encephalitis associated with antibodies to VGKC	Antibody mediated autoimmune encephalitis (AMAE)	3	6	Neurology
Epidermolysis bullosa acquisita	Epidermolysis bullosa acquisita	2	7	Dermatology
Epilepsy (rare childhood cases)	Epilepsy	2	7	Neurology
Evans syndrome	Evans syndrome	2	6	Haematology
Feto-maternal/neonatal alloimmune thrombocytopenia (Antenatal)	Feto-maternal/neonatal alloimmune thrombocytopenia (FMAIT/NAIT)	2	6	Haematology

Specific Condition Name	Medical Condition Name	Version	Chapter	Speciality
Feto-maternal/neonatal alloimmune thrombocytopenia (Neonatal)	Feto-maternal/neonatal alloimmune thrombocytopenia (FMAIT/NAIT)	2	6	Haematology
Graves ophthalmopathy	Graves ophthalmopathy	2	7	Neurology
Guillain–Barré syndrome	Guillain–Barré syndrome (GBS)	2	5	Neurology
Haemolytic disease of the newborn	Haemolytic disease of the newborn (HDN)	2	7	Haematology
Haemophagocytic lymphohistiocytosis	Haemophagocytic lymphohistiocytosis	3	6	Haematology
Haemophagocytic syndrome	Haemophagocytic syndrome	2	6	Haematology
Hashimoto encephalopathy	Hashimoto encephalopathy	2	7	Neurology
Idiopathic dilated cardiomyopathy	Idiopathic dilated cardiomyopathy	2	8	Haematology
IgG subclass deficiency (existing authorisation)	Specific antibody deficiency (SAD)	2	6	Immunology
IgM para-proteinaemic neuropathy	IgM paraproteinaemic demyelinating neuropathy	2	6	Neurology
Inclusion body myositis	Inflammatory myopathies: polymyositis (PM), dermatomyositis (DM) and inclusion body myositis (IBM)	2	5	Neurology
ITP associated with HIV	Immune thrombocytopenic purpura (ITP) — adult	2	5	Haematology
ITP in children	Immune thrombocytopenic purpura (ITP) — in children 15 years and younger	2	6	Haematology
ITP in pregnancy	Immune thrombocytopenic purpura (ITP) — adult	2	5	Haematology
ITP in specific circumstances (surgery, other therapy contraindicated, chronic ITP, concurrent risk factors)	Immune thrombocytopenic purpura (ITP) — adult	2	5	Haematology
ITP refractory acute	Immune thrombocytopenic purpura (ITP) — adult	2	5	Haematology

Specific Condition Name	Medical Condition Name	Version	Chapter	Speciality
ITP with life-threatening haemorrhage or potential life-threatening haemorrhage	Immune thrombocytopenic purpura (ITP) — adult	2	5	Haematology
Kawasaki disease	Kawasaki disease	2	5	Immunology
Kidney transplantation post-transplant	Kidney transplantation	2	6	Nephrology
Kidney transplantation pre-transplant	Kidney transplantation	2	6	Nephrology
Lambert–Eaton myasthenic syndrome	Lambert–Eaton myasthenic syndrome (LEMS)	2	5	Neurology
LETMs	Neuromyelitis optica spectrum disorders (NMOSD)	3	7	Neurology
Limbic encephalitis	Paraneoplastic neurological syndromes	2	7	Neurology
Limbic encephalitis, nonparaneoplastic	Limbic encephalitis — nonparaneoplastic	2	7	Neurology
Lymphoproliferative syndromes (e.g. XLP1, XLP2, CD27 def)	Primary immunodeficiency diseases (PID) with antibody deficiency	2	5	Immunology
Macrophage activation syndrome	Haemophagocytic lymphohistiocytosis	3	6	Haematology
Memory B cell deficiency secondary to haemopoietic stem cell transplantation (HSCT)	Acquired hypogammaglobulinaemia — haematological malignancy and post HSCT	3	5	Haematology
Microscopic polyangiitis	ANCA-positive systemic necrotising vasculitis	2	6	Immunology
Multifocal motor neuropathy with or without persistent conduction block	Multifocal motor neuropathy (MMN)	2	5	Neurology
Multiple myeloma	Acquired hypogammaglobulinaemia — haematological malignancy and post HSCT	2	5	Haematology
Multiple sclerosis - severe relapse with no response to high dose methylprednisolone	Multiple sclerosis (MS)	2	6	Neurology

Specific Condition Name	Medical Condition Name	Version	Chapter	Speciality
Multiple sclerosis in pregnancy and the immediate post-partum period	Multiple sclerosis (MS)	2	6	Neurology
Multiple sclerosis in young patients severe/relapsing/remitting in whom other therapies have failed	Multiple sclerosis (MS)	2	6	Neurology
Myasthenia gravis	Myasthenia gravis (MG)	2	5	Neurology
Myocarditis in children	Myocarditis in children	2	7	Immunology
Necrotising autoimmune myopathy (NAM)	Inflammatory myopathies: polymyositis (PM), dermatomyositis (DM) and inclusion body myositis (IBM)	3	5	Neurology
Neonatal haemochromatosis	Neonatal haemochromatosis (NH)	2	5	Haematology
Newly Diagnosed Immune thrombocytopenic purpura (ITP)	Immune thrombocytopenic purpura (ITP) — adult	3	5	Haematology
NMOSD–AQP4 ab positive	Neuromyelitis optica spectrum disorders (NMOSD)	3	7	Neurology
NMOSD–MOG ab positive	Neuromyelitis optica spectrum disorders (NMOSD)	3	7	Neurology
NMOSD–seronegative	Neuromyelitis optica spectrum disorders (NMOSD)	3	7	Neurology
Non-Hodgkin lymphoma	Acquired hypogammaglobulinaemia — haematological malignancy and post HSCT	2	5	Haematology
Opsoclonus myoclonus ataxia	Opsoclonus-myoclonus ataxia (OMA)	2	6	Neurology
Other primary immunodeficiency	Primary immunodeficiency diseases (PID) with antibody deficiency	2	5	Immunology
Other relevant haematological malignancies	Acquired hypogammaglobulinaemia — haematological malignancy and post HSCT	2	5	Haematology
PANDAS/tic disorders	Paediatric autoimmune neuropsychiatric disorder associated with streptococcal infection (PANDAS)	2	7	Neurology

Specific Condition Name	Medical Condition Name	Version	Chapter	Speciality
Paraneoplastic Subacute Sensory Neuropathy	Paraneoplastic Subacute Sensory Neuropathy	3	8	Neurology
Pemphigus foliaceus	Pemphigus foliaceus (PF)	2	6	Dermatology
Pemphigus vulgaris	Pemphigus vulgaris (PV)	2	6	Dermatology
Polymyositis	Inflammatory myopathies: polymyositis (PM), dermatomyositis (DM) and inclusion body myositis (IBM)	2	5	Neurology
Possible Common variable immune deficiency (CVID) - below normal serum IgG but normal serum IgA level	Primary immunodeficiency diseases (PID) with antibody deficiency	3	5	Immunology
Post-haemopoietic stem cell transplantation	Acquired hypogammaglobulinaemia — haematological malignancy and post HSCT	2	5	Haematology
Post-tranfusion purpura	Post-transfusion purpura (PTP)	2	6	Haematology
Post-transfusion purpura (PTP)	Post-transfusion purpura (PTP)	3	6	Haematology
Potassium channel antibody-associated encephalopathy	Potassium channel antibody-associated encephalopathy	2	7	Neurology
PR3 or MPO ANCA-positive idiopathic rapidly progressive glomerulonephritis	ANCA-positive systemic necrotising vasculitis	2	6	Immunology
Pure red cell aplasia	Pure red cell aplasia (PRCA)	2	7	Haematology
Pure white cell aplasia	Pure white cell aplasia (PWCA)	2	7	Haematology
Pyoderma gangrenosum	Pyoderma gangrenosum	2	7	Dermatology
Rasmussen syndrome	Rasmussen syndrome	2	7	Neurology
Relapsing remitting multiple sclerosis	Multiple sclerosis (MS)	2	6	Neurology
Scleromyxedema	Scleromyxedema	2	7	Neurology

