NATIONAL BLOOD AUTHORITY
AUSTRALIA

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

ANNUAL REPORT 2020-21

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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 immunoglobulin (IVIg), subcutaneous immunoglobulin (SCIg), and normal human immunoglobulin (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 2020-21. 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 revision 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.

Version 3 of the Criteria clearly articulates and standardises the qualifying and continuing Ig access requirements. In 2020-21, 139 specific conditions or 56 medical conditions were classified into 4 categories:

(i) conditions for which Ig has an established therapeutic
(ii) conditions that have an emerging therapeutic role
(iii) conditions where Ig has application in exceptional circumstances only
(iv) conditions for which Ig should not be supplied under the national blood arrangements.

The differences between versions of the Criteria should be taken into consideration when comparing data from the 2020-21 Ig Annual Report with previous annual reports.

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 role can request patient authorisation for access to government-funded Ig. Under the governance arrangements, persons in 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 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 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 about 89 per cent of all Ig supplied in 2020-21, 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 an annual rate of more than 10 per cent up to and including 2017-18. This growth in demand moderated and did not exceed 7.4 per cent in each of the last three years. This is the lowest annual rate of increase since 2004-05, when Australia first secured an adequate national sufficiency of Ig supply through the importation of Ig by the NBA. Growth since 2016-17 is shown below.

Table 1: Ig growth for the last 5 years

2016-17	2017-18	2018-19	2019-20	2020-21
11.2%	10.6%	7.2%	6.7%	7.4%

In 2020-21, a total of approximately 7.5 million grams of Ig was issued nationally at a cost of $742.3 million (including the cost of plasma for fractionation). Of this amount, about 53 per cent of Ig was produced in Australia and 47 per cent was imported.

The NBA maintains arrangements with a diverse set of suppliers to secure a range of Ig products. Immunoglobulin products imported from overseas complement the supply of domestic plasma-derived products supplied by CSL Behring under the National Fractionation Agreement for Australia (NaFAA) and ensure that the overall clinical demand for blood products in Australia is met.

In 2020-21, the NBA completed a procurement for imported Ig products to replace expiring contracts. The NBA negotiated new contracts with 4 suppliers, which replaced 2 previous contracts for part of 2020-21. This improved the diversity and security of supply arrangements in a difficult global market and achieved good average price outcomes.

The supply of Ig products from the combination of all 4 suppliers (CSL Behring, Grifols Australia, Takeda Pharmaceutical Company and Octapharma Pty Ltd) was sufficient to meet the clinical demand for these products in Australia in 2020-21.

Report Snapshot

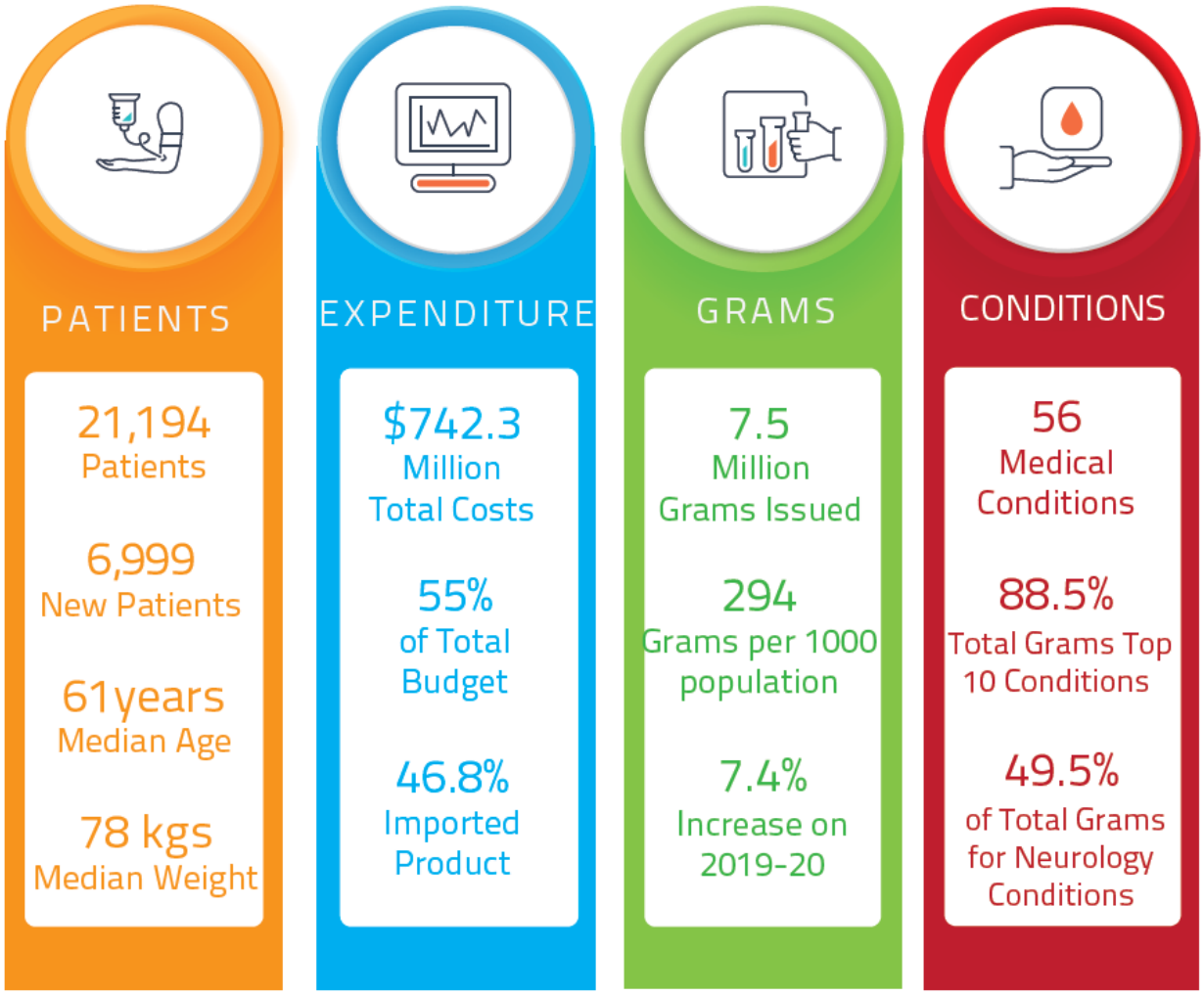

Figure 1: Snapshot

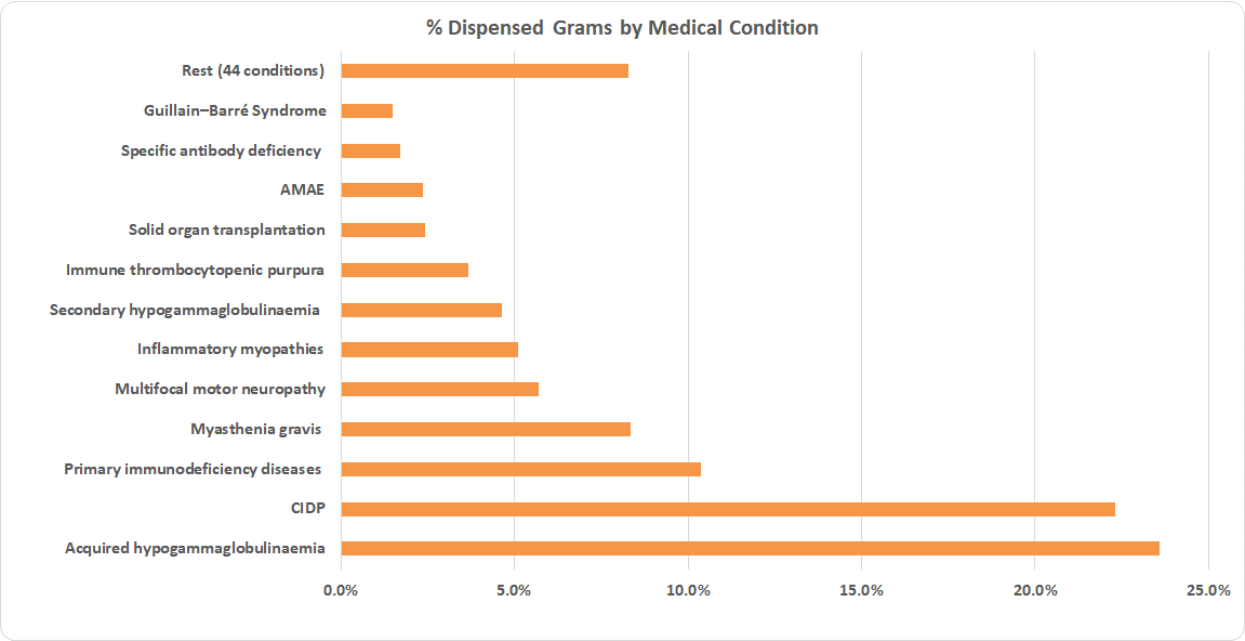

Figure 2: Per cent dispensed grams by medical condition

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 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. It 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 include weight. Legacy data entered in BloodSTAR did not include 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 since 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, not the treating facility state or territory.
- 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 and in BloodSTAR these are known as Dispense Events. In this document we have used Dispense Events.
- 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,
  - dispense events recorded at both 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 and are used in reporting from 2019-20.
- 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.
- Dispensed data can be entered into BloodSTAR at any time, if there is a valid and active authorisation. This means that a Dispense Event may be recorded in one month and the actual Dispense Event was in another month which means data for 2019-20 could be recorded in 2020-21.

- 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 NBA's IDMS,
2. Data 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 into 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 1.6 per cent represents less than 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	Difference Grams	Difference %
NSW	2,669,721	2,608,683	61,039	2.3%
VIC	1,633,350	1,610,766	22,585	1.4%
QLD	1,915,827	1,901,946	13,881	0.7%
SA	376,142	370,267	5,875	1.6%
WA	562,313	549,007	13,306	2.4%
TAS	167,750	165,617	2,133	1.3%
NT	27,863	27,187	676	2.4%
ACT	177,345	178,894	-1,549	-0.9%
Total	**7,530,311**	**7,412,365**	**117,946**	**1.6%**
Other	800			
Total	**7,531,111**			

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

Trends

DEMAND TRENDS

In 2020-21, a total of 7,530,311 grams of Ig was issued, representing an increase of 520,135 grams (7.4 per cent) over 2019-20. Prior to 2018-19, the increase in Ig use averaged 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.

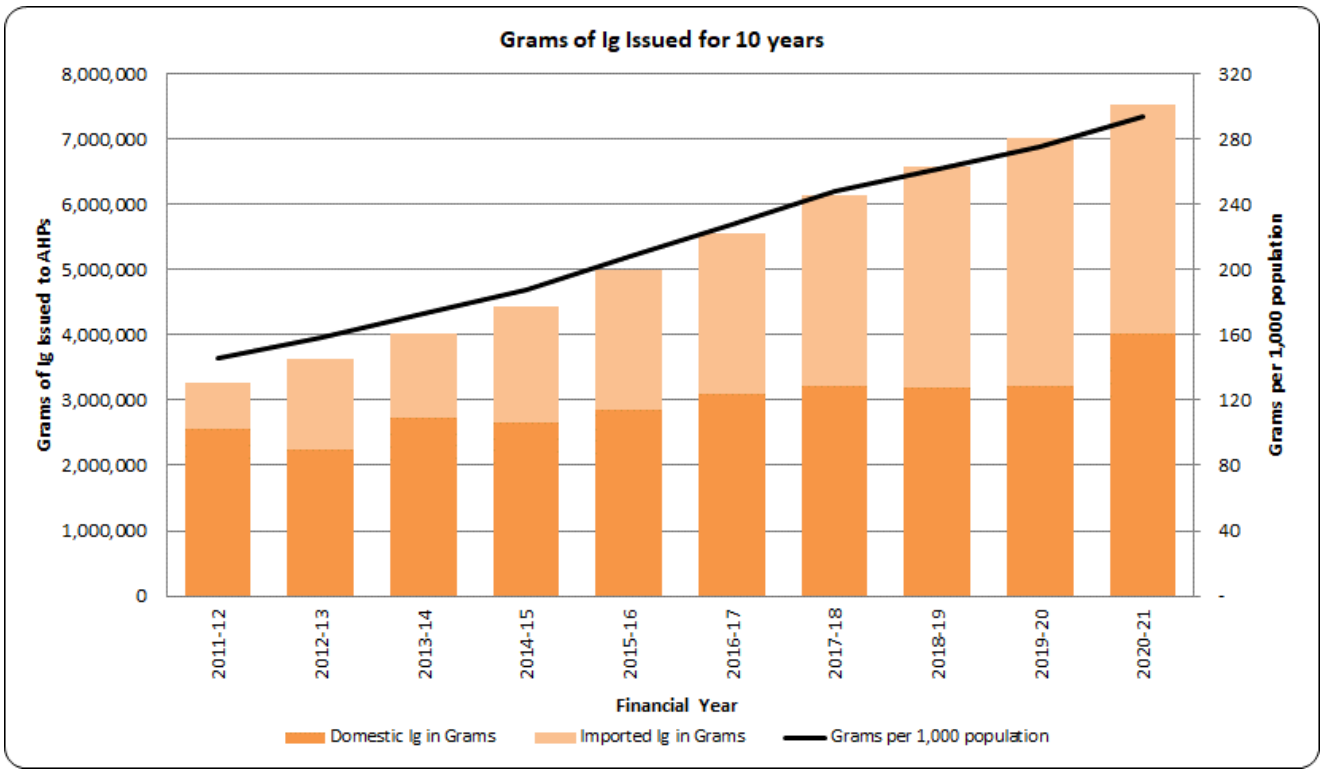

Figure 3: Ten-year trend in issues of Ig

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

Over the past 10 years, the Northern Territory (NT) has been growing at the fastest rate over the past 10 years at an average of 13 per cent.

Table 4: Percentage change in grams issued over time by state and territory

	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
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%**
2019-20	4%	7%	7%	7%	16%	9%	-11%	18%	**7%**
2020-21	8%	5%	6%	6%	16%	12%	0%	12%	7%
Average last 10 years	**10%**	**9%**	**10%**	**9%**	**11%**	**7%**	**13%**	**12%**	**10%**

FINANCIAL TRENDS

Total expenditure on Ig (excluding plasma for fractionation) in 2020-21 was $438.8 million, an increase of $74.5 million (20.5 per cent) over 2019-20 (**Figure 4**). The increased expenditure predominately represents increases in demand and increasing imported Ig prices.

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.

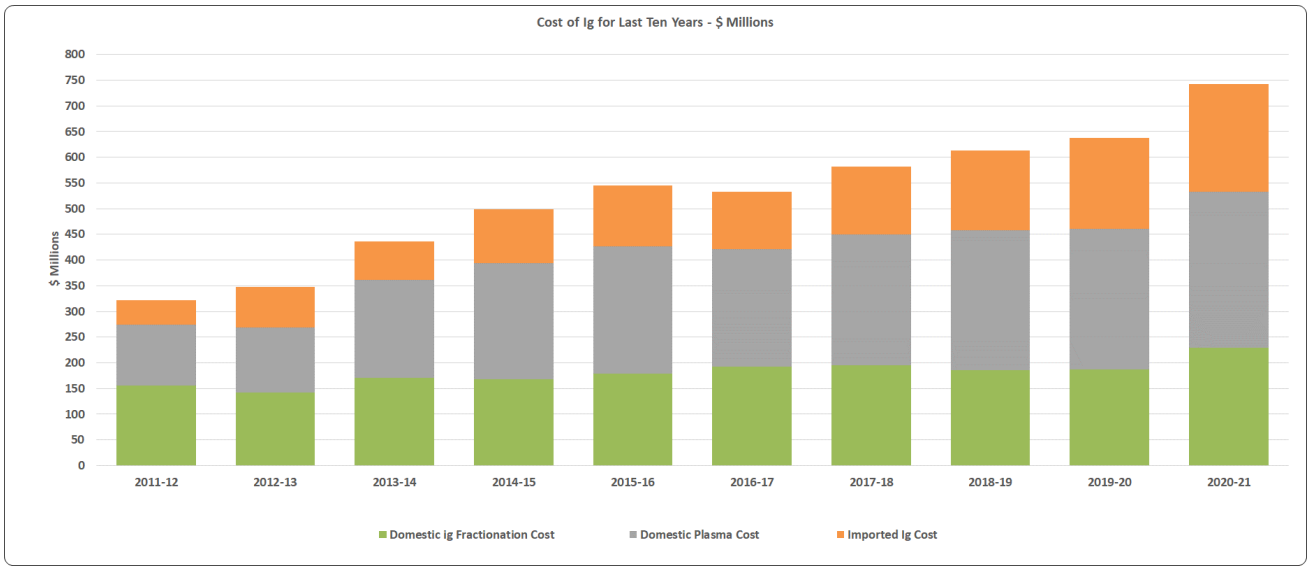

Figure 4: Ten-year trend in expenditure on Ig

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 largest budget item, representing 33 per cent of the total budget for blood and blood products. Combined with expenditure for plasma for fractionation, Ig accounts for 55 per cent of the total blood budget, at a total expenditure of $742.3 million (excluding specific hyperimmune plasma for fractionation).

