



NATIONAL BLOOD AUTHORITY  
AUSTRALIA

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

**ANNUAL REPORT 2019-20**





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# Contents

LIST OF TABLES .....	4
LIST OF FIGURES.....	4
<b>INTRODUCTION .....</b>	<b>5</b>
<b>REPORT SNAPSHOT.....</b>	<b>8</b>
<b>METHODOLOGY.....</b>	<b>9</b>
DATA QUALITY .....	10
<b>TRENDS.....</b>	<b>12</b>
DEMAND TRENDS.....	12
FINANCIAL TRENDS.....	13
<b>PATIENT DEMOGRAPHICS.....</b>	<b>17</b>
PATIENT NUMBERS.....	17
AGE AND WEIGHT .....	18
<b>IG DISPENSES .....</b>	<b>20</b>
IG DISPENSES BY CRITERIA CATEGORY .....	20
IG DISPENSES BY SPECIALITY .....	20
IG DISPENSES BY MEDICAL CONDITION .....	22
<b>IG DISPENSES - IVIG AND SCIG .....</b>	<b>24</b>
<b>IG ISSUED – NHIG.....</b>	<b>26</b>
<b>APPENDICES.....</b>	<b>27</b>
APPENDIX A – BACKGROUND .....	27
APPENDIX B – ACRONYMS AND GLOSSARY.....	30
APPENDIX C – CONDITIONS MAPPING TABLE .....	33
APPENDIX D – DATASET OF IG SUPPLY BY STATE/TERRITORY 2019-20 .....	43
APPENDIX E – SYSTEM SOURCE FOR TABLES AND FIGURES .....	73

## LIST OF TABLES

Table 1: Ig growth for the last 5 years .....	7
Table 2: Go live dates for BloodSTAR.....	9
Table 3: Grams recorded in the different systems held by the NBA .....	11
Table 4: Percentage change in grams issued compared to previous year over time by state and territory .....	13
Table 5: Issues of domestic Ig compared with imported Ig .....	15
Table 6: Issues of domestic Ig compared with imported Ig, and public versus private Australian Health Providers .....	16
Table 7: Patient numbers by state and territory .....	17
Table 8: Patient numbers and average weight by age range .....	19
Table 9: Ig grams dispensed by criteria category.....	20
Table 10: Ig grams dispensed by Speciality and state and territory for 2019-20 .....	21
Table 11: Patients dispensed Ig by speciality and state and territory for 2019-20 .....	21
Table 12: New patients dispensed Ig by speciality and state and territory for 2019-20.....	22
Table 13: Grams dispensed by states and territories and medical condition for 2019-20.....	23
Table 14: Patients dispensed by SCIg/IVIg, medical conditions and product for 2019-20 .....	24
Table 15: Grams dispensed by SCIg/IVIg, medical conditions and product for 2019-20.....	25
Table 16: Patients dispensed by SCIg medical conditions, and state and territory for 2019-20.....	25
Table 17: Grams dispensed by SCIg medical conditions, and state and territory for 2019-20.....	25

## LIST OF FIGURES

Figure 1: Snapshot .....	8
Figure 2: Per cent dispensed grams by medical condition .....	8
Figure 3: Ten-year trend in issues of Ig .....	12
Figure 4: Ten-year trend in expenditure on Ig .....	13
Figure 5: Ig expenditure as a proportion of the national blood budget.....	14
Figure 6: New and total patients for the last 10 years .....	17
Figure 7: Patient age relative to Australian average.....	18
Figure 8: Grams of Ig dispensed by speciality.....	21
Figure 9: Grams of Ig dispensed by top 10 medical conditions .....	22
Figure 10: NHIg grams issued and grams issued per 1,000 population.....	26

# Introduction

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

Immunoglobulin products analysed in this report include intravenous Ig (IVIg), subcutaneous Ig (SCIg) and normal human Ig (NHlg). Aggregated data for IVIg and SCIg are referred to as Ig unless specifically stated. NHlg 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 2019-20. It also considers trends in supply over the last 10 years.