Specific Condition Name	Medical Condition Name	Version	Chapter	Speciality
Secondary hypogammaglobulinaemia (excluding haematological malignancies)	Secondary hypogammaglobulinaemia (including iatrogenic immunodeficiency)	2	6	Immunology
Sepsis	Sepsis	2	8	Immunology
Sero-negative autoimmune encephalitis	Antibody mediated autoimmune encephalitis (AMAE)	3	6	Neurology
Sero-negative limbic encephalitis	Antibody mediated autoimmune encephalitis (AMAE)	3	6	Neurology
Severe combined immunodeficiency (SCID)	Primary immunodeficiency diseases (PID) with antibody deficiency	2	5	Immunology
Severe reduction in all Ig isotypes with decreased or absent B-cells (e.g. XLA def)	Primary immunodeficiency diseases (PID) with antibody deficiency	3	5	Immunology
Severe reduction in at least two Ig isotypes with low/normal B-cells (e.g. CVID)	Primary immunodeficiency diseases (PID) with antibody deficiency	3	5	Immunology
Severe reduction in serum IgG and IgA with normal/elevated IgM (e.g. CD40L def)	Primary immunodeficiency diseases (PID) with antibody deficiency	3	5	Immunology
Sjögren's syndrome	Sjögren's syndrome	2	7	Immunology
Solid organ - heart	Solid organ transplantation (other than kidney)	2	6	Transplant Medicine
Solid organ - heart/lung	Solid organ transplantation (other than kidney)	2	6	Transplant Medicine
Solid organ - liver	Solid organ transplantation (other than kidney)	2	6	Transplant Medicine
Solid organ - lung	Solid organ transplantation (other than kidney)	2	6	Transplant Medicine

Specific Condition Name	Medical Condition Name	Version	Chapter	Speciality
Solid organ - other	Solid organ transplantation (other than kidney)	2	6	Transplant Medicine
Specific antibody deficiency	Specific antibody deficiency (SAD)	2	6	Immunology
Staphylococcal TSS	Toxic shock syndrome (TSS)	2	6	Immunology
Stiff person syndrome	Stiff person syndrome	2	5	Neurology
Streptococcal TSS	Toxic shock syndrome (TSS)	2	6	Immunology
Subacute sensory neuropathy	Paraneoplastic neurological syndromes	2	7	Neurology
Susac syndrome	Susac syndrome	2	7	Immunology
Suspected autoimmune encephalitis	Antibody mediated autoimmune encephalitis (AMAE)	3	6	Neurology
Suspected autoimmune limbic encephalitis	Antibody mediated autoimmune encephalitis (AMAE)	3	6	Neurology
Systemic capillary leak syndrome	Systemic capillary leak syndrome (SCLS)	2	7	Haematology
Toxic epidermal necrolysis/Stevens–Johnson syndrome	Toxic epidermal necrolysis (TEN)/ Stevens–Johnson syndrome (SJS)	2	6	Dermatology
Transient hypogammaglobulinaemia of infancy	Primary immunodeficiency diseases (PID) with antibody deficiency	2	5	Immunology
Wegener granulomatosis	ANCA-positive systemic necrotising vasculitis	2	6	Immunology
Wiskott–Aldrich syndrome	Primary immunodeficiency diseases (PID) with antibody deficiency	2	5	Immunology
X-linked agammaglobulinaemia	Primary immunodeficiency diseases (PID) with antibody deficiency	2	5	Immunology

APPENDIX D – DATASET OF IG SUPPLY BY STATE/TERRITORY 2018-19

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Chapter 5 – has an established therapeutic role										
Acute leukaemia	Patients	73	28	24	14	11	<5			149
	Average Age	35	20	30	49	14	63			31
	Average Weight	58	40	48	72	46	72			54
	Grams	4,161	1,200	1,090	848	445	150			7,893
	Grams/Episode	20	16	13	26	16	30			18
	Grams per 1,000 Population	1	0	0	0	0	0			0
Chronic Immune thrombocytopenic purpura (ITP)	Patients	91	70	51	30	16	<5	<5	<5	264
	Average Age	56	56	57	56	54	35	63	35	56
	Average Weight	80	78	80	76	78	79	90	75	79
	Grams	15,893	8,223	7,426	3,323	1,468	955	180	295	37,761
	Grams/Episode	46	60	35	57	51	68	90	98	47
	Grams per 1,000 Population	2	1	1	2	1	2	1	1	2
Chronic inflammatory demyelinating polyneuropathy	Patients	1036	568	734	100	163	50	16	62	2,682
	Average Age	65	64	63	64	61	63	58	61	64
	Average Weight	82	83	83	80	83	86	80	81	83
	Grams	495,909	293,695	352,554	42,433	117,902	27,453	6,808	22,853	1,359,604
	Grams/Episode	40	41	28	40	45	43	52	41	37
	Grams per 1,000 Population	62	45	70	24	45	52	28	54	54
Chronic lymphocytic leukaemia	Patients	664	400	421	103	105	42	9	34	1,753
	Average Age	73	73	72	73	72	73	66	71	73
	Average Weight	78	77	78	78	74	77	77	79	78
	Grams	178,861	103,759	119,701	25,023	21,793	10,797	2,155	9,273	471,360
	Grams/Episode	27	26	24	27	24	26	28	29	26
	Grams per 1,000 Population	22	16	24	14	8	20	9	22	19
Combined immunodeficiency generally less profound than SCID (e.g. thymoma)	Patients	<5	<5	<5		<5			<5	<20
	Average Age	54	16	53		63			35	38
	Average Weight	51	39	50		77			110	59