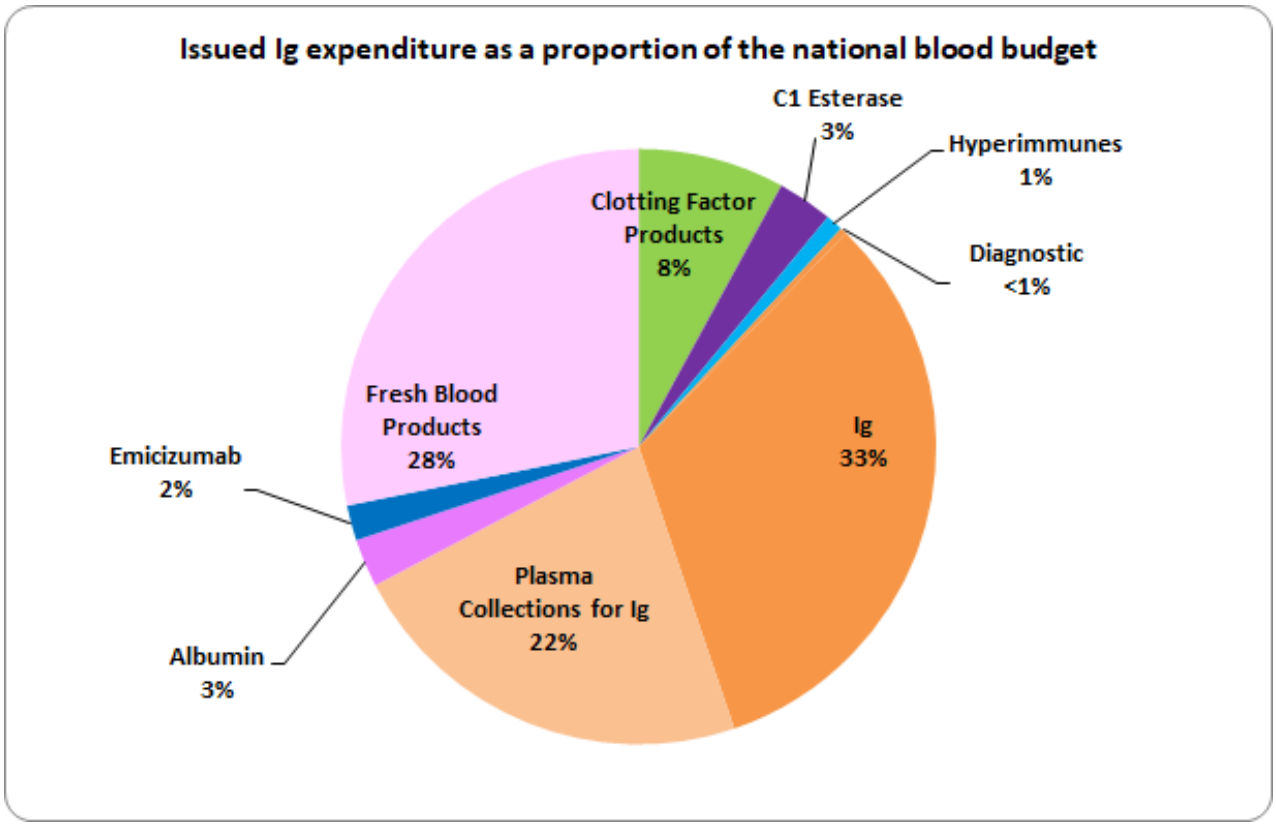

Figure 5: Ig expenditure as a proportion of the national blood budget

Of the Ig supplied under national blood arrangements in Australia in 2020-21, 53 per cent was manufactured domestically and 47 per cent was imported from overseas (see **Table 5**). This represents a 7 per cent decrease in product importation from 2019-20. Domestic supply is driven by the amount of plasma for fractionation collected in Australia and this increased by 8 per cent in 2020-21 over 2019-20. Intragam 10% (IVIg) and Evogam (SCIg) were Ig products manufactured domestically in 2020-21.

The imported products available were Privigen (IVIg), Flebogamma (IVIg), Gamunex (IVIg), Cuvitru (SCIg), Octagam (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 about 60 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 2020-21.

Table 5: Issues of domestic Ig compared with imported Ig

			NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Domestic Ig	Intragam 10	g	1,505,000	819,133	1,008,475	179,995	280,103	58,568	9,700	61,013	3,921,985
	Evogam	g	26,602	17,310	23,241	12,512	4,252	1,022	577	1,702	87,216
	Total Domestic	**g**	**1,531,602**	**836,442**	**1,031,716**	**192,507**	**284,355**	**59,589**	**10,277**	**62,714**	**4,009,201**
Imported Ig	**Total Imported**	**g**	**1,138,120**	**796,908**	**884,112**	**183,635**	**277,958**	**108,161**	**17,586**	**114,631**	**3,521,110**
Ig Cost excluding the cost of plasma for fractionation		$(m)	$155.3	$95.2	$111.6	$21.9	$32.8	$9.8	$1.6	$10.4	$438.8
Proportion of domestic to imported Ig		g%	57%	51%	54%	51%	51%	36%	37%	35%	53%

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	1,084,222	500,696	423,318	161,705	192,692	33,547	10,277	62,332	2,468,788
	Private	g	447,379	335,746	608,398	30,803	91,663	26,043	-	383	1,540,413
	Total Domestic	g	**1,531,602**	**836,442**	**1,031,716**	**192,507**	**284,355**	**59,589**	**10,277**	**62,714**	**4,009,201**
Imported Ig	Public	g	914,109	520,226	419,930	158,155	215,245	73,510	17,586	113,346	2,432,107
	Private	g	224,011	276,682	464,182	25,480	62,713	34,652	-	1,285	1,089,004
	Total Imported	g	**1,138,120**	**796,908**	**884,112**	**183,635**	**277,958**	**108,161**	**17,586**	**114,631**	**3,521,110**
Total Ig	Public	g	1,998,331	1,020,922	843,248	319,860	407,937	107,056	27,863	175,678	4,901,694
	Private	g	671,390	612,428	1,072,579	56,283	154,376	60,694	-	1,668	2,629,417
	Total Ig	g	**2,669,721**	**1,633,350**	**1,915,827**	**376,142**	**562,313**	**167,750**	**27,863**	**177,345**	**7,530,311**
Ig as portion of National	Public	g%	41%	21%	17%	7%	8%	2%	1%	4%	100%
	Private	g%	26%	23%	41%	2%	6%	2%	0%	0%	100%
	Total Ig	g%	**35%**	**22%**	**25%**	**5%**	**7%**	**2%**	**0%**	**2%**	**100%**
	% of Population		**32%**	**26%**	**20%**	**7%**	**11%**	**2%**	**1%**	**2%**	**100%**
Grams Per 1,000 Population	Public		247.2	155.5	162.4	178.0	149.3	189.3	111.8	389.2	191.2
	Private		83.0	93.3	206.6	31.3	56.5	107.3	-	3.7	102.6
	Total Ig		**330.2**	**248.9**	**369.0**	**209.3**	**205.8**	**296.6**	**111.8**	**392.9**	**293.8**

Note: Excludes Norfolk Island

Patient demographics

PATIENT NUMBERS

Immunoglobulin was dispensed to 21,194 patients under the national blood arrangements during 2020-21, including 6,999 new patients. This represents about a 3 per cent increase in the number of patients since 2019-20. A summary of new and total patient numbers is provided in **Figure 6**.

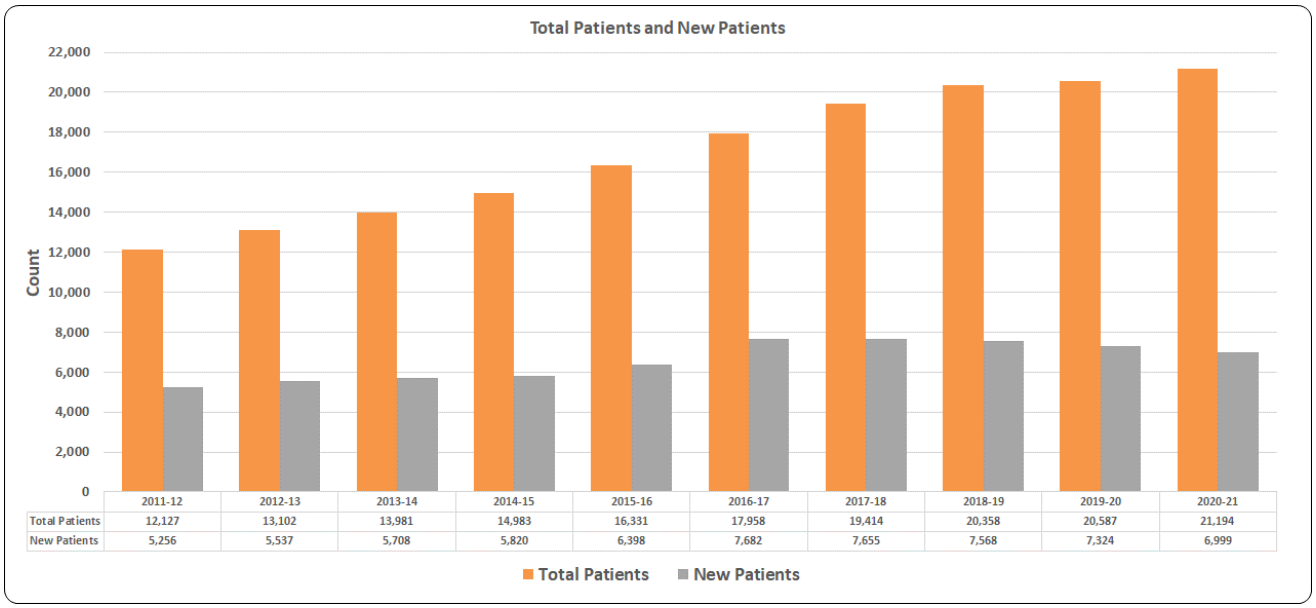

Figure 6: New and total patients for the last 10 years

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

2019-20	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Patient Counts	7,518	4,824	5,106	1,161	1,328	445	100	427	20,587
New Patients	2,665	1,878	1,524	436	536	159	37	143	7,324
Population	**8,074,458**	**6,583,405**	**5,136,760**	**1,781,686**	**2,693,499**	**558,864**	**247,602**	**445,816**	**25,522,090**
Proportion of Population	31.6%	25.8%	20.1%	7.0%	10.6%	2.2%	1.0%	1.7%	100.0%
Patients per 1,000 Population	0.93	0.73	0.99	0.65	0.49	0.80	0.40	0.96	0.81
2020.21									
Patient Counts	7,772	4,727	5,246	1,212	1,443	474	106	481	21,194
New Patients	2,656	1,635	1,442	451	517	149	41	156	6,999
Population	**8,084,192**	**6,563,465**	**5,191,354**	**1,796,955**	**2,731,729**	**565,557**	**249,163**	**451,431**	**25,633,846**
Proportion of Population	31.5%	25.6%	20.3%	7.0%	10.7%	2.2%	1.0%	1.8%	100.0%
Patients per 1,000 Population	0.96	0.72	1.01	0.67	0.53	0.84	0.43	1.07	0.83
% Change in Patients	**3.4%**	**-2.0%**	**2.7%**	**4.4%**	**8.7%**	**6.5%**	**6.0%**	**12.6%**	**2.9%**
% Change in New Patients	**-0.3%**	**-12.9%**	**-5.4%**	**3.4%**	**-3.5%**	**-6.3%**	**10.8%**	**9.1%**	**-4.4%**

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 September 2021.[1] A peak can be seen in the patient population treated with Ig, with most Ig recipients 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.

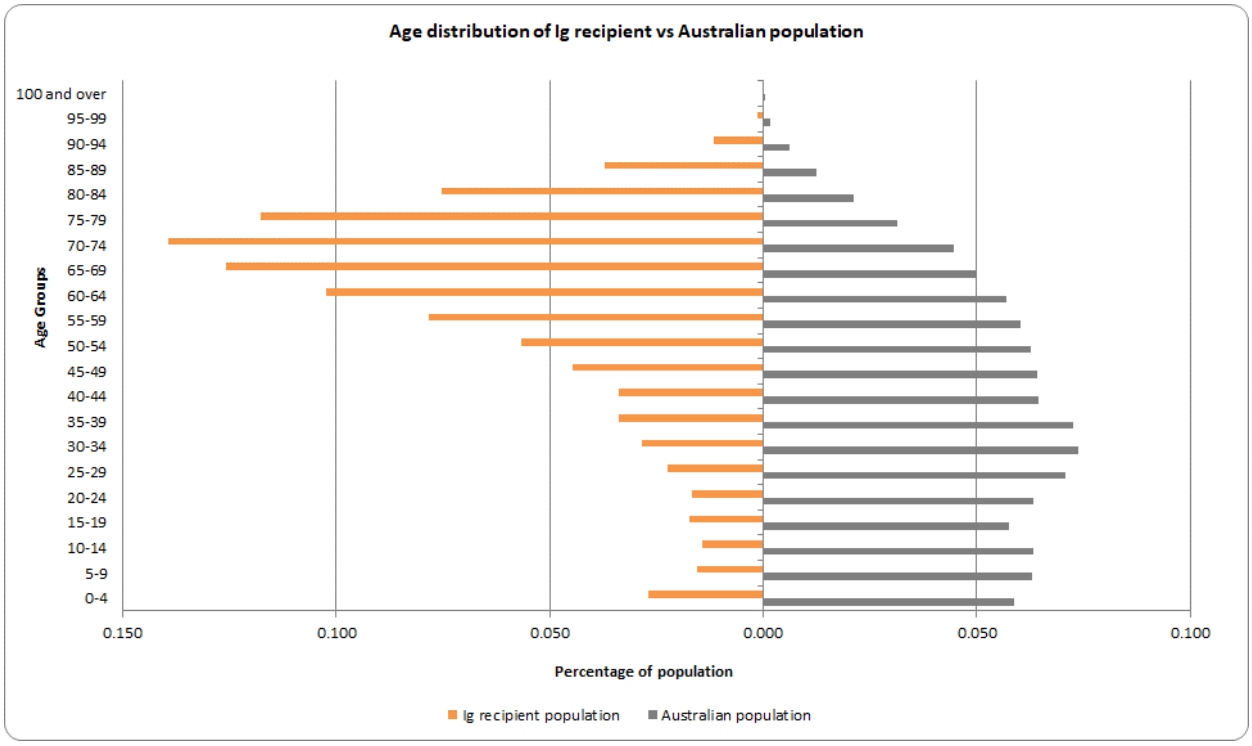

Figure 7: Patient age relative to Australian average

Note: The above figure calculations relate to only 2020-21 patients.