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

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

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

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

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

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

Although Version 3 of the Criteria was introduced in October 2018, not all patients transitioned at this time, with some patients continuing under existing authorisations until their scheduled review. This meant that in 2019-20, while most patients accessed treatment under Version 3 of the Criteria, some patients were still authorised to receive treatment under Version 2 until the end of the existing authorisation period. All patients were transitioned to the new Criteria by October 2019. Therefore, for this 2019-20 report, conditions are a combination of Version 3 and Version 2 Criteria.

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

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

Introduced in 2016, BloodSTAR was developed by the NBA on behalf of all Australian Governments to serve the needs of health providers and support users to meet their obligations under the National Policy. Through BloodSTAR, persons in prescriber 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 across Australia in July 2016 and was completed in October 2018.

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

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

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

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

Australia is in a unique position to provide analysis and commentary on the use of Ig due to its national supply arrangements. This report begins with an analysis of Ig supply over the last 10 years, then considers patient demographics, expenditure on Ig, clinical indications for which Ig was supplied, and finally analyses the dose prescribed for various conditions. The top 10 medical conditions account for 88 per cent of all Ig supplied in 2019-20, and for this reason specific analysis focuses on these groups.

### Issues of Immunoglobulin

Immunoglobulin comprises approximately 50 per cent of total blood expenditure each year. Demand for Ig was growing at a consistent annual rate of more than 10 per cent up to and including 2017-18. This rate of growth has slowed to 6.7 per cent in 2019-20 as compared to 7.2 per cent in 2018-19. This is the lowest annual rate of increase since 2004-05, when Australia first secured supply sufficiency through national importation of Ig by the NBA.

**Table 1: Ig growth for the last 5 years**

2015-16	2016-17	2017-18	2018-19	2019-20
12.4%	11.2%	10.6%	7.2%	6.7%

In 2019-20, a total of approximately 7 million grams of Ig was issued nationally representing a cost of \$637.1 million (including the cost of plasma for fractionation) or about 52 percent of total blood and blood product issues. Of this amount, about 46 per cent was Ig produced in Australia and 54 per cent was imported.

Two contracts were in place for the supply of imported Ig under the national blood arrangements during the 2019-20 reporting period.