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams	153	333	130		180			299	1,094
	Grams/Episode	25	13	16		30			43	21
	Grams per 1,000 Population	0	0	0		0			1	0
Common variable immunodeficiency disease (CVID)	Patients	909	319	341	104	101	26	7	57	1,847
	Average Age	54	46	53	50	45	47	54	48	52
	Average Weight	72	71	75	70	78	73	79	77	73
	Grams	308,191	107,955	125,111	31,855	33,349	9,622	2,037	20,989	639,109
	Grams/Episode	24	24	25	24	24	27	52	23	24
	Grams per 1,000 Population	38	17	25	18	13	18	8	50	25
Dermatomyositis	Patients	102	55	62	15	24	<5		12	268
	Average Age	50	50	49	58	47	44		46	50
	Average Weight	67	70	71	73	78	70		62	69
	Grams	33,986	20,076	25,395	5,368	8,653	210		4,293	97,980
	Grams/Episode	34	40	25	36	27	70		34	31
	Grams per 1,000 Population	4	3	5	3	3	0		10	4
Guillain–Barré syndrome	Patients	298	181	146	40	74	11	6	15	770
	Average Age	51	53	52	58	49	50	37	52	52
	Average Weight	80	76	79	78	80	80	63	82	79
	Grams	51,590	27,210	22,009	5,778	10,820	1,590	690	2,375	122,061
	Grams/Episode	36	39	25	42	32	48	30	68	34
	Grams per 1,000 Population	6	4	4	3	4	3	3	6	5
Inclusion body myositis	Patients	68	52	44	17	5	<5		<5	191
	Average Age	72	71	69	72	69	74		70	71
	Average Weight	81	82	78	78	68	72		78	80
	Grams	22,553	27,841	18,885	6,703	840	1,170		1,545	79,536
	Grams/Episode	35	41	29	33	21	27		37	35
	Grams per 1,000 Population	3	4	4	4	0	2		4	3
ITP associated with HIV	Patients		<5	<5						<8
	Average Age		32	34						33
	Average Weight		72	79						76

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams		145	725						870
	Grams/Episode		73	104						97
	Grams per 1,000 Population		0	0						0
ITP in pregnancy	Patients	16	8	7	<5	<5				<40
	Average Age	29	28	31	33	34				30
	Average Weight	87	94	79	71	75				86
	Grams	5,345	1,438	633	70	333				7,818
	Grams/Episode	67	76	19	70	48				56
	Grams per 1,000	1	0	0	0	0				0
ITP in specific circumstances (surgery, other therapy contraindicated, chronic ITP, concurrent risk factors)	Patients	72	31	50	19	5	5	<5	<5	<188
	Average Age	65	67	61	62	68	75	68	46	64
	Average Weight	80	74	81	80	87	89	54	76	80
	Grams	14,460	4,045	11,995	3,220	1,680	500	55	140	36,095
	Grams/Episode	57	40	35	50	34	83	55	70	44
	Grams per 1,000 Population	2	1	2	2	1	1	0	0	1
ITP refractory acute	Patients	127	107	82	43	22	12		7	399
	Average Age	60	57	56	58	55	64		52	58
	Average Weight	77	77	82	79	77	90		97	79
	Grams	23,927	15,580	15,970	8,765	2,517	1,545		1,620	69,924
	Grams/Episode	52	54	36	61	61	64		81	49
	Grams per 1,000 Population	3	2	3	5	1	3		4	3
ITP with life-threatening haemorrhage or potential life-threatening haemorrhage	Patients	51	42	29	28	6	<5		<5	<168
	Average Age	55	61	55	63	73	53		73	59
	Average Weight	79	78	86	87	87	81		80	82
	Grams	8,640	4,585	4,320	4,250	605	460		340	23,200
	Grams/Episode	56	59	44	71	67	92		68	57
	Grams per 1,000 Population	1	1	1	2	0	1		1	1
Kawasaki disease	Patients	131	125	62	24	32	9	5	<5	<395
	Average Age	3	3	3	4	3	4	3	2	3
	Average Weight	17	15	16	17	17	19	15	13	16

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams	5,418	4,490	2,383	883	1,255	335	178	53	14,993
	Grams/Episode	29	25	16	22	31	30	30	26	24
	Grams per 1,000 Population	1	1	0	1	0	1	1	0	1
Lambert–Eaton myasthenic syndrome	Patients	10	6	9	<5	<5			<5	<38
	Average Age	59	58	63	69	77			74	61
	Average Weight	81	69	76	54	65			64	75
	Grams	5,245	3,445	4,248	150	700			780	14,568
	Grams/Episode	44	46	25	25	47			60	37
	Grams per 1,000 Population	1	1	1	0	0			2	1
Lymphoproliferative syndromes (e.g. XLP1, XLP2, CD27 def)	Patients		<5							<5
	Average Age		27							27
	Average Weight		76							76
	Grams		348							348
	Grams/Episode		23							23
	Grams per 1,000 Population		0							0
Memory B cell deficiency secondary to haemopoietic stem cell transplantation (HSCT)	Patients	21	24	20	9	6	<5		<5	<88
	Average Age	35	44	44	53	41	52		7	42
	Average Weight	53	64	60	81	69	108		23	63
	Grams	1,588	1,967	2,030	873	380	455		50	7,342
	Grams/Episode	19	20	16	19	29	38		10	19
	Grams per 1,000 Population	0	0	0	1	0	1		0	0
Multifocal motor neuropathy with or without persistent conduction block	Patients	230	112	136	46	43	10	9	20	596
	Average Age	60	56	58	61	59	63	58	58	59
	Average Weight	80	80	81	82	81	81	96	87	81
	Grams	119,221	70,127	77,460	35,315	42,390	6,658	7,760	13,945	372,875
	Grams/Episode	44	46	31	47	53	39	83	61	42
	Grams per 1,000 Population	15	11	15	20	16	13	32	33	15
Multiple myeloma	Patients	601	350	448	135	53	40	<5	15	1,638
	Average Age	71	70	71	69	68	68	67	71	71
	Average Weight	77	79	77	82	81	83	99	76	78

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams	143,872	86,293	120,932	29,595	8,812	11,721	1,160	3,402	405,785
	Grams/Episode	29	26	23	28	24	30	39	23	26
	Grams per 1,000 Population	18	13	24	17	3	22	5	8	16
Myasthenia gravis	Patients	392	337	363	50	88	14	<5	24	1,253
	Average Age	62	63	62	67	60	54	52	57	62
	Average Weight	81	81	83	81	79	74	59	81	81
	Grams	163,720	150,429	163,495	13,743	40,575	4,780	275	12,788	549,804
	Grams/Episode	35	39	25	34	35	30	25	44	32
	Grams per 1,000 Population	20	23	32	8	16	9	1	30	22
Necrotising autoimmune myopathy (NAM)	Patients	14	11	8	6	7	<5	<5	<5	<60
	Average Age	65	61	57	66	62	56	68	74	63
	Average Weight	75	77	73	72	86	98	63	44	76
	Grams	4,325	2,185	1,720	1,563	1,648	885	345	260	12,930
	Grams/Episode	31	40	19	41	36	98	31	29	33
	Grams per 1,000 Population	1	0	0	1	1	2	1	1	1
Neonatal haemochromatosis	Patients	<5	<5	<5		<5				<16
	Average Age	36	17	0		0				17
	Average Weight	97	31	2		2				40
	Grams	1,330	1,388	8		5				2,730
	Grams/Episode	95	43	3		3				54
	Grams per 1,000 Population	0	0	0		0				0
Newly Diagnosed Immune thrombocytopenic purpura (ITP)	Patients	139	146	111	43	23	6	<5	7	<484
	Average Age	59	60	57	61	53	52	37	45	58
	Average Weight	76	75	78	82	80	82	84	75	77
	Grams	17,570	15,860	13,883	5,743	1,998	775	358	1,345	57,530
	Grams/Episode	53	55	32	51	59	111	72	90	46
	Grams per 1,000 Population	2	2	3	3	1	1	1	3	2
Non-Hodgkin lymphoma	Patients	560	363	621	134	64	47	11	23	1,808
	Average Age	70	68	68	69	71	66	66	62	69
	Average Weight	76	77	77	78	77	82	71	75	77