Figure 7 compares the age of Ig recipients in Australia in 2020-21 and the Australian population using stats from the ABS 3101.

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.

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

[1] ABS 3101

[2] World Health Organization, Ageing and health (who.int)

Table 8 shows the number of distinct patients and the average weight by age ranges for patients with dispenses in 2020-21.

Table 8: Patient numbers and average weight by age range

Age Range	Patient Counts	Average Weight (kg)	Treatment Episodes	Grams Dispensed
0-4	569	13	2,242	19,396
5-9	327	26	2,534	34,461
10-14	305	46	2,972	70,723
15-17	224	62	2,157	57,720
18-19	141	67	1,451	37,470
20-29	830	73	8,907	265,157
30-39	1,323	78	14,507	459,971
40-49	1,665	82	21,031	696,039
50-59	2,863	83	34,354	1,137,037
60-69	4,833	82	58,928	1,864,720
70-79	5,453	79	63,518	1,951,830
80-89	2,386	74	26,017	746,491
90 or more	275	70	2,584	71,353
Total	**21,194**	**78**	**241,202**	**7,412,365**

Ig Dispenses

IG DISPENSES BY CRITERIA CATEGORY

The Criteria classifies medical conditions into 4our categories based on the level of evidence supporting the use of Ig, as follows:

- conditions for which Ig has an established therapeutic role
- conditions for which Ig has an emerging therapeutic role
- conditions for which Ig has application in exceptional circumstances only
- conditions for which Ig use is not supported.

Immunoglobulin was predominately dispensed for medical conditions within *Conditions for which Ig has an established therapeutic role*. Refer to **Appendix D** for further information.

Table 9: Ig grams dispensed by criteria category

Category	2016-17	2017-18	2018-19	2019-20	2020-21
Has an established therapeutic role	4,620,916	5,081,838	5,406,598	5,760,834	6,143,262
Has an emerging therapeutic role	645,636	721,766	792,821	908,889	1,046,454
Has application in exceptional circumstances only	220,122	271,817	246,231	181,777	220,762
Use is not supported	741	288	453	1,890	1,888
Other	96	25			
Total	**5,487,511**	**6,075,733**	**6,446,102**	**6,853,389**	**7,412,365**

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 2016-17, there has been a 37 per cent increase in Ig issues for neurological conditions, as compared with a 38 per cent increase for haematological conditions and a 32 per cent 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 2020-21.

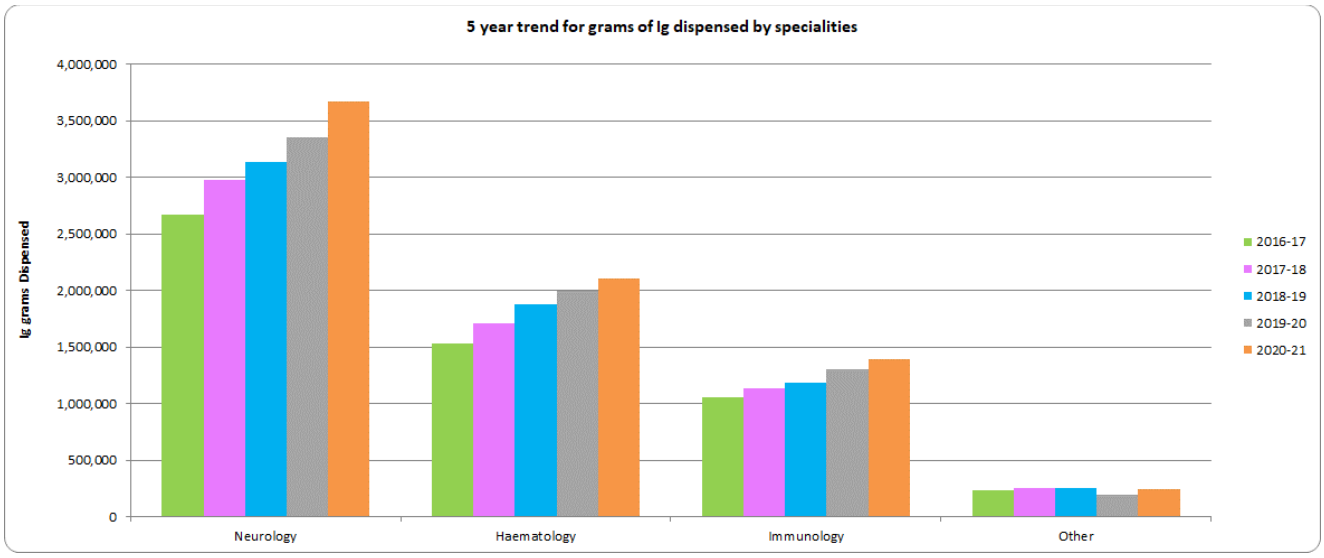

Figure 8: Grams of Ig dispensed by speciality

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, 18.6 cent of Western Australia's (WA's) dispensed grams was to haematology conditions while SA and Tasmania (TAS) dispensed about 38 per cent for haematology conditions. 27.6 per cent of SA patients where for neurology and they were dispensed with 41.6 per cent of SA's Ig grams. 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 2020-21

Specialities	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Dermatology*	10,440	20,165	15,450	3,855	7,265	1,820	-	2,640	61,635
Haematology	686,296	428,483	648,356	142,247	102,385	64,048	7,099	28,944	2,107,857
Immunology	552,190	294,827	298,762	64,813	112,706	24,515	3,950	44,314	1,396,076
Neurology	1,338,160	748,616	919,818	154,090	322,804	64,419	15,515	102,759	3,666,180
Transplant Medicine*	21,598	118,675	19,560	5,263	3,848	10,815	623	238	180,618
Total	**2,608,683**	**1,610,766**	**1,901,946**	**370,267**	**549,007**	**165,617**	**27,187**	**178,894**	**7,412,365**

**Included as Other in Figure 8*

Table 11: Patients dispensed Ig by speciality and state and territory for 2020-21

Specialities	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Dermatology*	11	30	22	<5	10	<5	-	<5	<88
Haematology	2,877	1,807	2,332	613	499	241	39	121	8,439
Immunology	1,888	1,003	982	233	398	86	22	137	4,667
Neurology	2,882	1,606	1,866	335	517	132	40	218	7,510
Transplant Medicine*	167	308	64	31	27	20	6	<5	620
Total	**7,772**	**4,727**	**5,246**	**1,212**	**1,443**	**474**	**106**	**<486**	**21,194**

**Included as Other in Figure 8*

Table 12: New patients dispensed Ig by speciality and state and territory for 2020-21

Specialities	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Dermatology*	<5	16	5	<5	6	-	-	-	<37
Haematology	1,112	672	728	230	215	82	13	43	3,078
Immunology	449	274	204	62	102	21	6	34	1,143
Neurology	992	542	478	134	176	37	18	75	2,436
Transplant Medicine*	126	135	33	21	21	9	<5	<5	<355
Total	**2,656**	**1,635**	**1,442**	**<452**	**517**	**149**	**<42**	**<157**	**6,999**

**Included as Other in Figure 8*

IG DISPENSES BY MEDICAL CONDITION

The top 10 medical conditions account for about 89 per cent of all Ig supplied, with the top 3 medical conditions accounting for 56 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 2020-21 (24 per cent), closely followed by chronic inflammatory demyelinating polyneuropathy (CIDP) (22 per cent). Primary immunodeficiency diseases (PID) with antibody deficiency accounted for around 10 per cent of total Ig use.

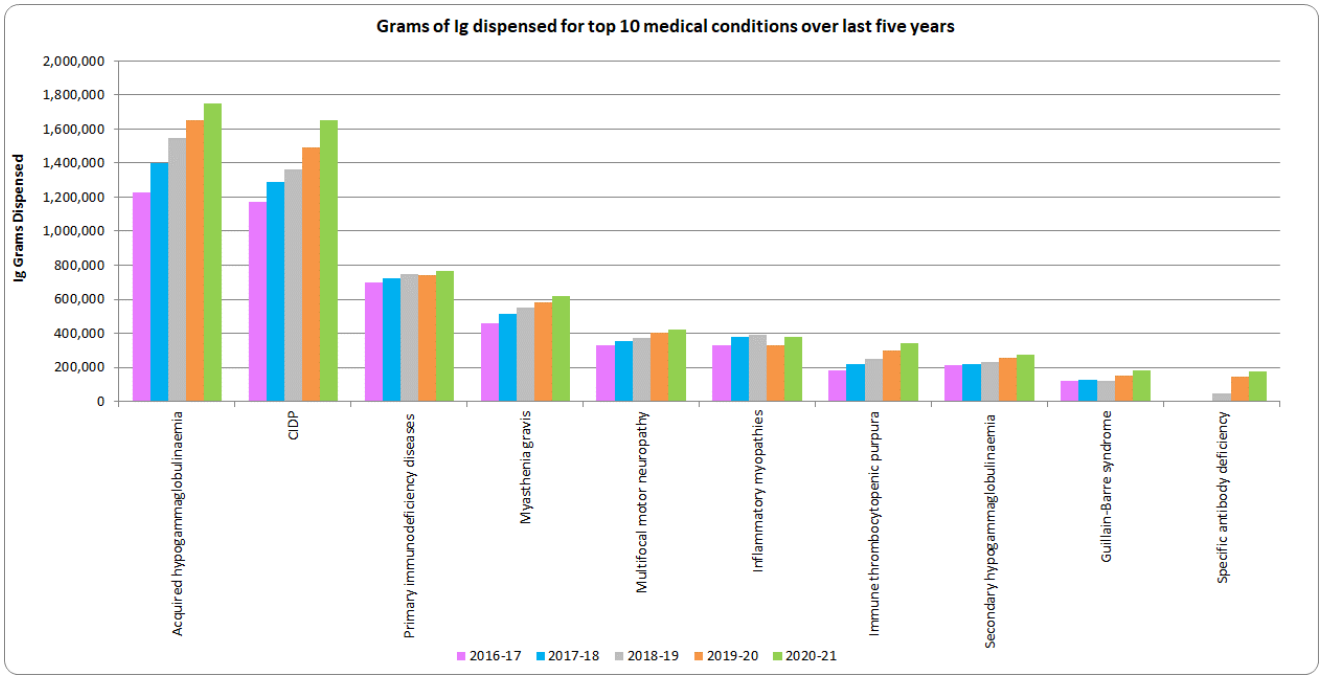

Figure 9: Grams of Ig dispensed by top 10 medical conditions

The top 10 medical conditions by state and territory for 2020-21 is presented in **Table 13**.

Table 13: Grams dispensed by states and territories and medical condition for 2020-21

Specialities	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Acquired hypogammaglobulinaemia	568,821	357,253	540,205	113,614	83,852	56,845	4,849	23,052	1,748,490
CIDP	640,014	326,773	429,927	44,602	134,424	36,182	5,538	36,010	1,653,468
Primary immunodeficiency diseases	336,498	148,927	150,411	40,321	49,083	11,910	2,594	28,188	767,930
Myasthenia gravis	197,249	146,507	167,369	16,530	68,635	7,005	500	14,958	618,752
Multifocal motor neuropathy	141,009	84,198	78,688	37,443	45,235	8,595	4,790	22,104	422,061
Inflammatory myopathies	116,377	78,771	98,582	31,165	37,978	3,745	1,025	10,053	377,694
Secondary hypogammaglobulinaemia	132,958	68,890	102,402	5,491	19,183	10,192	390	5,288	344,794
Immune thrombocytopenic purpura	91,658	54,765	79,052	23,050	12,233	6,265	1,918	3,388	272,327
Solid organ transplantation	21,598	118,675	19,560	5,263	3,848	10,815	623	238	180,618
AMAE	68,248	33,105	46,903	5,508	11,620	1,660	508	7,330	174,880
Total	**2,314,426**	**1,417,863**	**1,713,096**	**322,985**	**466,089**	**153,214**	**22,733**	**150,606**	**6,561,011**

Ig Dispenses - IVIg and SCIg

In March 2013, the Jurisdictional Blood Committee (JBC) approved the introduction of SCIg under the national blood arrangements. In 2020-21 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), and
- Cuvitru 1g/5ml, 2g/10ml, 4g/20ml and 8g/40ml supplied by Takeda Pharmaceuticals (Australia) Pty Ltd (imported).

In addition to the clinical and diagnostic criteria for access to Ig 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 2020-21, the medical conditions that SCIg can be used to treat are:

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

These products are authorised and distributed by Lifeblood in the same manner as IVIg. **Tables 14-15** show the patient numbers and grams dispensed by SCIg medical condition, and by IVIg and SCIg products in 2020-21. **Tables 16-17** show the patient numbers and grams dispensed by SCIg medical condition, and by state and territory in 2020-21.

Table 14: Patients dispensed by SCIg/IVIg medical conditions and product for 2020-21

	IVIg						SCIg			
Medical Condition	**Flebogamma 5%**	**Flebogamma 10%**	**Gamunex 10%**	**Intragam 10**	**Octagam 10%**	**Privigen 10%**	**Cuvitru**	**Evogam**	**Hizentra**	**Total**
Acquired-hypogammaglobulinaemia	40	290	182	4,765	-	1,096	-	<5	51	**584**
Chronic inflammatory demyelinating polyneuropathy	118	349	34	1,476	<5	1,138	-	<5	<5	**142**
Primary immunodeficiency diseases	34	21	<5	1,461	<5	62	<5	<5	251	**563**
Secondary hypogammaglobulinaemia	37	79	28	915	-	216	-	<5	39	**176**
Specific antibody deficiency	<5	8	<5	291	<5	30	-	<5	31	**98**

Table 15: Grams dispensed by SCIg/IVIg medical conditions and product for 2020-21

	IVIg		SCIg			
Medical Condition	Imported IVIg	Intragam 10	Imported SCIg	Evogam	Hizentra	Total
Acquired-hypogammaglobulinaemia	385,520	1,180,343	-	-	11,630	**170,998**
Chronic inflammatory demyelinating polyneuropathy	900,852	650,953	-	234	147	**101,283**
Primary immunodeficiency diseases	35,556	487,928	363	180	54,750	**189,154**
Secondary hypogammaglobulinaemia	81,363	205,350	-	112	8,168	**49,801**
Specific antibody deficiency	9,609	82,613	-	5	7,298	**26,913**

Table 16: Patients dispensed by SCIg medical conditions, and state and territory for 2020-21

Products	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Acquired-hypogammaglobulinaemia	171	170	118	86	54	28	<5	14	**632**
Chronic inflammatory demyelinating polyneuropathy	49	26	45	-	6	9	-	13	**145**
Primary immunodeficiency diseases	303	193	169	67	51	11	<5	23	**805**
Secondary hypogammaglobulinaemia	75	36	73	8	13	7	-	<5	**<217**
Specific antibody deficiency	50	22	21	13	15	<5	<5	7	**<138**

Table 17: Grams dispensed by SCIg medical conditions, and state and territory for 2020-21

Products	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Acquired-hypogammaglobulinaemia	47,434	51,804	34,066	25,702	13,000	6,903	234	3,487	**182,628**
Chronic inflammatory demyelinating polyneuropathy	33,320	20,786	29,330	-	1,759	6,884	-	9,585	**101,664**
Primary immunodeficiency diseases	93,241	55,397	55,803	14,473	10,928	4,440	1,304	8,499	**244,084**
Secondary hypogammaglobulinaemia	20,665	8,438	21,201	1,693	3,150	2,140	-	793	**58,081**
Specific antibody deficiency	13,672	5,976	6,271	2,942	3,578	358	66	1,354	**34,216**

Ig Issued – NHIg

In 2013-14, due to the introduction of SCIg as discussed above, demand for NHIg reduced significantly by about 19 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.