# Report Snapshot

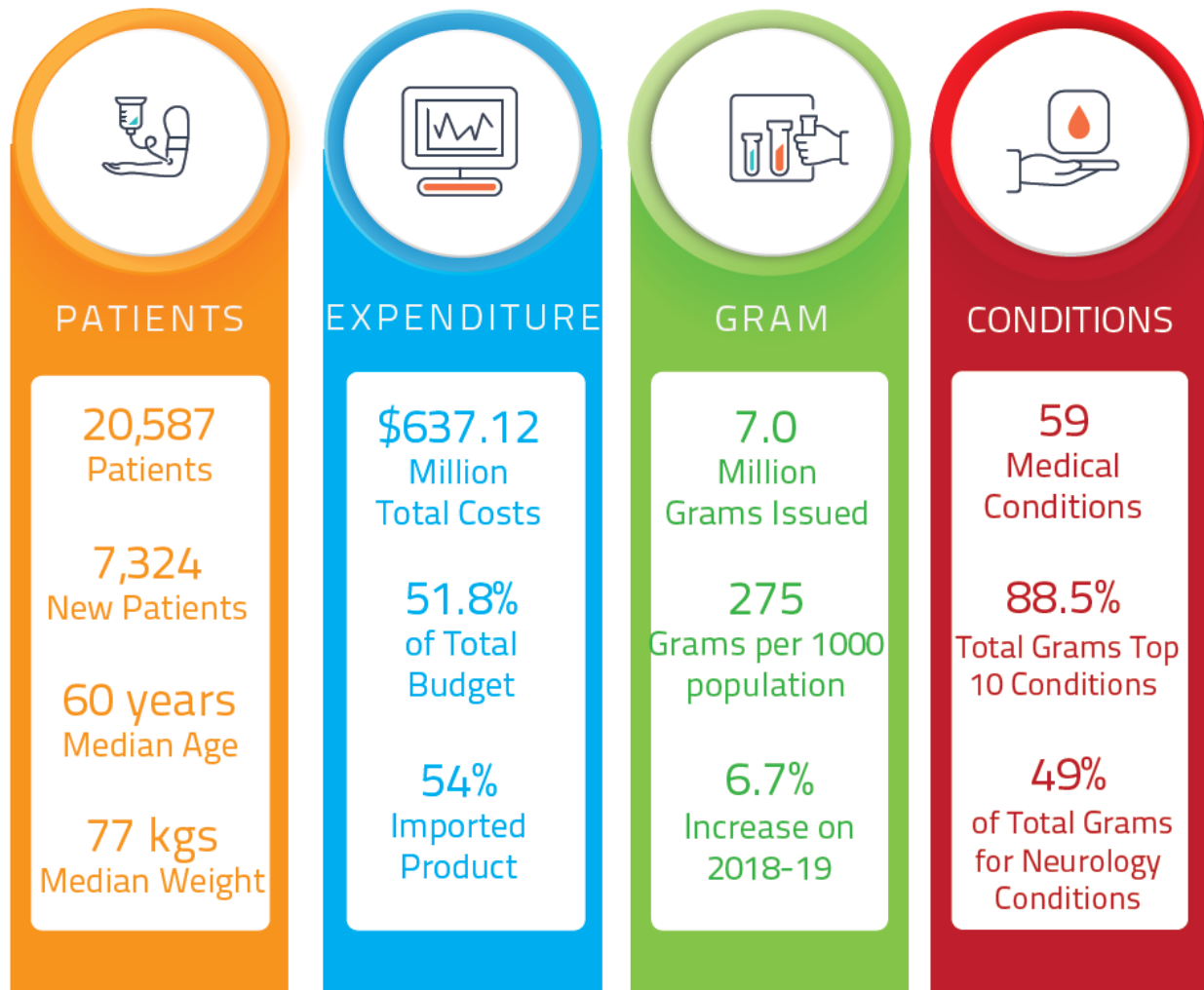


Figure 1: Snapshot

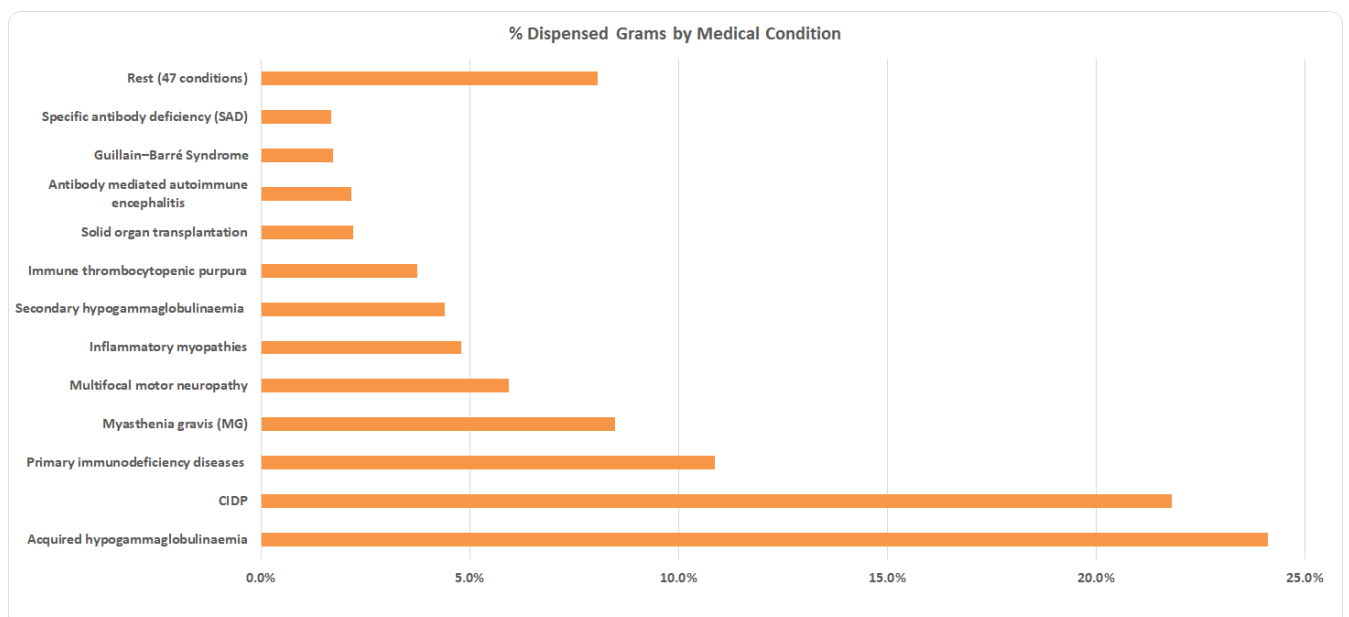


Figure 2: Per cent dispensed grams by medical condition



# 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 *Legacy* data. When comparing data across time, there are limitations to some data that may not be directly comparable due to changes in Criteria versions, or whether the data has come from BloodSTAR or STARS. More information about these differences can be found in the data quality section below.