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams	145,387	90,281	169,983	29,018	14,217	14,656	1,632	4,649	469,822
	Grams/Episode	28	25	23	24	25	29	27	22	25
	Grams per 1,000 Population	18	14	34	17	5	28	7	11	19
Other primary immunodeficiency	Patients	44	49	16	10	10	<5	<5	5	<144
	Average Age	44	42	25	31	51	39	47	24	40
	Average Weight	59	56	45	56	55	55	68	56	56
	Grams	11,134	12,731	3,399	2,757	2,558	1,325	513	960	35,377
	Grams/Episode	21	23	13	19	20	28	21	19	20
	Grams per 1,000 Population	1	2	1	2	1	2	2	2	1
Other relevant haematological malignancies	Patients	263	81	144	29	37	10	<5	<5	561
	Average Age	62	55	61	56	44	69	65	71	60
	Average Weight	71	66	70	76	66	79	80	91	70
	Grams	49,937	15,794	35,762	5,989	6,600	2,883	185	623	117,770
	Grams/Episode	26	23	20	25	22	28	37	35	24
	Grams per 1,000 Population	6	2	7	3	3	5	1	1	5
Polymyositis	Patients	201	89	133	37	18	6	<5	12	495
	Average Age	64	61	61	67	52	77	57	57	63
	Average Weight	77	80	81	76	76	91	73	74	78
	Grams	69,898	37,777	59,545	14,495	10,640	3,225	750	4,325	200,655
	Grams/Episode	34	40	29	41	33	44	39	30	34
	Grams per 1,000 Population	9	6	12	8	4	6	3	10	8
Possible Common variable immune deficiency (CVID) - below normal serum IgG but normal serum IgA level	Patients	20	15	7	<5	6	<5	<5	<5	<65
	Average Age	51	43	57	18	37	50	13	31	46
	Average Weight	74	58	73	69	85	87	34	58	70
	Grams	3,980	1,807	665	91	483	372	120	284	7,801
	Grams/Episode	29	23	17	13	17	34	15	24	24
	Grams per 1,000 Population	0	0	0	0	0	1	0	1	0
Post-haemopoietic stem cell transplantation	Patients	112	81	87	23	10	8		6	323
	Average Age	48	42	54	49	32	32		54	48
	Average Weight	71	65	74	73	58	56		66	70

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams	21,289	16,208	21,613	5,096	1,820	943		1,093	68,060
	Grams/Episode	25	21	18	21	22	15		21	21
	Grams per 1,000 Population	3	2	4	3	1	2		3	3
Severe combined immunodeficiency (SCID)	Patients	11	9	17	<5	<5				<47
	Average Age	20	15	22	14	32				20
	Average Weight	38	35	41	47	86				42
	Grams	3,706	1,821	3,647	582	740				10,496
	Grams/Episode	22	20	16	12	44				19
	Grams per 1,000 Population	0	0	1	0	0				0
Severe reduction in all Ig isotypes with decreased or absent B-cells (e.g. XLA def)	Patients	<5						<5		<8
	Average Age	27						28		30
	Average Weight	55						70		62
	Grams	532						294		826
	Grams/Episode	20						74		25
	Grams per 1,000 Population	0						1		0
Severe reduction in at least two Ig isotypes with low/normal B-cells (e.g. CVID)	Patients	22	19	13	5	<5	<5	<5	<5	<83
	Average Age	41	49	44	36	51	75	61	23	43
	Average Weight	66	77	73	76	73	89	50	62	71
	Grams	3,163	2,670	1,450	1,247	478	175	120	355	9,656
	Grams/Episode	21	14	18	35	27	35	13	25	19
	Grams per 1,000 Population	0	0	0	1	0	0	0	1	0
Severe reduction in serum IgG and IgA with normal/elevated IgM (e.g. CD40L def)	Patients	<5	<5							<8
	Average Age	33	6							24
	Average Weight	70	24							55
	Grams	258	50							308
	Grams/Episode	23	10							19
	Grams per 1,000 Population	0	0							0
Stiff person syndrome	Patients	48	12	19	<5	5	<5	<5	<5	<100
	Average Age	59	50	59	62	61	36	31	49	57
	Average Weight	78	69	78	75	79	70	62	68	76

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams	27,712	5,255	12,243	390	2,500	2,140	55	930	51,224
	Grams/Episode	44	51	33	30	27	46	28	30	39
	Grams per 1,000 Population	3	1	2	0	1	4	0	2	2
Transient hypogammaglobulinaemia of infancy	Patients	<5	<5	<5						<12
	Average Age	2	0	49						13
	Average Weight	13	8	60						22
	Grams	13	27	293						332
	Grams/Episode	3	2	23						11
	Grams per 1,000 Population	0	0	0						0
Wiskott–Aldrich syndrome	Patients	<5	<5		<5	<5		<5		<20
	Average Age	0	1		15	34		15		14
	Average Weight	6	12		28	69		28		32
	Grams	6	50		20	730		40		845
	Grams/Episode	3	4		10	24		10		16
	Grams per 1,000 Population	0	0		0	0		0		0
X-linked agammaglobulinaemia	Patients	40	45	16	7	7		<5	<5	<123
	Average Age	31	34	26	18	17		25	13	30
	Average Weight	63	63	55	54	50		50	57	61
	Grams	13,542	16,661	4,855	2,324	1,893		665	282	40,221
	Grams/Episode	27	23	19	23	21		17	15	23
	Grams per 1,000 Population	2	3	1	1	1		3	1	2
Chapter 5 Total	**Patients**	**6,263**	**3,632**	**4,119**	**1,035**	**928**	**317**	**89**	**321**	**16,522**
	Average Age	**62**	**58**	**61**	**61**	**55**	**60**	**52**	**56**	**60**
	Average Weight	**76**	**74**	**77**	**76**	**75**	**78**	**72**	**77**	**76**
	Grams	**1,976,508**	**1,153,743**	**1,405,551**	**287,502**	**341,002**	**105,778**	**26,373**	**110,141**	**5,406,598**
	Grams/Episode	**32**	**32**	**26**	**32**	**34**	**34**	**44**	**34**	**30**
	Grams per 1,000 Population	**246**	**177**	**278**	**165**	**131**	**199**	**107**	**260**	**215**
Chapter 6 – has an emerging therapeutic role										
Acute disseminated encephalomyelitis	Patients	29	13	23	<5	<5	<5	<5	<5	<90
	Average Age	39	19	20	2	11	15	7	39	27