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

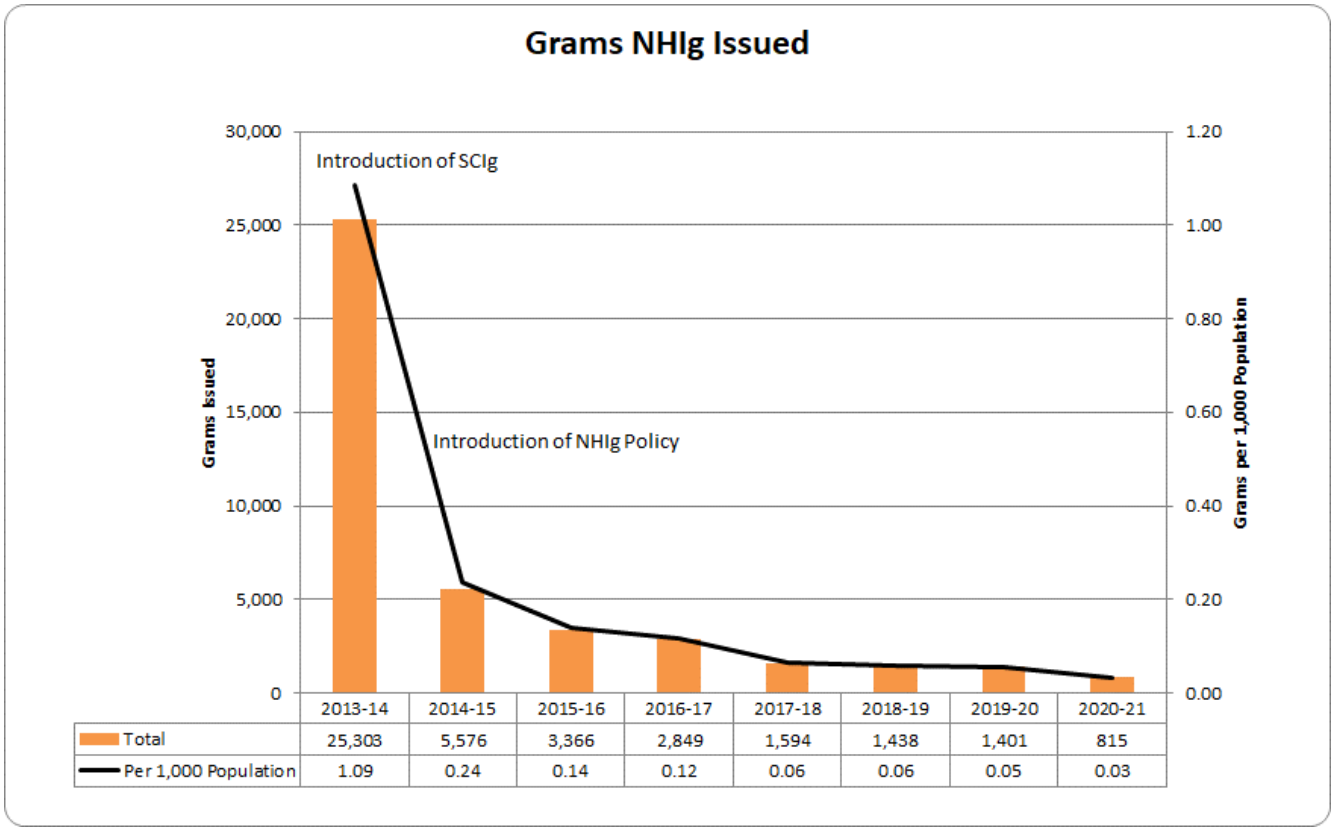

Figure 10: NHIg grams issued and grams issued per 1,000 population

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 free of charge to all patients who have a condition meeting qualifying criteria for supply 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* (v2) from August 2012. 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, some patients continued under existing authorisations until their scheduled review for some conditions, while others transitioned on 22 October 2018. All patients transitioned by October 2019.

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. In seeking authorisation through BloodSTAR, the requesting clinician will be asked to provide information to establish that the request in BloodSTAR meets the Criteria. For ongoing conditions, the Criteria may specify review criteria to be applied in reviewing the patient to determine whether access to funded Ig will 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 states or territories 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.

2020-21 Activities

The history of NBA activities prior to 2020-21 can be found in previous *National Report on the Issues and Use of Immunoglobulin (Ig) – Annual Reports*.

The NBA Ig Governance Program continued its work throughout **2020-21** to improve the governance and management of publicly funded Ig. This program aims to ensure that:

- 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, and
- capture of information on the need for, use of, and outcomes of treatment (including adverse events) with Ig products is improved, to better inform future changes to the Criteria.

During the **2020-21** period, the program focused on the key activities listed below:

- Continued to support BloodSTAR and enhancements,
- Continued implementation of the *National Immunoglobulin Program Performance Improvement Strategy,*
- Continued engagement with the program's network of committees to inform the work of the national Ig governance program,
- Continued to publish a selected set of Ig usage data on a regular monthly basis on the website,
- The Criteria was modified to enable supply of intravenous Ig under the national blood arrangements for COVID-19 vaccine-induced immune thrombotic thrombocytopenia, and
- New and additional contracts finalised for imported Ig products, increasing supply security and diversity.

COVID-19 also saw additional pressure placed on our suppliers of imported Ig products resulting from reduced plasma collections overseas, and challenges to logistics and supply chains. Two key strategies to mitigate supply risks have been (i) to improve the opportunity to increase domestic supply arrangements through increased plasma collections, and (ii) to increase and diversify the range of products and suppliers for imported Ig. In December 2020, the NBA finalised a major procurement to replace expiring contracts for imported Ig. This increased the number of suppliers from 2 to 4, thereby

improving the overall security and sustainability of Ig supply arrangements for Australia, as well as achieving good value for money for Australian governments.

In 2021, an external evaluation of the Ig governance program concluded that it was effective in reducing growth in demand for Ig. Prior to the introduction of the program, Ig usage per 1,000 population grew by 8 per cent annually. The evaluation showed that during the program's implementation phase (January 2014 to October 2019), this growth rate reduced to about 7 per cent and reduced even further to about 5 per cent after implementation.

The reduced growth in Ig demand, driven by the Ig governance arrangements, has delivered estimated savings of almost $90 million in potential product expenditure since 2018-19 and will grow to an estimated $2.2 billion by 2030-31. Since the program was implemented, there have been no major changes in use observed in the ten most commonly treated medical conditions, and no reduction in the doses administered. Indeed, average dose, age and weight of patients have increased slightly during the implementation and post-implementation stages.

Ig costs from 2020-21 to 2030-31 were projected assuming an annual growth rate of 8.4 per cent as the base-case, which is the estimated annual growth rate from the last three quarters of data (Q4 2019-20 and Q1 and Q2 2020-21). The base-case scenario was compared to a scenario without the program and an annual Ig growth rate of about 11 per cent. Forecast savings are based on a national weighted average price for the cost per gram of Ig (adopted in a recent HTA Review of $94/gram).

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
AMAE	Autoimmune encephalitis mediated by antibodies targeting cell-surface antigens
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
IDMS	Integrated Data Management System
Ig	Immunoglobulin products including IVIg and SCIg
IVIg	Intravenous immunoglobulin
JBC	Jurisdictional Blood Committee
NaFAA	National Fractionation Agreement for Australia
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 of 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 Australian 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 – VERSION 3 CONDITIONS BY SPECIALITY

Specific Condition Name	Medical Condition Name	Speciality	Category
Acquired bleeding disorder, other coagulation factors (Prothrombin, factor V, factor VII, factor X, factor XI, and factor XIII)	Coagulation factor inhibitors	Haematology	Has application in exceptional circumstances only
Acquired haemophilia A	Coagulation factor inhibitors	Haematology	Has application in exceptional circumstances only
Acquired von Willebrand syndrome	Coagulation factor inhibitors	Haematology	Has application in exceptional circumstances only
Acute leukaemia	Acquired-hypogammaglobulinaemia — haematological malignancy or post HSCT	Haematology	Has an established therapeutic role
Anti-neutrophil cytoplasmic antibody (ANCA) (PR3 or MPO)-positive idiopathic rapidly progressive glomerulonephritis	Anti-neutrophil cytoplasmic antibody (ANCA) associated vasculitis	Immunology	Has application in exceptional circumstances only
Ataxic sensory neuronopathy	Sjögren's syndrome	Neurology	Has application in exceptional circumstances only
Atypical rolandic epilepsy	Childhood epileptic encephalopathy	Neurology	Has application in exceptional circumstances only
Autoimmune haemolytic anaemia	Autoimmune haemolytic anaemia (AIHA)	Haematology	Has an emerging therapeutic role
Autoimmune neutropenia	Autoimmune neutropenia	Haematology	Has application in exceptional circumstances only
Autoimmune retinopathy	Autoimmune retinopathy (AIR)	Immunology	Has application in exceptional circumstances only
Autonomic neuropathy	Sjögren's syndrome	Neurology	Has application in exceptional circumstances only
Bullous Pemphigoid	Bullous pemphigoid	Immunology	Has an emerging therapeutic role
Catastrophic anti-phospholipid syndrome	Catastrophic anti-phospholipid syndrome (CAPS)	Immunology	Has application in exceptional circumstances only
Chronic Immune thrombocytopenic purpura (ITP)	Immune thrombocytopenic purpura (ITP) — adult	Haematology	Has an established therapeutic role
Chronic inflammatory demyelinating polyneuropathy (CIDP)	Chronic inflammatory demyelinating polyneuropathy (CIDP)	Neurology	Has an established therapeutic role
Chronic lymphocytic leukaemia (CLL)	Acquired-hypogammaglobulinaemia — haematological malignancy or post HSCT	Haematology	Has an established therapeutic role
Cicatricial pemphigoid (CP)	Cicatricial pemphigoid (CP) or Mucous Membrane Pemphigoid (MMP)	Dermatology	Has an emerging therapeutic role

Specific Condition Name	Medical Condition Name	Speciality	Category
Combined immunodeficiency generally less profound than SCID (e.g. thymoma)	Primary immunodeficiency diseases (PID)	Immunology	Has an established therapeutic role
Combined immunodeficiency with associated or syndromal features (e.g. Wiskott Aldrich syndrome; ataxia telangiectasia)	Primary immunodeficiency diseases (PID)	Immunology	Has an established therapeutic role
Confirmed autoimmune congenital heart block in a fetus	Autoimmune congenital heart block	Immunology	Has application in exceptional circumstances only
Congenital haemophilia A with acquired factor VIII inhibitor	Coagulation factor inhibitors	Haematology	Has application in exceptional circumstances only
Dermatomyositis (DM)	Inflammatory myopathies: polymyositis, dermatomyositis and necrotising autoimmune myopathy	Neurology	Has an established therapeutic role
Diabetic amyotrophy	Diabetic amyotrophy	Neurology	Use is not supported
Drug-induced pemphigus foliaceus	Pemphigus foliaceus (PF)	Immunology	Has an emerging therapeutic role
Encephalitis associated with antibodies to AMPA receptor	Antibody mediated autoimmune encephalitis (AMAE)	Neurology	Has an emerging therapeutic role
Encephalitis associated with antibodies to CASPR2	Antibody mediated autoimmune encephalitis (AMAE)	Neurology	Has an emerging therapeutic role
Encephalitis associated with antibodies to DPPX	Antibody mediated autoimmune encephalitis (AMAE)	Neurology	Has an emerging therapeutic role
Encephalitis associated with antibodies to GABA (A or B) receptor	Antibody mediated autoimmune encephalitis (AMAE)	Neurology	Has an emerging therapeutic role
Encephalitis associated with antibodies to glycine receptor	Antibody mediated autoimmune encephalitis (AMAE)	Neurology	Has an emerging therapeutic role
Encephalitis associated with antibodies to LGI1	Antibody mediated autoimmune encephalitis (AMAE)	Neurology	Has an emerging therapeutic role
Encephalitis associated with antibodies to NMDA receptor	Antibody mediated autoimmune encephalitis (AMAE)	Neurology	Has an emerging therapeutic role
Encephalitis associated with antibodies to VGKC	Antibody mediated autoimmune encephalitis (AMAE)	Neurology	Has an emerging therapeutic role
Endemic pemphigus foliaceus	Pemphigus foliaceus (PF)	Immunology	Has an emerging therapeutic role
Eosinophilic granulomatosis with polyangiitis (Churg-Strauss Syndrome)	Anti-neutrophil cytoplasmic antibody (ANCA) associated vasculitis	Immunology	Has application in exceptional circumstances only

Specific Condition Name	Medical Condition Name	Speciality	Category
Epidermolysis bullosa acquisita	Epidermolysis bullosa acquisita	Immunology	Has application in exceptional circumstances only
Evans syndrome - with significant Immune thrombocytopenic purpura (ITP) - adult	Immune thrombocytopenic purpura (ITP) — adult	Haematology	Has an established therapeutic role
Evans syndrome child - with significant ITP	Immune thrombocytopenic purpura (ITP) — in children 15 years and younger	Haematology	Has an emerging therapeutic role
Evans Syndrome with significant AIHA	Autoimmune haemolytic anaemia (AIHA)	Haematology	Has an emerging therapeutic role
Existing patient - authorisation for IgG subclass deficiency	Specific antibody deficiency (SAD)	Immunology	Has an emerging therapeutic role
Fetal alloimmune thrombocytopenia (FAIT)	Fetal and neonatal alloimmune thrombocytopenia (FNAIT)	Haematology	Has an established therapeutic role
Granulomatosis with polyangiitis (Wegener Granulomatosis)	Anti-neutrophil cytoplasmic antibody (ANCA) associated vasculitis	Immunology	Has application in exceptional circumstances only
Graves ophthalmopathy	Graves ophthalmopathy (GO)	Immunology	Has application in exceptional circumstances only
Guillain–Barré Syndrome (GBS)	Guillain–Barré Syndrome (GBS)	Neurology	Has an established therapeutic role
Guillain–Barré Syndrome (GBS) variants	Guillain–Barré Syndrome (GBS)	Neurology	Has an established therapeutic role
Haemolytic disease of the fetus	Haemolytic disease of the fetus (HDF)	Haematology	Has application in exceptional circumstances only
Haemophagocytic lymphohistiocytosis	Haemophagocytic lymphohistiocytosis	Haematology	Has an emerging therapeutic role
Heart and kidney transplant	Solid organ transplantation	Transplant Medicine	Has an emerging therapeutic role
Heart and lung transplant	Solid organ transplantation	Transplant Medicine	Has an emerging therapeutic role
Heart transplant	Solid organ transplantation	Transplant Medicine	Has an emerging therapeutic role
Hyperhaemolysis syndrome	Hyperhaemolysis syndrome	Haematology	Has application in exceptional circumstances only
Hypogammaglobulinaemia following B cell depletion therapy	Secondary hypogammaglobulinaemia (including iatrogenic immunodeficiency)	Immunology	Has an emerging therapeutic role
Hypogammaglobulinaemia following Solid organ transplantation	Secondary hypogammaglobulinaemia (including iatrogenic immunodeficiency)	Immunology	Has an emerging therapeutic role
Idiopathic opsoclonus-myoclonus ataxia	Opsoclonus-myoclonus ataxia (OMA)	Neurology	Has an emerging therapeutic role

Specific Condition Name	Medical Condition Name	Speciality	Category
IgA paraproteinaemic demyelinating neuropathy	Chronic inflammatory demyelinating polyneuropathy (CIDP)	Neurology	Has an established therapeutic role
IgA pemphigus foliaceus	Pemphigus foliaceus (PF)	Immunology	Has an emerging therapeutic role
IgG paraproteinaemic demyelinating neuropathy	Chronic inflammatory demyelinating polyneuropathy (CIDP)	Neurology	Has an established therapeutic role
IgM paraproteinaemic demyelinating neuropathy	IgM paraproteinaemic demyelinating neuropathy	Neurology	Has an emerging therapeutic role
Inclusion Body Myositis (IBM)	Inclusion Body Myositis (IBM)	Neurology	Has an established therapeutic role
ITP - child - chronic	Immune thrombocytopenic purpura (ITP) — in children 15 years and younger	Haematology	Has an emerging therapeutic role
ITP - child - newly diagnosed	Immune thrombocytopenic purpura (ITP) — in children 15 years and younger	Haematology	Has an emerging therapeutic role
ITP - child - persistent	Immune thrombocytopenic purpura (ITP) — in children 15 years and younger	Haematology	Has an emerging therapeutic role
Kawasaki disease	Kawasaki disease	Immunology	Has an established therapeutic role
Kidney transplant	Solid organ transplantation	Transplant Medicine	Has an emerging therapeutic role
Lambert–Eaton myasthenic syndrome	Lambert–Eaton myasthenic syndrome (LEMS)	Neurology	Has an established therapeutic role
Landau Kleffner syndrome	Childhood epileptic encephalopathy	Neurology	Has application in exceptional circumstances only
Lennox-Gastaut syndrome	Childhood epileptic encephalopathy	Neurology	Has application in exceptional circumstances only
LETMs	Neuromyelitis optica spectrum disorders (NMOSD)	Neurology	Has application in exceptional circumstances only
Liver and kidney transplant	Solid organ transplantation	Transplant Medicine	Has an emerging therapeutic role
Liver transplant	Solid organ transplantation	Transplant Medicine	Has an emerging therapeutic role
Lung transplant	Solid organ transplantation	Transplant Medicine	Has an emerging therapeutic role
Lymphoproliferative syndromes (e.g. XLP1, XLP2, CD27 def)	Primary immunodeficiency diseases (PID)	Immunology	Has an established therapeutic role
Macrophage activation syndrome	Haemophagocytic lymphohistiocytosis	Haematology	Has an emerging therapeutic role
Memory B cell deficiency secondary to haemopoietic stem cell transplantation (HSCT)	Acquired-hypogammaglobulinaemia — haematological malignancy or post HSCT	Haematology	Has an established therapeutic role

Specific Condition Name	Medical Condition Name	Speciality	Category
Microscopic polyangiitis	Anti-neutrophil cytoplasmic antibody (ANCA) associated vasculitis	Immunology	Has application in exceptional circumstances only
Monophasic acute disseminated encephalomyelitis (ADEM)	Acute disseminated encephalomyelitis (ADEM)	Neurology	Has an emerging therapeutic role
Mucous Membrane Pemphigoid (MMP)	Cicatricial pemphigoid (CP) or Mucous Membrane Pemphigoid (MMP)	Dermatology	Has an emerging therapeutic role
Multifocal motor neuropathy with or without persistent conduction block	Multifocal motor neuropathy (MMN)	Neurology	Has an established therapeutic role
Multiphasic acute disseminated encephalomyelitis (ADEM)	Acute disseminated encephalomyelitis (ADEM)	Neurology	Has an emerging therapeutic role
Multiple myeloma (MM)	Acquired-hypogammaglobulinaemia — haematological malignancy or post HSCT	Haematology	Has an established therapeutic role
Myasthenia gravis (MG)	Myasthenia gravis (MG)	Neurology	Has an established therapeutic role
Myocarditis in children	Myocarditis in children	Immunology	Use is not supported
Necrotising autoimmune myopathy (NAM)	Inflammatory myopathies: polymyositis, dermatomyositis and necrotising autoimmune myopathy	Neurology	Has an established therapeutic role
Neonatal alloimmune thrombocytopenia (NAIT)	Fetal and neonatal alloimmune thrombocytopenia (FNAIT)	Haematology	Has an established therapeutic role
Neonate with haemochromatosis	Neonatal haemochromatosis (NH)	Haematology	Has an established therapeutic role
Newly Diagnosed Immune thrombocytopenic purpura (ITP)	Immune thrombocytopenic purpura (ITP) — adult	Haematology	Has an established therapeutic role
NMOSD–AQP4 ab positive	Neuromyelitis optica spectrum disorders (NMOSD)	Neurology	Has application in exceptional circumstances only
NMOSD–MOG ab positive	Neuromyelitis optica spectrum disorders (NMOSD)	Neurology	Has application in exceptional circumstances only
NMOSD–seronegative	Neuromyelitis optica spectrum disorders (NMOSD)	Neurology	Has application in exceptional circumstances only
Non-Hodgkin lymphoma (NHL)	Acquired-hypogammaglobulinaemia — haematological malignancy or post HSCT	Haematology	Has an established therapeutic role
Other Haematological malignancy	Acquired-hypogammaglobulinaemia — haematological malignancy or post HSCT	Haematology	Has an established therapeutic role
Other Hypogammaglobulinaemia unrelated to haematological malignancies or haemopoietic stem cell transplantation (HSCT)	Secondary hypogammaglobulinaemia (including iatrogenic immunodeficiency)	Immunology	Has an emerging therapeutic role

Specific Condition Name	Medical Condition Name	Speciality	Category
Other transplant	Solid organ transplantation	Transplant Medicine	Has an emerging therapeutic role
Paediatric acute neuropsychiatric disorders (PANS)	PANDAS/PANS	Neurology	Has application in exceptional circumstances only
Paediatric autoimmune neuropsychiatric disorder (PANDAS)	PANDAS/PANS	Neurology	Has application in exceptional circumstances only
Painful small fibre neuropathy	Sjögren's syndrome	Neurology	Has application in exceptional circumstances only
Pancreas and kidney transplant	Solid organ transplantation	Transplant Medicine	Has an emerging therapeutic role
Paraneoplastic associated breast cancer	Opsoclonus-myoclonus ataxia (OMA)	Neurology	Has an emerging therapeutic role
Paraneoplastic associated neuroblastoma	Opsoclonus-myoclonus ataxia (OMA)	Neurology	Has an emerging therapeutic role
Paraneoplastic associated other tumour type	Opsoclonus-myoclonus ataxia (OMA)	Neurology	Has an emerging therapeutic role
Paraneoplastic associated small cell lung cancer	Opsoclonus-myoclonus ataxia (OMA)	Neurology	Has an emerging therapeutic role
Pemphigus erythematosus	Pemphigus foliaceus (PF)	Immunology	Has an emerging therapeutic role
Pemphigus herpetiformis	Pemphigus foliaceus (PF)	Immunology	Has an emerging therapeutic role
Pemphigus vulgaris	Pemphigus vulgaris (PV)	Dermatology	Has an emerging therapeutic role
Persistent Immune thrombocytopenic purpura (ITP)	Immune thrombocytopenic purpura (ITP) — adult	Haematology	Has an established therapeutic role
Polymyositis (PM)	Inflammatory myopathies: polymyositis, dermatomyositis and necrotising autoimmune myopathy	Neurology	Has an established therapeutic role
Polyneuropathy of critical illness	Polyneuropathy of critical illness	Immunology	Use is not supported
Possible Common variable immune deficiency (CVID) - below normal serum IgG but normal serum IgA level	Primary immunodeficiency diseases (PID)	Immunology	Has an established therapeutic role
Pregnant woman with previous fetal loss	Neonatal haemochromatosis (NH)	Haematology	Has an established therapeutic role
Pure red cell aplasia – associated B19 infection	Pure red cell aplasia (PRCA)	Haematology	Has application in exceptional circumstances only
Pure red cell aplasia – autoimmune mediated	Pure red cell aplasia (PRCA)	Haematology	Has application in exceptional circumstances only
Pyoderma Gangrenosum	Pyoderma Gangrenosum (PG)	Immunology	Has application in exceptional circumstances only

Specific Condition Name	Medical Condition Name	Speciality	Category
Rasmussen encephalitis	Rasmussen encephalitis	Neurology	Has application in exceptional circumstances only
Recurrent acute disseminated encephalomyelitis (ADEM)	Acute disseminated encephalomyelitis (ADEM)	Neurology	Has an emerging therapeutic role
Relapsing remitting multiple sclerosis	Multiple sclerosis (MS – RMMS)	Neurology	Has application in exceptional circumstances only
Risk of autoimmune congenital heart block – previously affected sibling	Autoimmune congenital heart block	Immunology	Has application in exceptional circumstances only
Scleromyxedema – skin and systemic disease	Scleromyxedema	Immunology	Has application in exceptional circumstances only
Scleromyxedema – skin involvement only	Scleromyxedema	Immunology	Has application in exceptional circumstances only
Sensorimotor axonal neuropathy	Sjögren's syndrome	Neurology	Has application in exceptional circumstances only
Sepsis	Sepsis	Immunology	Use is not supported
Sero-negative autoimmune encephalitis	Antibody mediated autoimmune encephalitis (AMAE)	Neurology	Has an emerging therapeutic role
Sero-negative limbic encephalitis	Antibody mediated autoimmune encephalitis (AMAE)	Neurology	Has an emerging therapeutic role
Severe combined immunodeficiency (SCID)	Primary immunodeficiency diseases (PID)	Immunology	Has an established therapeutic role
Severe reduction in all Ig isotypes with decreased or absent B-cells (e.g. XLA def)	Primary immunodeficiency diseases (PID)	Immunology	Has an established therapeutic role
Severe reduction in at least two Ig isotypes with low/normal B-cells (e.g. CVID)	Primary immunodeficiency diseases (PID)	Immunology	Has an established therapeutic role
Severe reduction in serum IgG and IgA with normal/elevated IgM (e.g. CD40L def)	Primary immunodeficiency diseases (PID)	Immunology	Has an established therapeutic role
Specific antibody deficiency	Specific antibody deficiency (SAD)	Immunology	Has an emerging therapeutic role
Staphylococcal TSS	Toxic shock syndrome	Immunology	Has an emerging therapeutic role
Stevens–Johnson syndrome / toxic epidermal necrolysis overlap (SJS/TEN)	Toxic epidermal necrolysis / Stevens–Johnson syndrome	Immunology	Has an emerging therapeutic role
Stiff person syndrome	Stiff person syndrome	Neurology	Has an established therapeutic role
Streptococcal TSS	Toxic shock syndrome	Immunology	Has an emerging therapeutic role
Susac syndrome	Susac syndrome	Neurology	Has application in exceptional circumstances only

Specific Condition Name	Medical Condition Name	Speciality	Category
Suspected autoimmune encephalitis	Antibody mediated autoimmune encephalitis (AMAE)	Neurology	Has an emerging therapeutic role
Suspected autoimmune limbic encephalitis	Antibody mediated autoimmune encephalitis (AMAE)	Neurology	Has an emerging therapeutic role
Systemic capillary leak syndrome	Systemic Capillary leak syndrome	Immunology	Has application in exceptional circumstances only
Thymoma-associated hypogammaglobulinaemia (Goods Syndrome)	Secondary hypogammaglobulinaemia (including iatrogenic immunodeficiency)	Immunology	Has an emerging therapeutic role
Toxic epidermal necrolysis (TEN)	Toxic epidermal necrolysis / Stevens–Johnson syndrome	Immunology	Has an emerging therapeutic role
Transient hypogammaglobulinaemia of infancy	Primary immunodeficiency diseases (PID)	Immunology	Has an established therapeutic role
Vaccine induced immune thrombotic thrombocytopenia (VITT)	Vaccine induced immune thrombotic thrombocytopenia (VITT)	Haematology	Has application in exceptional circumstances only
West syndrome	Childhood epileptic encephalopathy	Neurology	Has application in exceptional circumstances only

APPENDIX D – DATASET OF IG SUPPLY BY STATE/TERRITORY 2020-21

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Has an established therapeutic role										
Acute leukaemia	Patients	177	87	56	23	24	5		<5	369
	Average Age	45	45	49	16	49	31		54	44
	Average Weight	64	75	72	37	84	68		67	69
	Grams	20,426	15,032	10,166	1,699	4,095	975		215	52,607
	Grams/Episode	21	21	22	13	17	15		9	20
	Grams per 1,000 Population	3	2	2	1	1	2		0	2
Chronic Immune thrombocytopenic purpura (ITP)	Patients	149	112	124	23	52	11	5	8	483
	Average Age	61	61	58	67	57	53	23	58	59
	Average Weight	85	79	82	81	82	87	51	87	82
	Grams	29,795	19,895	28,149	2,998	7,615	1,990	698	1,098	92,237
	Grams/Episode	45	51	34	38	64	80	47	61	43
	Grams per 1,000 Population	4	3	5	2	3	4	3	2	4
Chronic inflammatory demyelinating polyneuropathy (CIDP)	Patients	1,113	566	748	169	84	60	12	70	2,785
	Average Age	64	64	62	61	66	63	60	61	63
	Average Weight	83	85	86	85	82	90	89	87	85
	Grams	630,669	325,266	419,862	133,867	43,720	34,724	5,538	35,205	1,628,848
	Grams/Episode	46	44	30	46	43	41	56	48	40
	Grams per 1,000 Population	78	50	81	74	16	61	22	78	64
Chronic lymphocytic leukaemia (CLL)	Patients	576	356	401	110	118	55	7	32	1,640
	Average Age	73	74	74	71	72	74	66	73	73
	Average Weight	77	78	78	77	81	82	89	82	78
	Grams	167,161	107,921	125,527	26,951	31,827	15,724	2,336	9,290	486,736
	Grams/Episode	28	26	24	22	25	28	32	26	26
	Grams per 1,000 Population	21	16	24	15	12	28	9	21	19
Combined immunodeficiency generally less profound than SCID (e.g. thymoma)	Patients	18	17	7	5	<5	<5	<5	<5	<67
	Average Age	49	28	38	65	14	61	3	37	40
	Average Weight	63	45	56	72	40	99	18	111	56

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams	4,995	3,203	3,058	1,860	366	350	40	176	14,048
	Grams/Episode	22	14	19	32	15	39	10	88	20
	Grams per 1,000 Population	1	0	1	1	0	1	0	0	1
Combined immunodeficiency with associated or syndromal features (e.g. Wiskott Aldrich syndrome; ataxia telangiectasia)	Patients	11	11	13	6	<5		<5	<5	<56
	Average Age	21	33	18	13	8		16	28	20
	Average Weight	47	69	39	35	22		30	66	46
	Grams	3,051	2,851	2,674	993	173		178	740	10,659
	Grams/Episode	23	23	15	7	6		11	18	16
	Grams per 1,000 Population	0	0	1	1	0		1	2	0
Dermatomyositis (DM)	Patients	100	67	61	19	20	<5		10	<283
	Average Age	52	47	55	50	51	62		43	52
	Average Weight	68	72	79	80	78	74		71	74
	Grams	35,229	25,388	28,383	10,695	9,115	1,360		4,133	114,302
	Grams/Episode	34	45	25	44	48	49		40	34
	Grams per 1,000 Population	4	4	5	6	3	2		9	4
Evans syndrome - with significant Immune thrombocytopenic purpura (ITP) - adult	Patients	9	<5	<5		<5		<5		<29
	Average Age	53	43	62		69		30		56
	Average Weight	100	54	72		70		55		79
	Grams	973	235	840		210		90		2,348
	Grams/Episode	46	78	25		70		23		37
	Grams per 1,000 Population	0	0	0		0		0		0
Fetal alloimmune thrombocytopenia (FAIT)	Patients	<5	<5	<5						<15
	Average Age	27	30	34						34
	Average Weight	80	86	70						72
	Grams	853	1,125	5,370						7,348
	Grams/Episode	85	70	31						37
	Grams per 1,000 Population	0	0	1						0
Guillain–Barré Syndrome (GBS)	Patients	204	119	92	42	22	11	<5	9	<505
	Average Age	56	54	51	57	68	50	36	55	55
	Average Weight	80	79	80	86	82	89	74	86	81
	Grams	34,395	17,080	15,723	6,235	2,985	1,750	470	1,385	80,023