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Average Weight	61	48	46	14	33	56	31	112	52
	Grams	6,730	3,183	3,153	73	330	113	320	190	14,090
	Grams/Episode	31	35	22	15	21	56	80	48	29
	Grams per 1,000 Population	1	0	1	0	0	0	1	0	1
Autoimmune haemolytic anaemia	Patients	29	34	27	10	9	<5	<5		<119
	Average Age	58	60	58	72	60	27	49		59
	Average Weight	72	68	75	75	80	56	54		72
	Grams	5,388	4,005	4,158	3,020	700	735	368		18,373
	Grams/Episode	40	54	31	47	47	43	26		40
	Grams per 1,000 Population	1	1	1	2	0	1	1		1
Bullous pemphigoid	Patients	13	13	10	<5	<5	<5		<5	<51
	Average Age	75	72	65	68	84	28		66	71
	Average Weight	94	92	91	100	82	80		64	91
	Grams	5,413	5,345	12,190	590	695	160		130	24,523
	Grams/Episode	58	75	47	84	58	80		26	55
	Grams per 1,000 Population	1	1	2	0	0	0		0	1
Churg-Strauss syndrome	Patients					<5				<5
	Average Age					62				62
	Average Weight					60				60
	Grams					705				705
	Grams/Episode					24				24
	Grams per 1,000 Population					0				0
Cicatricial pemphigoid/ mucous membrane pemphigoid	Patients	<5	<5	12	<5	<5	<5		<5	<38
	Average Age	56	66	73	63	62	62		61	67
	Average Weight	72	105	82	98	85	61		102	84
	Grams	2,770	2,220	7,000	620	2,665	2,040		2,715	20,030
	Grams/Episode	62	93	34	78	35	102		82	48
	Grams per 1,000 Population	0	0	1	0	1	4		6	1
Encephalitis associated with antibodies to CASPR2	Patients	6		<5						<11
	Average Age	50		17						46

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Average Weight	74		65						73
	Grams	2,010		305						2,315
	Grams/Episode	30		22						28
	Grams per 1,000 Population	0		0						0
Encephalitis associated with antibodies to GABA (A or B) receptor	Patients	<5	<5	<5		<5				<16
	Average Age	64	60	80		53				64
	Average Weight	98	50	56		69				78
	Grams	475	20	113		140				748
	Grams/Episode	40	20	11		28				27
	Grams per 1,000 Population	0	0	0		0				0
Encephalitis associated with antibodies to glycine receptor	Patients	<5	<5	<5						<12
	Average Age	47	2	30						26
	Average Weight	42	16	50						36
	Grams	15	15	20						50
	Grams/Episode	15	15	20						17
	Grams per 1,000 Population	0	0	0						0
Encephalitis associated with antibodies to LGI1	Patients	<5	<5	<5						<8
	Average Age	68	56	51						61
	Average Weight	80	81	85						82
	Grams	938	325	425						1,688
	Grams/Episode	27	33	39						30
	Grams per 1,000 Population	0	0	0						0
Encephalitis associated with antibodies to NMDA receptor	Patients	16	18	7	<5	<5	<5	<5	<5	<64
	Average Age	31	30	29	54	26	2	32	43	31
	Average Weight	65	54	76	78	85	12	90	75	65
	Grams	2,993	2,090	1,138	705	665	35	180	150	7,955
	Grams/Episode	30	26	19	37	35	18	36	150	28
	Grams per 1,000 Population	0	0	0	0	0	0	1	0	0
Encephalitis associated with antibodies to VGKC	Patients	<5	5	<5				<5		<16
	Average Age	54	74	39				83		59

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Average Weight	105	83	68				70		82
	Grams	610	670	575				115		1,970
	Grams/Episode	47	32	14				23		25
	Grams per 1,000 Population	0	0	0				0		0
Evans syndrome	Patients	<5	7	<5	<5	<5	<5			<24
	Average Age	63	34	60	34	77	33			47
	Average Weight	88	48	93	60	84	133			72
	Grams	805	738	670	60	65	235			2,573
	Grams/Episode	73	46	45	60	65	78			55
	Grams per 1,000 Population	0	0	0	0	0	0			0
Feto-maternal/neonatal alloimmune thrombocytopenia (Antenatal)	Patients	6	5	<5	<5	<5				<28
	Average Age	31	31	32	41	36				33
	Average Weight	80	86	76	53	76				79
	Grams	3,498	3,990	2,798	473	2,890				13,648
	Grams/Episode	70	77	30	36	60				54
	Grams per 1,000 Population	0	1	1	0	1				1
Feto-maternal/neonatal alloimmune thrombocytopenia (Neonatal)	Patients	12	9	7	<5	<5	<5			<43
	Average Age	0	0	13	15	0	0			4
	Average Weight	3	3	33	28	3	4			11
	Grams	70	45	3,530	830	18	5			4,498
	Grams/Episode	3	3	56	44	2	3			35
	Grams per 1,000 Population	0	0	1	0	0	0			0
Haemophagocytic lymphohistiocytosis	Patients	6	12	11						29
	Average Age	55	38	48						46
	Average Weight	65	62	58						61
	Grams	545	1,028	1,963						3,535
	Grams/Episode	50	41	34						38
	Grams per 1,000 Population	0	0	0						0
Haemophagocytic syndrome	Patients	10	6	5		<5				<27
	Average Age	44	56	70		23				52

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Average Weight	53	68	65		55				60
	Grams	1,390	1,110	730		110				3,340
	Grams/Episode	50	79	33		18				48
	Grams per 1,000 Population	0	0	0		0				0
IgG subclass deficiency (existing authorisation)	Patients	8	16	<5	<5	<5	<5			<46
	Average Age	69	67	55	67	62	62			66
	Average Weight	99	75	65	81	73	63			80
	Grams	3,284	6,105	833	1,195	1,210	825			13,452
	Grams/Episode	22	24	15	29	24	25			23
	Grams per 1,000 Population	0	1	0	1	0	2			1
IgM para-proteinaemic neuropathy	Patients	29	16	23	<5	<5	5		<5	<91
	Average Age	74	74	66	65	75	69		73	72
	Average Weight	81	83	90	85	75	89		69	83
	Grams	14,168	5,538	12,179	510	3,018	1,520		343	37,274
	Grams/Episode	39	38	30	32	51	34		34	36
	Grams per 1,000 Population	2	1	2	0	1	3		1	1
ITP in children	Patients	33	49	33	9	5	<5		<5	<142
	Average Age	6	5	6	8	4	6		10	6
	Average Weight	24	24	28	39	18	24		46	26
	Grams	3,237	3,438	1,153	903	218	273		173	9,392
	Grams/Episode	26	21	14	20	18	34		19	21
	Grams per 1,000 Population	0	1	0	1	0	1		0	0
Kidney transplantation post-transplant	Patients	112	219	41	15	30	20	5	<5	<449
	Average Age	46	50	49	46	51	46	42	48	48
	Average Weight	75	76	76	68	75	78	72	70	76
	Grams	16,435	71,405	11,212	2,158	4,933	10,210	730	738	117,820
	Grams/Episode	23	29	14	22	39	49	16	41	26
	Grams per 1,000 Population	2	11	2	1	2	19	3	2	5
Kidney transplantation pre-transplant	Patients	21	8	<5	<5	<5				<47
	Average Age	44	64	39	54	47				49

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Average Weight	71	82	60	86	57				73
	Grams	1,860	320	93	425	343				3,040
	Grams/Episode	29	13	31	30	57				27
	Grams per 1,000 Population	0	0	0	0	0				0
Macrophage activation syndrome	Patients	<5	5	<5						<13
	Average Age	7	53	69						49
	Average Weight	34	67	68						62
	Grams	68	690	180						938
	Grams/Episode	68	53	30						47
	Grams per 1,000 Population	0	0	0						0
Microscopic polyangiitis	Patients			<5		<5				<8
	Average Age			67		39				48
	Average Weight			62		55				57
	Grams			125		1,385				1,510
	Grams/Episode			25		37				36
	Grams per 1,000 Population			0		1				0
Multiple sclerosis - severe relapse with no response to high dose methylprednisolone	Patients	7		<5						<12
	Average Age	47		34						44
	Average Weight	90		64						83
	Grams	1,750		370						2,120
	Grams/Episode	33		46						35
	Grams per 1,000 Population	0		0						0
Multiple sclerosis in pregnancy and the immediate post-partum period	Patients	<5	<5							<8
	Average Age	36	39							38
	Average Weight	100	70							77
	Grams	80	578							658
	Grams/Episode	40	53							51
	Grams per 1,000	0	0							0
Multiple sclerosis in young patients	Patients	11	<5	<5					<5	<24
	Average Age	44	44	66					44	46