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams/Episode	32	43	24	35	34	47	39	63	32
	Grams per 1,000	4	3	3	3	1	3	2	3	3
Guillain–Barré Syndrome (GBS) variants	Patients	92	39	25	12	14	<5		9	<196
	Average Age	53	55	50	59	65	45		59	54
	Average Weight	78	80	80	84	76	85		85	79
	Grams	14,268	5,948	3,538	1,785	2,095	555		1,395	29,583
	Grams/Episode	33	40	20	30	35	43		66	33
	Grams per 1,000 Population	2	1	1	1	1	1		3	1
IgA paraproteinaemic demyelinating neuropathy	Patients	7	<5	7						<19
	Average Age	81	72	67						72
	Average Weight	79	63	97						90
	Grams	2,810	355	5,825						8,990
	Grams/Episode	41	27	40						39
	Grams per 1,000 Population	0	0	1						0
IgG paraproteinaemic demyelinating neuropathy	Patients	18	<5	11	<5	<5	<5		<5	< 54
	Average Age	74	82	76	55	62	79		67	73
	Average Weight	79	79	84	74	89	84		76	81
	Grams	6,535	1,153	4,240	558	883	1,458		805	15,630
	Grams/Episode	35	30	30	15	49	32		35	32
	Grams per 1,000 Population	1	0	1	0	0	3		2	1
Inclusion Body Myositis (IBM)	Patients	36	48	41	<5	13	<5		7	<155
	Average Age	73	72	70	75	73	77		71	72
	Average Weight	82	82	85	69	74	65		84	82
	Grams	14,082	24,943	19,078	1,495	5,693	935		3,180	69,404
	Grams/Episode	37	43	28	40	36	33		37	36
	Grams per 1,000 Population	2	4	4	1	2	2		7	3
Kawasaki disease	Patients	99	75	50	28	19	7	<5	8	<291
	Average Age	3	3	3	3	3	3	5	3	3
	Average Weight	17	16	16	17	16	19	31	18	17
	Grams	4,030	3,215	1,743	1,098	788	380	190	393	11,835
	Grams/Episode	27	29	14	30	24	38	63	33	25

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams per 1,000 Population	0	0	0	1	0	1	1	1	0
Lambert–Eaton myasthenic syndrome	Patients	11	<5	10	<5	<5			<5	<41
	Average Age	67	69	59	77	58			76	64
	Average Weight	67	84	78	72	62			65	74
	Grams	4,490	3,503	4,273	815	300			780	14,160
	Grams/Episode	36	70	20	41	25			60	33
	Grams per 1,000 Population	1	1	1	0	0			2	1
Lymphoproliferative syndromes (e.g. XLP1, XLP2, CD27 def)	Patients	5	<5		<5	<5	<5			<25
	Average Age	39	29		13	17	44			31
	Average Weight	69	75		40	54	67			63
	Grams	1,556	352		93	163	360			2,523
	Grams/Episode	26	25		4	13	24			20
	Grams per 1,000 Population	0	0		0	0	1			0
Memory B cell deficiency secondary to haemopoietic stem cell transplantation (HSCT)	Patients	119	59	116	11	39	10	<5	<5	<364
	Average Age	49	52	59	55	54	55	64	44	54
	Average Weight	70	71	73	74	71	84	75	50	72
	Grams	22,059	13,212	31,960	2,583	7,956	2,830	60	527	81,185
	Grams/Episode	23	23	21	27	22	29	15	13	22
	Grams per 1,000 Population	3	2	6	1	3	5	0	1	3
Multifocal motor neuropathy with or without persistent conduction block	Patients	211	112	115	47	42	14	6	25	564
	Average Age	58	58	58	60	61	63	55	58	59
	Average Weight	79	82	82	81	83	82	80	88	81
	Grams	141,009	84,198	78,688	45,235	37,443	8,595	4,790	22,104	422,061
	Grams/Episode	47	50	30	51	55	40	84	61	44
	Grams per 1,000 Population	17	13	15	25	14	15	19	49	16
Multiple myeloma (MM)	Patients	616	379	519	93	125	55	<5	23	1,797
	Average Age	71	69	71	69	70	68	61	68	71
	Average Weight	77	81	77	80	86	83	98	76	79
	Grams	145,223	92,453	145,108	21,390	31,480	16,966	510	5,143	458,273
	Grams/Episode	28	25	23	24	22	29	39	25	25
	Grams per 1,000 Population	18	14	28	12	12	30	2	11	18

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Myasthenia gravis (MG)	Patients	439	323	343	127	42	17	<5	33	1,313
	Average Age	63	63	62	62	63	57	44	56	63
	Average Weight	81	81	85	81	84	79	69	81	82
	Grams	197,249	146,507	167,369	68,635	16,530	7,005	500	14,958	618,752
	Grams/Episode	37	41	24	37	37	38	38	39	33
	Grams per 1,000 Population	24	22	32	38	6	12	2	33	24
Necrotising autoimmune myopathy (NAM)	Patients	69	48	58	29	23	<5	5	<5	<242
	Average Age	66	63	63	55	68	55	59	66	63
	Average Weight	79	79	84	83	73	97	76	52	81
	Grams	26,040	23,575	24,268	18,535	11,103	2,125	1,025	830	107,500
	Grams/Episode	35	48	23	43	46	76	47	18	35
	Grams per 1,000 Population	3	4	5	10	4	4	4	2	4
Neonatal alloimmune thrombocytopenia (NAIT)	Patients	8	5	<5	5	<5	<5			<33
	Average Age	31	-	22	28	-	-			26
	Average Weight	66	3	73	84	3	3			63
	Grams	2,358	13	103	1,630	3	10			4,115
	Grams/Episode	52	3	21	78	3	3			51
	Grams per 1,000 Population	0	0	0	1	0	0			0
Neonate with haemochromatosis	Patients	<5	<5	<5			<5			<20
	Average Age	-	-	-			-			-
	Average Weight	3	2	2			4			2
	Grams	8	13	25			5			50
	Grams/Episode	2	3	4			5			3
	Grams per 1,000 Population	0	0	0			0			0
Newly Diagnosed Immune thrombocytopenic purpura (ITP)	Patients	269	182	204	48	67	17	5	8	799
	Average Age	61	62	58	62	62	63	47	73	60
	Average Weight	82	80	83	78	80	84	85	78	82
	Grams	36,723	20,345	30,518	5,183	9,550	2,145	760	1,090	106,313
	Grams/Episode	52	58	32	60	65	61	63	73	46
	Grams per 1,000 Population	5	3	6	3	3	4	3	2	4
	Patients	602	421	656	127	144	67	12	25	2,019

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Non-Hodgkin lymphoma (NHL)	Average Age	71	68	69	68	70	69	57	70	69
	Average Weight	76	78	78	78	79	77	80	67	77
	Grams	166,577	115,023	195,142	26,410	35,113	17,840	1,943	5,712	563,758
	Grams/Episode	28	24	24	24	23	25	29	19	25
	Grams per 1,000 Population	21	18	38	15	13	32	8	13	22
Other Haematological malignancy	Patients	193	58	118	20	14	10		7	416
	Average Age	69	65	69	63	51	56		77	68
	Average Weight	75	78	75	80	67	77		88	76
	Grams	47,375	13,613	32,301	4,821	3,144	2,512		2,165	105,931
	Grams/Episode	28	23	20	23	20	22		29	24
	Grams per 1,000 Population	6	2	6	3	1	4		5	4
Persistent Immune thrombocytopenic purpura (ITP)	Patients	123	105	88	33	33	8	<5	8	<403
	Average Age	59	62	61	60	59	46	36	77	60
	Average Weight	78	81	81	80	82	105	74	96	80
	Grams	24,168	14,290	19,545	4,053	5,675	2,130	370	1,200	71,430
	Grams/Episode	48	48	36	62	57	79	53	92	46
	Grams per 1,000 Population	3	2	4	2	2	4	1	3	3
Polymyositis (PM)	Patients	144	62	95	16	24	<5		11	346
	Average Age	62	63	60	57	69	94		62	62
	Average Weight	78	76	81	71	84	56		76	79
	Grams	55,108	29,808	45,932	8,748	10,948	260		5,090	155,892
	Grams/Episode	34	45	25	48	43	20		38	34
	Grams per 1,000 Population	7	5	9	5	4	0		11	6
Possible Common variable immune deficiency (CVID) - below normal serum IgG but normal serum IgA level	Patients	429	145	127	44	34	8	<5	31	805
	Average Age	59	48	56	46	52	42	26	50	55
	Average Weight	77	70	77	69	73	77	45	80	75
	Grams	149,397	45,265	44,752	11,691	8,852	2,582	289	10,632	273,460
	Grams/Episode	29	22	23	20	23	20	18	23	26
	Grams per 1,000 Population	18	7	9	7	3	5	1	24	11
Pregnant woman with previous fetal loss	Patients	<5	<5		<5					<15
	Average Age	38	33		36					36

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Average Weight	90	64		80					79
	Grams	1,800	1,645		1,440					4,885
	Grams/Episode	43	51		80					53
	Grams per 1,000 Population	0	0		1					0
Severe combined immunodeficiency (SCID)	Patients	12	11	12		<5				<40
	Average Age	19	29	21		24				23
	Average Weight	50	53	54		79				54
	Grams	2,932	2,825	3,476		527				9,759
	Grams/Episode	23	20	14		20				18
	Grams per 1,000 Population	0	0	1		0				0
Severe reduction in all Ig isotypes with decreased or absent B-cells (e.g. XLA def)	Patients	37	37	25	11	10		<5	<5	<130
	Average Age	30	34	29	25	22		18	31	30
	Average Weight	68	65	62	61	52		41	83	64
	Grams	15,081	12,964	8,259	2,799	2,909		800	1,041	43,853
	Grams/Episode	31	23	24	19	22		38	20	25
	Grams per 1,000 Population	2	2	2	2	1		3	2	2
Severe reduction in at least two Ig isotypes with low/normal B-cells (e.g. CVID)	Patients	450	206	218	92	81	21	<5	42	1,090
	Average Age	50	50	51	45	50	46	63	43	50
	Average Weight	73	76	75	75	70	78	82	73	74
	Grams	154,972	79,556	82,903	31,240	24,818	8,540	1,288	15,593	398,910
	Grams/Episode	30	25	25	23	25	22	36	25	26
	Grams per 1,000 Population	19	12	16	17	9	15	5	35	16
Severe reduction in serum IgG and IgA with normal/elevated IgM (e.g. CD40L def)	Patients	19	7	19	<5	7	<5			<62
	Average Age	31	49	47	57	48	54			44
	Average Weight	48	75	61	75	71	96			60
	Grams	4,346	1,912	5,235	401	2,495	-			14,388
	Grams/Episode	23	29	15	14	30	-			20
	Grams per 1,000 Population	1	0	1	0	1				1
Stiff person syndrome	Patients	56	10	26	7	<5	<5	<5	5	<119
	Average Age	60	45	61	68	60	41	44	44	59
	Average Weight	77	74	82	71	71	59	85	71	78

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams	29,826	4,585	17,718	3,950	730	2,240	450	1,643	61,141
	Grams/Episode	46	44	27	33	41	48	45	22	36
	Grams per 1,000 Population	4	1	3	2	0	4	2	4	2
Transient hypogammaglobulinaemia of infancy	Patients	<5		<5	<5	<5	<5		<5	<30
	Average Age	2		-	-	1	4		-	2
	Average Weight	10		10	2	8	13		14	10
	Grams	169		55	5	18	78		5	330
	Grams/Episode	2		5	3	2	5		5	3
	Grams per 1,000 Population	0		0	0	0	0		0	0
Has an established therapeutic role Total	**Patients**	**6,262**	**3,594**	**4,301**	**1,134**	**1,032**	**391**	**82**	**387**	**16,968**
	Average Age	**63**	**62**	**63**	**59**	**62**	**62**	**52**	**57**	**62**
	Average Weight	**78**	**79**	**80**	**78**	**78**	**81**	**77**	**79**	**79**
	Grams	**2,197,730**	**1,259,261**	**1,611,799**	**449,886**	**319,317**	**136,421**	**22,323**	**146,525**	**6,143,262**
	Grams/Episode	**35**	**33**	**26**	**34**	**31**	**32**	**44**	**35**	**31**
	Grams per 1,000 Population	**272**	**192**	**310**	**250**	**117**	**241**	**90**	**325**	**240**
Has an emerging therapeutic role										
Autoimmune haemolytic anaemia	Patients	33	28	43	10	<5	<5	<5	<5	<134
	Average Age	59	60	64	49	72	20	33	60	60
	Average Weight	73	62	78	71	54	103	58	60	74
	Grams	5,168	2,998	7,288	1,003	75	300	115	60	17,005
	Grams/Episode	53	46	35	44	19	60	23	60	42
	Grams per 1,000 Population	1	0	1	1	0	1	0	0	1
Bullous Pemphigoid	Patients	6	17	13	5	<5	<5		<5	48
	Average Age	74	60	64	57	72	59		69	65
	Average Weight	87	101	87	78	78	186		101	90
	Grams	4,470	11,270	10,660	4,870	3,700	220		4,340	39,530
	Grams/Episode	60	58	34	57	47	110		82	49
	Grams per 1,000 Population	1	2	2	3	1	0		10	2
Cicatricial pemphigoid (CP)	Patients	<5	<5	9	<5					<24
	Average Age	58	62	71	82					71

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Average Weight	75	80	84	71					82
	Grams	2,410	1,245	7,115	1,880					12,650
	Grams/Episode	62	83	25	43					33
	Grams per 1,000 Population	0	0	1	1					0
Encephalitis associated with antibodies to AMPA receptor	Patients	<5			<5					<10
	Average Age	56			50					54
	Average Weight	72			69					72
	Grams	350			50					400
	Grams/Episode	25			10					21
	Grams per 1,000 Population	0			0					0
Encephalitis associated with antibodies to CASPR2	Patients	11	<5	<5		<5	<5			<31
	Average Age	55	74	43		72	76			54
	Average Weight	82	77	79		72	93			81
	Grams	4,928	480	1,305		145	420			7,278
	Grams/Episode	42	69	24		29	35			37
	Grams per 1,000 Population	1	0	0		0	1			0
Encephalitis associated with antibodies to GABA (A or B) receptor	Patients	<5		<5		<5				<15
	Average Age	51		51		76				52
	Average Weight	78		103		50				93
	Grams	425		920		20				1,365
	Grams/Episode	35		40		20				38
	Grams per 1,000 Population	0		0		0				0
Encephalitis associated with antibodies to glycine receptor	Patients			5						5
	Average Age			49						49
	Average Weight			73						73
	Grams			2,545						2,545
	Grams/Episode			23						23
	Grams per 1,000 Population			0						0
Encephalitis associated with antibodies to LGI1	Patients	12	11	5		5				33
	Average Age	64	66	53		63				62
	Average Weight	68	78	80		74				74

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams	3,995	3,645	1,255		945				9,840
	Grams/Episode	35	34	21		33				32
	Grams per 1,000 Population	0	1	0		0				0
Encephalitis associated with antibodies to NMDA receptor	Patients	44	15	24	<5	<5	<5		<5	<103
	Average Age	37	43	37	35	47	35		24	38
	Average Weight	74	76	72	72	78	77		86	74
	Grams	11,880	3,328	6,370	1,210	675	200		865	24,528
	Grams/Episode	33	38	21	48	25	22		48	30
	Grams per 1,000 Population	1	1	1	1	0	0		2	1
Encephalitis associated with antibodies to VGKC	Patients	7	<5	7	<5				<5	<29
	Average Age	49	56	50	67				80	54
	Average Weight	71	81	67	74				60	72
	Grams	2,570	1,370	1,738	1,688				120	7,485
	Grams/Episode	30	26	14	34				120	24
	Grams per 1,000 Population	0	0	0	1				0	0
Endemic pemphigus foliaceus	Patients		<5	<5						<10
	Average Age		47	60						55
	Average Weight		60	70						66
	Grams		240	80						320
	Grams/Episode		60	13						32
	Grams per 1,000 Population		0	0						0
Evans syndrome child - with significant ITP	Patients					<5		<5		<10
	Average Age					9		8		9
	Average Weight					72		35		61
	Grams					260		58		318
	Grams/Episode					52		29		45
	Grams per 1,000 Population					0		0		0
Evans Syndrome with significant AIHA	Patients	<5	<5	<5	<5					<20
	Average Age	23	82	45	2					39
	Average Weight	65	89	104	14					83
	Grams	323	160	195	15					693

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams/Episode	54	80	24	15					41
	Grams per 1,000 Population	0	0	0	0					0
Existing patient - authorisation for IgG subclass deficiency	Patients	5	16	<5	<5	<5	<5	<5		<46
	Average Age	70	67	63	75	68	82	2		66
	Average Weight	109	80	73	100	71	53	12		81
	Grams	2,363	5,963	775	752	958	340	45		11,194
	Grams/Episode	30	24	19	47	27	20	3		25
	Grams per 1,000 Population	0	1	0	0	0	1	0		0
Haemophagocytic lymphohistiocytosis	Patients	26	14	14	<5	<5				<64
	Average Age	56	42	52	23	25				49
	Average Weight	71	71	66	33	66				68
	Grams	2,763	2,768	1,890	95	483				7,998
	Grams/Episode	50	56	23	32	40				39
	Grams per 1,000 Population	0	0	0	0	0				0
Heart and kidney transplant	Patients		<5	<5						<10
	Average Age		32	61						57
	Average Weight		77	73						74
	Grams		185	383						568
	Grams/Episode		26	10						12
	Grams per 1,000 Population		0	0						0
Heart and lung transplant	Patients	<5				<5				<10
	Average Age	40				17				31
	Average Weight	70				44				59
	Grams	223				70				293
	Grams/Episode	37				18				29
	Grams per 1,000 Population	0				0				0
Heart transplant	Patients	7	<5	5	<5					<22
	Average Age	58	61	40	70					47
	Average Weight	73	82	61	59					65
	Grams	398	163	1,740	120					2,420
	Grams/Episode	14	41	27	24					23

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams per 1,000 Population	0	0	0	0					0
Histiolymphocytosis	Patients			<5						<51
	Average Age			45						45
	Average Weight			65						65
	Grams			195						195
	Grams/Episode			22						22
	Grams per 1,000 Population			0						0
Hypogammaglobulinaemia following B cell depletion therapy	Patients	140	86	98	32	8	11		<5	<380
	Average Age	55	48	59	46	52	63		52	54
	Average Weight	75	74	75	66	82	79		74	74
	Grams	34,067	19,050	25,427	8,675	983	3,667		1,200	93,068
	Grams/Episode	28	23	18	19	25	20		29	22
	Grams per 1,000 Population	4	3	5	5	0	6		3	4
Hypogammaglobulinaemia following Solid organ transplantation	Patients	164	103	76	<5	<5	5		5	<363
	Average Age	54	58	58	58	62	37		53	57
	Average Weight	69	68	73	83	77	69		77	71
	Grams	33,603	25,932	16,580	758	586	1,180		1,590	80,228
	Grams/Episode	23	22	14	20	20	26		26	20
	Grams per 1,000 Population	4	4	3	0	0	2		4	3
Idiopathic opsoclonus-myoclonus ataxia	Patients	7	<5	<5	<5	<5				<27
	Average Age	4	8	9	26	45				16
	Average Weight	16	19	37	56	68				33
	Grams	608	300	105	360	2,008				3,380
	Grams/Episode	13	11	7	60	74				27
	Grams per 1,000 Population	0	0	0	0	1				0
IgA pemphigus foliaceus	Patients			<5						<5
	Average Age			56						56
	Average Weight			70						70
	Grams			435						435
	Grams/Episode			12						12
	Grams per 1,000 Population			0						0

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
IgM paraproteinaemic demyelinating neuropathy	Patients	35	10	23	5	<5	<5		<5	<88
	Average Age	76	75	69	81	61	72		56	73
	Average Weight	80	85	88	67	80	83		82	83
	Grams	17,463	3,820	10,835	3,578	1,053	1,398		435	38,580
	Grams/Episode	42	37	25	45	29	34		33	34
	Grams per 1,000 Population	2	1	2	2	0	2		1	2
ITP - child - chronic	Patients	<5	7	<5	<5	<5				<27
	Average Age	12	8	6	11	14				8
	Average Weight	54	40	19	38	62				32
	Grams	383	660	535	273	50				1,900
	Grams/Episode	35	21	11	30	50				19
	Grams per 1,000	0	0	0	0	0				0
ITP - child - newly diagnosed	Patients	15	21	10	<5	5	<5		<5	<66
	Average Age	4	3	9	15	5	1		10	5
	Average Weight	20	18	45	112	21	10		45	26
	Grams	458	583	520	80	140	18		45	1,843
	Grams/Episode	15	15	22	80	14	9		45	17
	Grams per 1,000 Population	0	0	0	0	0	0		0	0
ITP - child - persistent	Patients	<5	8	<5		<5	<5		<5	<33
	Average Age	12	5	6		11	13		13	8
	Average Weight	55	24	25		69	60		68	39
	Grams	185	375	73		100	60		135	928
	Grams/Episode	15	23	12		50	60		68	24
	Grams per 1,000 Population	0	0	0		0	0		0	0
Kidney transplant	Patients	107	236	54	16	27	16	6	<5	462
	Average Age	47	52	54	46	49	53	45	47	52
	Average Weight	77	74	79	68	81	81	77	77	76
	Grams	13,805	100,298	16,588	2,455	4,755	9,985	623	238	148,745
	Grams/Episode	20	31	15	35	30	42	15	8	27
	Grams per 1,000 Population	2	15	3	1	2	18	2	1	6
Liver and kidney transplant	Patients		<5							<5

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Average Age		62							62
	Average Weight		66							66
	Grams		108							108
	Grams/Episode		7							7
	Grams per 1,000 Population		0							0
Liver transplant	Patients	<5	<5	<5						<15
	Average Age	55	35	51						48
	Average Weight	57	51	78						61
	Grams	385	103	158						645
	Grams/Episode	30	13	20						22
	Grams per 1,000 Population	0	0	0						0
Lung transplant	Patients	43	64	<5	8	<5	<5			<130
	Average Age	49	54	40	43	34	52			52
	Average Weight	67	74	55	69	65	60			71
	Grams	6,243	14,353	223	1,015	438	830			23,100
	Grams/Episode	34	25	32	44	20	21			27
	Grams per 1,000 Population	1	2	0	1	0	1			1
Macrophage activation syndrome	Patients	7	<5	<5	<5					<22
	Average Age	55	49	59	69					56
	Average Weight	71	57	66	80					68
	Grams	890	110	250	120					1,370
	Grams/Episode	47	22	25	40					37
	Grams per 1,000 Population	0	0	0	0					0
Monophasic acute disseminated encephalomyelitis (ADEM)	Patients	22	7	9	<5		<5			<48
	Average Age	32	33	31	6		2			30
	Average Weight	51	47	33	23		14			42
	Grams	1,798	648	1,228	45		90			3,808
	Grams/Episode	24	22	24	23		9			23
	Grams per 1,000 Population	0	0	0	0		0			0
Mucous Membrane Pemphigoid (MMP)	Patients	<5	7	<5	5		<5		<5	<32
	Average Age	68	66	68	71		49		80	69

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Average Weight	63	88	86	72		72		75	81
	Grams	595	7,050	1,915	2,320		1,820		2,640	16,340
	Grams/Episode	40	66	20	29		140		80	48
	Grams per 1,000 Population	0	1	0	1		3		6	1
Multiphasic acute disseminated encephalomyelitis (ADEM)	Patients	<5	<5	<5						<15
	Average Age	67	31	22						43
	Average Weight	56	62	52						54
	Grams	615	195	678						1,488
	Grams/Episode	22	49	22						24
	Grams per 1,000 Population	0	0	0						0
Other Hypogammaglobulinaemia unrelated to haematological malignancies or haemopoietic stem cell transplantation (HSCT)	Patients	229	100	212	37	13	18	<5	9	614
	Average Age	64	58	64	45	53	55	68	64	61
	Average Weight	76	71	74	67	75	67	65	77	74
	Grams	63,438	23,198	59,315	8,563	3,847	4,920	390	2,248	165,918
	Grams/Episode	27	22	21	19	21	25	30	28	23
	Grams per 1,000 Population	8	4	11	5	1	9	2	5	6
Other transplant	Patients	<5	<5		<5					<15
	Average Age	56	63		11					53
	Average Weight	55	57		53					56
	Grams	55	323		100					478
	Grams/Episode	55	40		50					43
	Grams per 1,000 Population	0	0		0					0
Pancreas and kidney transplant	Patients	<5	6	<5	<5					<21
	Average Age	37	41	29	38					37
	Average Weight	67	89	89	80					84
	Grams	490	3,145	470	158					4,263
	Grams/Episode	17	51	11	53					31
	Grams per 1,000 Population	0	0	0	0					0
Paraneoplastic associated breast cancer	Patients				<5		<5			<10
	Average Age				82		56			76
	Average Weight				85		56			78

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams				340		130			470
	Grams/Episode				49		65			52
	Grams per 1,000 Population				0		0			0
Paraneoplastic associated neuroblastoma	Patients	5		<5			<5			<15
	Average Age	6		1			2			4
	Average Weight	27		10			10			19
	Grams	868		280			10			1,158
	Grams/Episode	22		7			10			14
	Grams per 1,000 Population	0		0			0			0
Paraneoplastic associated other tumour type	Patients		<5			<5				<10
	Average Age		81			75				79
	Average Weight		76			50				68
	Grams		330			100				430
	Grams/Episode		25			17				23
	Grams per 1,000 Population		0			0				0
Paraneoplastic associated small cell lung cancer	Patients	<5								<5
	Average Age	59								59
	Average Weight	73								73
	Grams	240								240
	Grams/Episode	30								30
	Grams per 1,000 Population	0								0
Pemphigus erythematosus	Patients		<5							<5
	Average Age		55							55
	Average Weight		96							96
	Grams		1,975							1,975
	Grams/Episode		60							60
	Grams per 1,000 Population		0							0
Pemphigus herpetiformis	Patients	<5							<5	<10
	Average Age	60							43	56
	Average Weight	60							70	62
	Grams	1,130							240	1,370

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams/Episode	49							34	46
	Grams per 1,000 Population	0							1	0
Pemphigus vulgaris	Patients	8	19	9	<5	<5				<46
	Average Age	55	53	63	68	67				60
	Average Weight	85	72	86	98	80				82
	Grams	7,435	11,870	6,420	3,065	3,855				32,645
	Grams/Episode	71	57	28	50	41				47
	Grams per 1,000 Population	1	2	1	2	1				1
Post-transfusion purpura (PTP)	Patients	<5				<5				<10
	Average Age	50				42				47
	Average Weight	98				80				92
	Grams	100				80				180
	Grams/Episode	25				40				30
	Grams per 1,000 Population	0				0				0
Recurrent acute disseminated encephalomyelitis (ADEM)	Patients	10	<5	5	<5					<25
	Average Age	47	14	30	4					35
	Average Weight	71	61	36	14					58
	Grams	2,835	1,650	595	30					5,110
	Grams/Episode	35	53	13	15					32
	Grams per 1,000 Population	0	0	0	0					0
Sero-negative autoimmune encephalitis	Patients	63	19	19	<5	<5	<5		<5	<121
	Average Age	47	55	63	62	70	15		48	53
	Average Weight	72	79	81	71	72	48		67	75
	Grams	19,140	5,578	4,615	2,515	288	95		415	32,645
	Grams/Episode	33	38	19	39	22	48		83	31
	Grams per 1,000 Population	2	1	1	1	0	0		1	1
Sero-negative limbic encephalitis	Patients	14	<5	21	<5		<5		5	<55
	Average Age	60	70	51	58		44		63	54
	Average Weight	74	66	70	73		83		93	72
	Grams	4,938	560	7,055	438		945		1,170	15,106
	Grams/Episode	38	33	21	36		35		47	27

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams per 1,000 Population	1	0	1	0		2		3	1
Specific antibody deficiency	Patients	170	60	59	82	26	<5	<5	15	406
	Average Age	56	55	58	51	57	22	5	36	54
	Average Weight	70	72	75	69	66	99	17	78	71
	Grams	46,222	17,540	19,339	21,451	6,342	393	57	3,901	115,244
	Grams/Episode	25	22	22	21	20	23	5	23	23
	Grams per 1,000 Population	6	3	4	12	2	1	0	9	4
Staphylococcal TSS	Patients	15	13	7	<5	<5				<45
	Average Age	47	44	44	24	47				44
	Average Weight	90	67	104	74	89				86
	Grams	2,235	1,218	1,180	180	460				5,273
	Grams/Episode	83	68	84	36	115				78
	Grams per 1,000 Population	0	0	0	0	0				0
Stevens–Johnson syndrome / toxic epidermal necrolysis overlap (SJS/TEN)	Patients	15	15	<5	<5	<5	<5		<5	<55
	Average Age	47	54	72	66	31	56		55	50
	Average Weight	81	84	92	76	224	140		82	90
	Grams	2,400	1,868	40	153	260	175		600	5,495
	Grams/Episode	53	52	20	153	65	58		75	56
	Grams per 1,000 Population	0	0	0	0	0	0		1	0
Streptococcal TSS	Patients	26	30	14	19	9	5	<5		<108
	Average Age	40	50	46	43	51	41	55		45
	Average Weight	77	86	80	82	97	70	96		82
	Grams	3,713	4,123	1,843	2,220	1,345	710	320		14,273
	Grams/Episode	81	92	53	82	103	101	107		81
	Grams per 1,000 Population	0	1	0	1	0	1	1		1
Suspected autoimmune encephalitis	Patients	73	91	43	9	18		<5	11	<250
	Average Age	48	58	42	54	52		36	50	49
	Average Weight	69	77	70	79	68		83	84	73
	Grams	15,848	16,323	9,458	3,385	2,660		330	1,720	49,723
	Grams/Episode	32	36	20	48	28		33	44	30
	Grams per 1,000 Population	2	2	2	2	1		1	4	2

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Suspected autoimmune limbic encephalitis	Patients	19	12	35	5	5		<5	9	<90
	Average Age	50	62	46	58	62		15	60	50
	Average Weight	67	74	77	72	65		44	85	75
	Grams	4,175	1,823	11,643	2,335	775		178	3,040	23,968
	Grams/Episode	31	31	24	51	26		44	56	29
	Grams per 1,000 Population	1	0	2	1	0		1	7	1
Thymoma-associated hypogammaglobulinaemia (Goods Syndrome)	Patients	6	<5	<5	<5	<5	<5		<5	<36
	Average Age	57	76	66	73	74	67		57	66
	Average Weight	66	52	73	65	64	77		65	67
	Grams	1,850	710	1,081	1,188	75	426		250	5,580
	Grams/Episode	30	25	25	26	25	11		25	24
	Grams per 1,000 Population	0	0	0	1	0	1		1	0
Toxic epidermal necrolysis (TEN)	Patients	<5	6	<5	<5	<5				<26
	Average Age	70	56	58	68	72				61
	Average Weight	87	75	67	50	60				72
	Grams	738	850	523	100	120				2,330
	Grams/Episode	74	77	21	50	40				46
	Grams per 1,000 Population	0	0	0	0	0				0
Has an emerging therapeutic role Total	**Patients**	**1,342**	**1,025**	**849**	**276**	**159**	**82**	**16**	**80**	**3,785**
	Average Age	**55**	**54**	**57**	**53**	**55**	**55**	**34**	**52**	**55**
	Average Weight	**73**	**74**	**75**	**70**	**73**	**75**	**57**	**81**	**74**
	Grams	**331,205**	**300,475**	**243,854**	**77,578**	**37,648**	**28,331**	**2,114**	**25,251**	**1,046,454**
	Grams/Episode	**29**	**30**	**20**	**27**	**29**	**31**	**20**	**39**	**27**
	Grams per 1,000 Population	**41**	**46**	**47**	**43**	**14**	**50**	**8**	**56**	**41**
Has application in exceptional circumstances only										
Acquired bleeding disorder, other coagulation factors (Prothrombin, factor V, factor VII, factor X, factor XI, and factor XIII)	Patients	<5								<5
	Average Age	81								81
	Average Weight	53								53
	Grams	55								55