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
severe/relapsing/remitting in whom other therapies have failed	Average Weight	74	66	83					59	72
	Grams	3,203	575	515					348	4,640
	Grams/Episode	31	29	30					23	30
	Grams per 1,000 Population	0	0	0					1	0
Opsoclonus myoclonus ataxia	Patients	12	<5	<5	<5	<5	<5			<40
	Average Age	26	23	46	44	14	61			28
	Average Weight	42	30	46	69	38	85			43
	Grams	2,283	603	195	1,405	240	170			4,895
	Grams/Episode	23	17	22	70	17	57			27
	Grams per 1,000 Population	0	0	0	1	0	0			0
Pemphigus foliaceus	Patients	<5	<5	<5	<5			<5		<20
	Average Age	58	90	56	48			62		61
	Average Weight	62	68	72	44			105		69
	Grams	1,240	135	880	450			168		2,873
	Grams/Episode	40	135	31	45			56		39
	Grams per 1,000 Population	0	0	0	0			1		0
Pemphigus vulgaris	Patients	14	7	8	<5	<5			<5	<43
	Average Age	57	53	59	60	68			92	58
	Average Weight	82	72	85	100	104			60	82
	Grams	12,898	3,060	6,838	600	1,358			120	24,873
	Grams/Episode	72	45	39	67	36			60	53
	Grams per 1,000 Population	2	0	1	0	1			0	1
Post-transfusion purpura (PTP)	Patients	<5	<5							<8
	Average Age	65	81							69
	Average Weight	70	98							77
	Grams	420	100							520
	Grams/Episode	47	100							52
	Grams per 1,000 Population	0	0							0
	Patients	<5	<5	5						<13
	Average Age	74	49	77						73

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
PR3 or MPO ANCA-positive idiopathic rapidly progressive glomerulonephritis	Average Weight	119	192	77						102
	Grams	785	640	1,625						3,050
	Grams/Episode	49	58	36						42
	Grams per 1,000 Population	0	0	0						0
Relapsing remitting multiple sclerosis	Patients	7	<5	<5	<5					<25
	Average Age	43	40	54	57					45
	Average Weight	74	78	77	103					76
	Grams	2,566	278	490	120					3,453
	Grams/Episode	28	35	16	40					26
	Grams per 1,000 Population	0	0	0	0					0
Secondary hypogammaglobulinaemia (excluding haematological malignancies)	Patients	426	222	295	20	50	32	<5	16	1,045
	Average Age	57	55	60	49	49	55	66	59	57
	Average Weight	72	69	74	58	69	71	66	75	71
	Grams	101,188	48,082	78,655	3,747	10,328	7,660	165	3,058	252,882
	Grams/Episode	25	22	22	21	20	28	28	25	23
	Grams per 1,000 Population	13	7	16	2	4	14	1	7	10
Sero-negative autoimmune encephalitis	Patients	14	7	9			<5			31
	Average Age	45	58	41			51			47
	Average Weight	75	76	85			77			78
	Grams	3,620	1,510	2,239			330			7,699
	Grams/Episode	28	44	19			37			27
	Grams per 1,000 Population	0	0	0			1			0
Sero-negative limbic encephalitis	Patients	6	<5	10						<24
	Average Age	43	65	37						44
	Average Weight	69	77	67						69
	Grams	1,245	355	2,035						3,635
	Grams/Episode	31	32	21						24
	Grams per 1,000 Population	0	0	0						0
Solid organ - heart	Patients	10	<5	<5		<5				<29
	Average Age	48	60	54		48				51

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Average Weight	83	66	79		69				78
	Grams	1,215	703	1,845		140				3,903
	Grams/Episode	23	31	36		70				30
	Grams per 1,000 Population	0	0	0		0				0
Solid organ - heart/lung	Patients	<5								<5
	Average Age	36								36
	Average Weight	44								44
	Grams	460								460
	Grams/Episode	20								20
	Grams per 1,000 Population	0								0
Solid organ - liver	Patients	<5	<5	<5						<12
	Average Age	21	72	32						30
	Average Weight	59	79	68						64
	Grams	495	130	192						817
	Grams/Episode	29	19	6						15
	Grams per 1,000 Population	0	0	0						0
Solid organ - lung	Patients	28	78	5	6	<5	5	<5		<128
	Average Age	39	52	35	55	56	65	58		48
	Average Weight	61	72	55	77	52	75	72		69
	Grams	3,760	16,883	395	625	70	835	35		22,603
	Grams/Episode	26	25	12	39	35	26	35		25
	Grams per 1,000 Population	0	3	0	0	0	2	0		1
Solid organ - other	Patients		<5		<5					<8
	Average Age		61		61					61
	Average Weight		80		75					78
	Grams		80		80					160
	Grams/Episode		80		40					53
	Grams per 1,000 Population		0		0					0
Specific antibody deficiency	Patients	144	56	54	25	68	<5		7	354
	Average Age	52	58	52	50	46	31		36	51

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Average Weight	69	73	75	64	68	71		75	70
	Grams	37,690	14,194	15,402	6,714	18,263	571		2,662	95,495
	Grams/Episode	20	24	21	21	21	34		18	21
	Grams per 1,000 Population	5	2	3	4	7	1		6	4
Staphylococcal TSS	Patients	8	17	8		5			<5	<45
	Average Age	29	38	34		49			37	36
	Average Weight	44	71	81		84			90	70
	Grams	655	2,123	975		675			280	4,708
	Grams/Episode	41	79	44		96			70	62
	Grams per 1,000 Population	0	0	0		0			1	0
Streptococcal TSS	Patients	38	46	16	7	19	8	<5	5	<145
	Average Age	46	46	36	44	48	37	7	42	44
	Average Weight	73	76	64	70	76	71	26	95	73
	Grams	5,013	5,178	1,358	890	2,590	1,100	105	800	17,033
	Grams/Episode	96	81	39	81	100	100	18	114	80
	Grams per 1,000 Population	1	1	0	1	1	2	0	2	1
Suspected autoimmune encephalitis	Patients	42	36	27	6	6	<5	<5	5	<129
	Average Age	44	55	49	45	49	2	56	59	49
	Average Weight	60	75	68	48	71	13	61	59	65
	Grams	5,510	5,420	4,836	550	670	50	245	890	18,171
	Grams/Episode	27	43	21	21	22	13	35	39	28
	Grams per 1,000 Population	1	1	1	0	0	0	1	2	1
Suspected autoimmune limbic encephalitis	Patients	10	6	13	<5	<5	<5	<5		<45
	Average Age	63	53	46	78	80	83	76		58
	Average Weight	67	86	73	80	75	60	71		73
	Grams	1,600	1,033	2,360	95	805	120	210		6,222
	Grams/Episode	24	52	24	32	50	120	23		29
	Grams per 1,000 Population	0	0	0	0	0	0	1		0
	Patients	20	21	<5	<5		<5	<5	<5	<58
	Average Age	45	47	31	65		78	69	28	47