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams/Episode	28								28
	Grams per 1,000 Population	0								0
Acquired haemophilia A	Patients	<5	<5			<5			<5	,20
	Average Age	73	90			57			71	75
	Average Weight	84	80			160			90	101
	Grams	85	160			200			180	625
	Grams/Episode	43	53			100			90	69
	Grams per 1,000 Population	0	0			0			0	0
Acquired haemophilia B	Patients					<5				<5
	Average Age					69				69
	Average Weight					65				65
	Grams					800				800
	Grams/Episode					67				67
	Grams per 1,000 Population					0				0
Acquired von Willebrand syndrome	Patients	<5	<5	<5	<5	5				<25
	Average Age	72	79	56	70	72				63
	Average Weight	54	70	85	80	69				77
	Grams	1,470	420	5,395	650	2,745				10,680
	Grams/Episode	51	70	43	59	61				49
	Grams per 1,000 Population	0	0	1	0	1				0
Anti-neutrophil cytoplasmic antibody (ANCA) (PR3 or MPO)-positive idiopathic rapidly progressive glomerulonephritis	Patients	<5	<5	<5	<5					<20
	Average Age	69	51	83	62					66
	Average Weight	78	165	63	55					94
	Grams	310	620	75	55					1,060
	Grams/Episode	24	78	13	14					34
	Grams per 1,000 Population	0	0	0	0					0
Ataxic sensory neuronopathy	Patients	7		<5		<5				<17
	Average Age	59		54		48				57
	Average Weight	83		61		57				72
	Grams	2,945		610		-55				3,500
	Grams/Episode	51		12		-55				32

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams per 1,000 Population	0		0		-0				0
Atypical rolandic epilepsy	Patients	<5	<5	<5	<5					<20
	Average Age	6	9	12	10					10
	Average Weight	20	36	36	34					33
	Grams	360	470	1,340	268					2,438
	Grams/Episode	18	24	18	18					19
	Grams per 1,000 Population	0	0	0	0					0
Autoimmune neutropenia	Patients	6	6	5						17
	Average Age	30	66	54						41
	Average Weight	52	73	97						65
	Grams	1,868	690	615						3,173
	Grams/Episode	39	53	34						40
	Grams per 1,000 Population	0	0	0						0
Autoimmune retinopathy	Patients		<5							<5
	Average Age		50							50
	Average Weight		100							100
	Grams		350							350
	Grams/Episode		88							88
	Grams per 1,000 Population		0							0
Autonomic neuropathy	Patients	<5		<5		<5				<15
	Average Age	57		72		27				59
	Average Weight	59		76		85				69
	Grams	980		606		150				1,736
	Grams/Episode	27		21		17				23
	Grams per 1,000 Population	0		0		0				0
Catastrophic anti-phospholipid syndrome	Patients	9	<5	<5	<5			<5		<29
	Average Age	48	49	45	71			30		47
	Average Weight	92	78	93	86			54		88
	Grams	1,868	390	705	155			250		3,368
	Grams/Episode	37	49	21	22			25		31
	Grams per 1,000 Population	0	0	0	0			1		0

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Confirmed autoimmune congenital heart block in a fetus	Patients	<5	<5							<103
	Average Age	34	30							30
	Average Weight	79	63							66
	Grams	80	378							458
	Grams/Episode	80	76							76
	Grams per 1,000 Population	0	0							0
Congenital haemophilia A with acquired factor VIII inhibitor	Patients		<5							<5
	Average Age		80							80
	Average Weight		78							78
	Grams		80							80
	Grams/Episode		80							80
	Grams per 1,000 Population		0							0
Eosinophilic granulomatosis with polyangiitis (Churg-Strauss Syndrome)	Patients				<5					<5
	Average Age				82					82
	Average Weight				56					56
	Grams				375					375
	Grams/Episode				15					15
	Grams per 1,000 Population				0					0
Epidermolysis bullosa acquisita	Patients		<5		<5					<10
	Average Age		61		73					69
	Average Weight		113		115					114
	Grams		810		1,090					1,900
	Grams/Episode		68		50					56
	Grams per 1,000 Population		0		1					0
Granulomatosis with polyangiitis (Wegener Granulomatosis)	Patients		<5		<5					<10
	Average Age		71		32					34
	Average Weight		68		78					78
	Grams		45		1,053					1,098
	Grams/Episode		23		27					27
	Grams per 1,000 Population		0		1					0
Graves ophthalmopathy	Patients			<5	<5					<10

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Average Age			81	46					59
	Average Weight			82	86					85
	Grams			100	570					670
	Grams/Episode			20	63					48
	Grams per 1,000 Population			0	0					0
Haemolytic disease of the fetus	Patients	<5	<5	<5	<5	<5			<5	<30
	Average Age	27	35	27	32	20			37	30
	Average Weight	53	52	91	62	67			80	73
	Grams	1,048	1,050	2,838	250	203			1,750	7,138
	Grams/Episode	44	42	52	63	68			76	53
	Grams per 1,000 Population	0	0	1	0	0			4	0
Hyperhaemolysis syndrome	Patients	<5		<5						<10
	Average Age	16		77						57
	Average Weight	70		94						86
	Grams	175		295						470
	Grams/Episode	58		49						52
	Grams per 1,000 Population	0		0						0
Landau Kleffner syndrome	Patients	<5	<5	<5						<15
	Average Age	24	7	7						15
	Average Weight	76	21	20						46
	Grams	950	183	80						1,213
	Grams/Episode	73	17	16						42
	Grams per 1,000 Population	0	0	0						0
Lennox-Gastaut syndrome	Patients	<5		<5	<5				<5	<20
	Average Age	8		4	11				12	6
	Average Weight	22		19	40				36	21
	Grams	798		580	40				220	1,638
	Grams/Episode	42		11	40				44	21
	Grams per 1,000 Population	0		0	0				0	0
LETMs	Patients	<5	<5							<10
	Average Age	54	17							52

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Average Weight	72	58							71
	Grams	1,020	115							1,135
	Grams/Episode	28	58							29
	Grams per 1,000 Population	0	0							0
Microscopic polyangiitis	Patients				<5					<5
	Average Age				44					44
	Average Weight				59					59
	Grams				1,620					1,620
	Grams/Episode				52					52
	Grams per 1,000 Population				1					0
NMOSD–AQP4 ab positive	Patients	5	<5		<5					<15
	Average Age	60	13		69					59
	Average Weight	59	50		120					62
	Grams	1,708	100		200					2,008
	Grams/Episode	31	50		50					33
	Grams per 1,000 Population	0	0		0					0
NMOSD–MOG ab positive	Patients	13	7	<5	<5	<5		<5		<40
	Average Age	41	32	18	10	51		63		36
	Average Weight	87	64	84	33	80		80		76
	Grams	4,028	2,620	548	428	1,390		150		9,163
	Grams/Episode	38	33	25	31	39		30		35
	Grams per 1,000 Population	0	0	0	0	1		1		0
NMOSD–seronegative	Patients	22	8	<5	<5		<5	<5		<50
	Average Age	52	37	26	24		15	62		46
	Average Weight	79	68	56	47		51	87		73
	Grams	7,028	1,618	433	890		103	180		10,251
	Grams/Episode	32	34	16	39		51	60		32
	Grams per 1,000 Population	1	0	0	0		0	1		0
Paediatric acute neuropsychiatric disorders (PANS)	Patients	20	<5	14	<5					<44
	Average Age	13	16	11	18					12
	Average Weight	49	72	55	73					54

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams	9,775	815	6,283	1,520					18,393
	Grams/Episode	63	91	22	80					39
	Grams per 1,000 Population	1	0	1	1					1
Paediatric autoimmune neuropsychiatric disorder (PANDAS)	Patients	<5	<5	5						<15
	Average Age	10	11	12						11
	Average Weight	44	39	64						55
	Grams	778	778	2,945						4,500
	Grams/Episode	46	26	38						36
	Grams per 1,000 Population	0	0	1						0
Painful small fibre neuropathy	Patients	<5	<5	<5		<5		<5	<5	<30
	Average Age	64	63	28		58		73	64	62
	Average Weight	77	62	63		75		68	77	72
	Grams	1,550	825	505		1,105		1,043	2,163	7,190
	Grams/Episode	36	22	46		28		36	57	36
	Grams per 1,000 Population	0	0	0		0		4	5	0
Pure red cell aplasia – associated B19 infection	Patients	<5	<5	<5					<5	<20
	Average Age	48	62	55					36	52
	Average Weight	79	88	75					56	76
	Grams	1,345	423	1,150					335	3,253
	Grams/Episode	45	70	19					56	32
	Grams per 1,000 Population	0	0	0					1	0
Pure red cell aplasia – autoimmune mediated	Patients	<5	6	<5			<5			<21
	Average Age	63	62	75			71			67
	Average Weight	73	77	90			93			80
	Grams	1,205	810	305			258			2,578
	Grams/Episode	75	51	23			129			55
	Grams per 1,000 Population	0	0	0			0			0
Pyoderma Gangrenosum	Patients	7	28	15	<5	<5	<5	<5	<5	<75
	Average Age	54	62	64	52	42	73	59	20	60
	Average Weight	86	83	93	74	125	65	53	60	86
	Grams	4,605	19,903	6,668	3,005	1,200	195	105	270	35,950

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams/Episode	85	64	31	46	67	49	18	16	52
	Grams per 1,000 Population	1	3	1	2	0	0	0	1	1
Rasmussen encephalitis	Patients	9	5	6	<5	<5	<5	<5	<5	<45
	Average Age	28	40	35	13	38	5	36	63	34
	Average Weight	70	71	63	60	114	22	82	64	69
	Grams	5,103	2,978	1,788	720	770	23	250	325	11,955
	Grams/Episode	44	38	16	51	55	23	36	25	33
	Grams per 1,000 Population	1	0	0	0	0	0	1	1	0
Relapsing remitting multiple sclerosis	Patients	27	9	7		<5			<5	<53
	Average Age	41	36	62		47			49	45
	Average Weight	84	66	81		85			60	78
	Grams	5,965	2,373	1,430		170			780	10,718
	Grams/Episode	32	29	20		43			60	30
	Grams per 1,000 Population	1	0	0		0			2	0
Risk of autoimmune congenital heart block – previously affected sibling	Patients	<5							<5	<10
	Average Age	32							36	35
	Average Weight	65							57	58
	Grams	130							235	365
	Grams/Episode	65							21	28
	Grams per 1,000 Population	0							1	0
Scleromyxedema – skin and systemic disease	Patients	5	<5		<5	<5				<20
	Average Age	69	67		69	76				70
	Average Weight	75	54		75	57				66
	Grams	3,718	980		1,950	2,365				9,013
	Grams/Episode	51	22		56	43				43
	Grams per 1,000 Population	0	0		1	1				0
Scleromyxedema – skin involvement only	Patients	<5	<5		<5	<5				<20
	Average Age	31	84		49	76				54
	Average Weight	91	94		78	52				84
	Grams	1,560	1,515		2,525	105				5,705
	Grams/Episode	71	72		55	35				62

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams per 1,000 Population	0	0		1	0				0
Sensorimotor axonal neuropathy	Patients	<5	<5			<5		<5		<20
	Average Age	64	73			61		71		66
	Average Weight	70	57			67		85		70
	Grams	1,470	248			150		613		2,480
	Grams/Episode	33	19			19		47		31
	Grams per 1,000 Population	0	0			0		2		0
Susac syndrome	Patients	13	<5	11	<5	<5				<40
	Average Age	37	47	46	55	37				44
	Average Weight	95	70	86	64	81				85
	Grams	9,325	2,275	6,925	2,215	200				20,940
	Grams/Episode	47	39	31	31	25				37
	Grams per 1,000 Population	1	0	1	1	0				1
Systemic capillary leak syndrome	Patients	7	5	<5	<5	<5			<5	<32
	Average Age	44	70	64	31	50			57	55
	Average Weight	82	75	71	84	68			73	76
	Grams	2,933	3,503	1,535	1,040	1,360			760	11,130
	Grams/Episode	36	63	24	80	65			109	46
	Grams per 1,000 Population	0	1	0	1	0			2	0
Vaccine induced immune thrombotic thrombocytopenia (VITT)	Patients	25	18	15	7	<5	<5	<5		<80
	Average Age	68	68	66	67	57	73	70		67
	Average Weight	75	82	83	86	91	74	81		80
	Grams	3,283	2,385	2,060	745	445	288	160		9,365
	Grams/Episode	58	64	40	62	74	96	80		56
	Grams per 1,000 Population	0	0	0	0	0	1	1		0
West syndrome	Patients			<5						<5
	Average Age			6						6
	Average Weight			18						18
	Grams			233						233
	Grams/Episode			10						10
	Grams per 1,000 Population			0						0

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Has application in exceptional circumstances only Total	**Patients**	**212**	**132**	**117**	**43**	**26**	**<25**	**<25**	**<25**	**555**
	Average Age	**43**	**51**	**40**	**48**	**59**	**57**	**61**	**47**	**45**
	Average Weight	**75**	**72**	**71**	**70**	**76**	**66**	**71**	**68**	**73**
	Grams	**79,516**	**49,905**	**46,044**	**21,363**	**13,303**	**865**	**2,750**	**7,018**	**220,762**
	Grams/Episode	**43**	**48**	**27**	**44**	**47**	**72**	**37**	**52**	**39**
	Grams per 1,000 Population	**10**	**8**	**9**	**12**	**5**	**2**	**11**	**16**	**9**
Use is not supported										
Congestive cardiac failure	Patients		<5							<5
	Average Age		52							52
	Average Weight		100							100
	Grams		100							100
	Grams/Episode		100							100
	Grams per 1,000 Population		0							0
Diabetic amyotrophy	Patients		<5							<5
	Average Age		81							81
	Average Weight		86							86
	Grams		868							868
	Grams/Episode		35							35
	Grams per 1,000 Population		0							0
Sepsis	Patients	<5	<5	<5	<5				<5	<25
	Average Age	70	5	54	24				52	46
	Average Weight	85	31	97	90				100	81
	Grams	233	158	250	180				100	920
	Grams/Episode	47	53	42	90				100	54
	Grams per 1,000 Population	0	0	0	0				0	0
Use is not supported Total	**Patients**	**<5**	**<5**	**<5**	**<5**				**<5**	**<25**
	Average Age	**70**	**72**	**54**	**24**				**52**	**67**
	Average Weight	**85**	**81**	**97**	**90**				**100**	**85**
	Grams	**233**	**1,125**	**250**	**180**				**100**	**1,888**
	Grams/Episode	**47**	**39**	**42**	**90**				**100**	**44**

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams per 1,000 Population	0	0	0	0				0	0
Total	Patients	7,772	4,727	5,246	1,443	1,212	474	106	481	21,194
	Average Age	61	60	61	57	62	61	50	56	61
	Average Weight	77	77	79	77	78	80	73	79	78
	Grams	2,608,683	1,610,766	1,901,946	549,007	370,267	165,617	27,187	178,894	7,412,365
	Grams/Episode	34	33	25	33	31	32	40	36	31
	Grams per 1,000 Population	323	245	366	306	136	293	109	396	289

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: Grams are rounded, and the totals may not sum.

APPENDIX E – SYSTEM SOURCE FOR TABLES AND FIGURES