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Toxic epidermal necrolysis/Stevens–Johnson syndrome	Average Weight	84	73	45	56		85	63	69	76
	Grams	3,405	3,695	250	110		170	128	595	8,353
	Grams/Episode	58	56	125	55		57	64	99	60
	Grams per 1,000 Population	0	1	0	0		0	1	1	0
Wegener granulomatosis	Patients		<5	<5						<8
	Average Age		61	55						58
	Average Weight		45	60						53
	Grams		45	95						140
	Grams/Episode		11	24						18
	Grams per 1,000 Population		0	0						0
Chapter 6 Total	**Patients**	**1,138**	**935**	**678**	**125**	**235**	**94**	**22**	**55**	**3,248**
	Average Age	**52**	**49**	**52**	**48**	**47**	**48**	**46**	**48**	**51**
	Average Weight	**70**	**69**	**71**	**64**	**69**	**70**	**62**	**74**	**70**
	Grams	**263,778**	**217,673**	**186,085**	**26,946**	**55,226**	**27,157**	**2,768**	**13,189**	**792,821**
	Grams/Episode	**27**	**29**	**24**	**28**	**27**	**39**	**25**	**33**	**27**
	Grams per 1,000 Population	**33**	**33**	**37**	**15**	**21**	**51**	**11**	**31**	**31**
Chapter 7 - has application in exceptional circumstances only										
Acute leukaemia in children	Patients			<5		<5				<8
	Average Age			3		1				2
	Average Weight			13		7				10
	Grams			15		20				35
	Grams/Episode			5		3				3
	Grams per 1,000 Population			0		0				0
Autoimmune neutropenia	Patients	5	<5	<5	<5	<5			<5	<20
	Average Age	38	60	72	60	24			48	50
	Average Weight	57	100	68	75	78			66	70
	Grams	785	400	450	175	30			130	1,970
	Grams/Episode	49	67	38	25	30			22	41
	Grams per 1,000 Population	0	0	0	0	0			0	0
Autoimmune retinopathy	Patients		<5							<5

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Average Age		38							38
	Average Weight		110							110
	Grams		200							200
	Grams/Episode		40							40
	Grams per 1,000 Population		0							0
Autoimmune uveitis	Patients		<5							<5
	Average Age		55							55
	Average Weight		82							82
	Grams		1,700							1,700
	Grams/Episode		71							71
	Grams per 1,000 Population		0							0
Catastrophic antiphospholipid syndrome	Patients	5	<5	7		<5	<5	<5		<27
	Average Age	56	66	50		65	59	18		53
	Average Weight	88	75	75		66	70	70		78
	Grams	910	220	1,253		60	140	140		2,723
	Grams/Episode	38	110	30		60	28	28		34
	Grams per 1,000 Population	0	0	0		0	0	1		0
Cerebellar degeneration	Patients	<5	5	<5	<5	<5	<5		<5	<28
	Average Age	55	59	74	63	69	66		74	66
	Average Weight	117	78	70	69	73	98		82	79
	Grams	225	1,775	543	540	180	210		373	3,845
	Grams/Episode	45	40	22	30	60	19		37	33
	Grams per 1,000 Population	0	0	0	0	0	0		1	0
Coagulation factor inhibitors	Patients	5	<5	<5	10					<23
	Average Age	73	71	55	63					66
	Average Weight	59	82	102	71					74
	Grams	1,620	810	1,820	2,585					6,835
	Grams/Episode	49	54	55	44					49
	Grams per 1,000 Population	0	0	0	1					0
	Patients	28	<5	7	<5	<5				<50

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Devic disease (neuromyelitis optica)	Average Age	51	24	50	23	58				49
	Average Weight	70	54	82	60	69				71
	Grams	9,619	1,270	1,755	120	1,505				14,269
	Grams/Episode	32	49	18	40	50				31
	Grams per 1,000 Population	1	0	0	0	1				1
Diabetic amyotrophy	Patients	<5	9	5	<5					<23
	Average Age	62	67	55	47					62
	Average Weight	70	89	71	122					83
	Grams	625	2,430	980	200					4,235
	Grams/Episode	16	43	31	40					32
	Grams per 1,000 Population	0	0	0	0					0
Epidermolysis bullosa acquisita	Patients		<5		<5	<5			<5	<16
	Average Age		59		49	72			49	58
	Average Weight		100		92	116			73	95
	Grams		150		740	1,955			850	3,695
	Grams/Episode		150		39	63			45	53
	Grams per 1,000 Population		0		0	1			2	0
Epilepsy (rare childhood cases)	Patients	8	5	16						28
	Average Age	12	10	13						12
	Average Weight	38	29	34						34
	Grams	1,838	1,280	3,425						6,543
	Grams/Episode	26	20	13						16
	Grams per 1,000 Population	0	0	1						0
Graves ophthalmopathy	Patients			<5		<5				<8
	Average Age			55		58				56
	Average Weight			75		59				70
	Grams			880		648				1,528
	Grams/Episode			31		25				28
	Grams per 1,000 Population			0		0				0
	Patients	16	<5	6		<5		<5	<5	<43

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Haemolytic disease of the newborn	Average Age	6	8	33		0		0	28	14
	Average Weight	14	23	84		3		3	54	33
	Grams	943	738	4,930		5		3	2,633	9,250
	Grams/Episode	27	49	62		3		3	54	51
	Grams per 1,000 Population	0	0	1		0		0	6	0
Hashimoto encephalopathy	Patients	10	<5	<5		<5				<27
	Average Age	41	35	74		47				42
	Average Weight	78	70	78		58				75
	Grams	3,825	920	570		690				6,005
	Grams/Episode	37	46	16		38				34
	Grams per 1,000 Population	0	0	0		0				0
LETMs	Patients	<5								<5
	Average Age	9								9
	Average Weight	60								60
	Grams	135								135
	Grams/Episode	45								45
	Grams per 1,000 Population	0								0
Limbic encephalitis	Patients	11	<5	9		<5				<28
	Average Age	60	69	52		17				56
	Average Weight	78	72	70		49				74
	Grams	2,683	235	2,698		220				5,835
	Grams/Episode	30	26	19		55				24
	Grams per 1,000 Population	0	0	1		0				0
Limbic encephalitis, nonparaneoplastic	Patients	76	45	92	<5	7	<5	<5	<5	<236
	Average Age	47	48	45	62	46	62	52	66	47
	Average Weight	73	67	80	60	88	82	78	61	75
	Grams	17,982	10,268	35,415	70	2,285	345	155	270	66,789
	Grams/Episode	35	32	25	18	42	35	31	21	28
	Grams per 1,000 Population	2	2	7	0	1	1	1	1	3
Myocarditis in children	Patients		5		<5	<5		<5		<19

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Average Age		3		0	1		0		2
	Average Weight		21		4	8		6		14
	Grams		405		10	3		10		428
	Grams/Episode		45		5	1		10		29
	Grams per 1,000 Population		0		0	0		0		0
NMOSD–AQP4 ab positive	Patients	<5	<5	<5						<12
	Average Age	76	43	58						59
	Average Weight	79	70	94						81
	Grams	210	140	188						538
	Grams/Episode	26	35	13						20
	Grams per 1,000 Population	0	0	0						0
NMOSD–MOG ab positive	Patients	<5	<5							<8
	Average Age	3	20							14
	Average Weight	18	38							31
	Grams	53	300							353
	Grams/Episode	18	25							24
	Grams per 1,000 Population	0	0							0
NMOSD–seronegative	Patients	9	<5	<5	<5				<5	<24
	Average Age	45	9	36	67				23	41
	Average Weight	76	48	83	55				78	74
	Grams	1,780	465	320	110				155	2,830
	Grams/Episode	46	47	107	55				155	51
	Grams per 1,000 Population	0	0	0	0				0	0
PANDAS/tic disorders	Patients	8	<5	12		<5				<30
	Average Age	10	14	11		12				11
	Average Weight	38	46	59		49				48
	Grams	4,668	370	6,338		1,088				12,463
	Grams/Episode	63	31	27		39				36
	Grams per 1,000 Population	1	0	1		0				0
	Patients	11	<5	<5	<5	<5	<5			<32

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Potassium channel antibody-associated encephalopathy	Average Age	56	59	59	67	67	58			58
	Average Weight	72	80	74	80	65	87			74
	Grams	3,598	1,418	1,735	620	588	1,363			9,320
	Grams/Episode	27	39	53	31	35	33			33
	Grams per 1,000 Population	0	0	0	0	0	3			0
Pure red cell aplasia	Patients	14	11	7	<5	<5	<5		<5	<51
	Average Age	52	38	52	60	55	64		56	50
	Average Weight	65	54	81	80	78	92		57	69
	Grams	3,321	1,165	2,305	605	310	1,068		93	8,866
	Grams/Episode	41	51	32	43	78	43		46	40
	Grams per 1,000 Population	0	0	0	0	0	2		0	0
Pure white cell aplasia	Patients					<5				<5
	Average Age					13				13
	Average Weight					34				34
	Grams					33				33
	Grams/Episode					33				33
	Grams per 1,000 Population					0				0
Pyoderma gangrenosum	Patients	5	22	5	<5	<5			<5	<45
	Average Age	74	62	70	40	39			18	63
	Average Weight	82	87	88	125	63			70	87
	Grams	1,365	13,545	1,957	400	1,090			130	18,487
	Grams/Episode	49	54	19	57	39			26	44
	Grams per 1,000 Population	0	2	0	0	0			0	1
Rasmussen Syndrome	Patients	13	6	<5	<5	<5			<5	<35
	Average Age	34	19	40	36	11			61	32
	Average Weight	65	47	70	118	55			62	63
	Grams	7,461	1,615	1,205	660	385			325	11,651
	Grams/Episode	35	27	20	51	48			25	32
	Grams per 1,000 Population	1	0	0	0	0			1	0
Scleromyxedema	Patients	5	5	<5	<5	<5				<25

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Average Age	61	64	70	74	52				63
	Average Weight	75	68	80	57	78				72
	Grams	3,370	1,398	155	1,675	2,505				9,103
	Grams/Episode	47	23	13	37	49				38
	Grams per 1,000 Population	0	0	0	1	1				0
Sjögren's syndrome	Patients	9	<5	<5	<5				<5	<29
	Average Age	61	75	56	64				67	62
	Average Weight	74	80	79	70				75	74
	Grams	3,695	160	310	1,155				2,553	7,873
	Grams/Episode	31	53	24	36				57	37
	Grams per 1,000 Population	0	0	0	1				6	0
Subacute sensory neuropathy	Patients	5	<5	7	<5	<5		<5		<28
	Average Age	59	70	61	66	51		62		62
	Average Weight	67	76	79	72	66		103		75
	Grams	1,575	475	1,575	300	165		668		4,758
	Grams/Episode	32	26	31	30	55		67		34
	Grams per 1,000 Population	0	0	0	0	0		3		0
Susac syndrome	Patients	11	<5	6						21
	Average Age	42	30	49						42
	Average Weight	91	68	91						87
	Grams	9,035	1,380	3,360						13,775
	Grams/Episode	43	25	46						41
	Grams per 1,000 Population	1	0	1						1
Systemic capillary leak syndrome	Patients	7	<5	<5		<5			<5	<26
	Average Age	34	56	11		34			68	37
	Average Weight	61	69	43		93			70	67
	Grams	3,250	3,333	405		1,455			1,680	10,123
	Grams/Episode	32	57	37		77			84	48
	Grams per 1,000 Population	0	1	0		1			4	0
Chapter 7 Total	**Patients**	**264**	**155**	**208**	**34**	**36**	**8**	**5**	**22**	**729**

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Average Age	**45**	**46**	**44**	**58**	**39**	**62**	**26**	**53**	**46**
	Average Weight	**68**	**67**	**75**	**73**	**67**	**87**	**52**	**67**	**70**
	Grams	**84,567**	**48,563**	**74,585**	**9,965**	**15,218**	**3,125**	**975**	**9,190**	**246,231**
	Grams/Episode	**36**	**40**	**26**	**38**	**45**	**34**	**44**	**50**	**33**
	Grams per 1,000 Population	**11**	**7**	**15**	**6**	**6**	**6**	**4**	**22**	**10**
Chapter 8 - use is not supported										
Idiopathic dilated cardiomyopathy	Patients							<5		<5
	Average Age							0		0
	Average Weight							3		3
	Grams							3		3
	Grams/Episode							3		3
	Grams per 1,000 Population							0		0
Paraneoplastic Subacute Sensory Neuropathy	Patients		<5							<5
	Average Age		72							72
	Average Weight		47							47
	Grams		45							45
	Grams/Episode		15							15
	Grams per 1,000 Population		0							0
Sepsis	Patients	<5	<5	<5						<12
	Average Age	67	48	36						54
	Average Weight	79	75	108						85
	Grams	180	150	120						450
	Grams/Episode	90	150	40						75
	Grams per 1,000 Population	0	0	0						0
Chapter 8 Total	**Patients**	**<5**	**<5**	**<5**				**<5**		**<17**
	Average Age	**67**	**60**	**36**				**0**		**43**
	Average Weight	**90**	**98**	**120**				**3**		**69**
	Grams	**180**	**195**	**120**				**3**		**453**
	Grams/Episode	**90**	**49**	**40**				**3**		**65**
	Grams per 1,000 Population	**0**	**0**	**0**				**0**		**0**

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Total	Patients	7,649	4,679	4,952	1,188	1,193	410	115	394	20,358
	Average Age	60	56	59	60	53	57	50	55	58
	Average Weight	75	73	76	75	74	77	69	76	75
	Grams	2,325,032	1,420,173	1,666,341	324,413	411,445	136,059	30,118	132,520	6,446,102
	Grams/Episode	31	32	25	32	33	35	41	34	30
	Grams per 1,000 Population	289	218	330	186	158	256	123	313	256

Note 1: The national patient count only includes one count for each patient. This may result in the sum of the state and territory totals being greater than the national total.

Note 2: To maintain the anonymity of individual patients and health providers, data showing less than five (5) have be suppressed or aggregated if there is a potential to re-identify or exceptions are agreed between national and state/territory data custodians.

APPENDIX E – SYSTEM SOURCE FOR TABLES AND FIGURES