**Table 2: Go live dates for BloodSTAR**

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

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

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

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

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

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

## DATA QUALITY

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

- The reconciliation of data held in STARS, BloodSTAR/BloodNet and Integrated Data Management System (IDMS) indicates minor variances at a national level. In some cases, these differences can be explained by product being ordered and recorded in IDMS the month prior to product being dispensed to a patient.
- Patient and authorisation data for some records are incomplete. For example, data from STARS and BloodSTAR may not always include patient weight. Legacy data entered in BloodSTAR did not include patient weight.
- The Australian Bureau of Statistics (ABS) Australian Demographic Statistics (cat. No 3101.0) was used from 2011-12.
- Care should be taken when interpreting the data relating to the smaller states and territories, as one or 2 patients can overly influence the use as compared to larger states.
- There has been no adjustment for Ig dispensed in one state or territory for patients residing in a different state or territory.
- States and territories are based on the state or territory of the facility which dispensed the product.
- The STARS data have age and weight data recorded at treatment dates (first reported in 2009-10). This data changes over time. Weight data is complete in 2018-19 based on the transition to BloodSTAR. Age data are based on the patient's age on 1 January each year for both STARS and BloodSTAR.
- Episodes in STARS were known as Treatment Episodes. In BloodSTAR, these are known as Dispense Events. In this document we have used Treatment Episodes for consistency.
- Patient Counts are distinct counts and will not sum for National or Total rows and columns, as patients may have:
  - more than one specific condition,
  - product dispensed in more than one state or territory,
  - treatment episodes recorded both at a private facility and at a public facility,
  - received IVIg and SCIg, or
  - received both domestic and imported product.
- In some cases, grams issued or dispensed may not total, as the aggregate may be round to the nearest integer.
- Earlier versions of the Criteria classified medical conditions into 4 Chapters based on the level of evidence supporting the use of Ig. In BloodSTAR, these are known as Categories 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.
- Specific and Medical Conditions are based on Version 2 and 3 of the Criteria as per the mapping at **Appendix C**.

- Dispensed data can be entered into BloodSTAR at any time, if there is a valid and active authorisation. This means that a treatment episode may be recorded in one month and the actual treatment episode was in another month, which means data for 2018-19 could be recorded in 2019-20.
- In order to maintain the anonymity of individual patients and health providers, data showing less than 5 may be suppressed or aggregated if there is a potential to re-identify or exceptions are agreed between national and state/territory data custodians.

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

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

**Table 3** shows the reconciliation between the 3 systems used for this report. A variance of 2.2 per cent represents about one week of issues. This difference relates to timing of data entry or product held as imprest stock.

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

	Total Issued Grams	BloodSTAR Dispensed Grams	Difference Grams	Difference %
NSW	2,466,203	2,383,254	82,949	3.4%
VIC	1,561,787	1,521,910	39,878	2.6%
QLD	1,803,292	1,794,398	8,894	0.5%
SA	356,205	344,825	11,380	3.2%
WA	486,809	476,791	10,018	2.1%
TAS	149,962	149,557	405	0.3%
NT	27,895	27,065	830	3.0%
ACT	158,023	155,590	2,432	1.5%
<b>Total</b>	<b>7,010,176</b>	<b>6,853,389</b>	<b>156,787</b>	<b>2.2%</b>
Other	543			
<b>Total</b>	<b>7,010,719</b>			

Note 1: Includes NHlg

Note 2: Other includes Norfolk Island

# Trends

## DEMAND TRENDS

In 2019-20, a total of 7,010,176 grams of Ig was issued, representing an increase of 437,701 grams (6.7 per cent) from 2018-19. Prior to 2018-19, the increase in Ig use averaged about 11 per cent, with the greatest proportion of that increase comprising imported products (**Figure 3**).

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

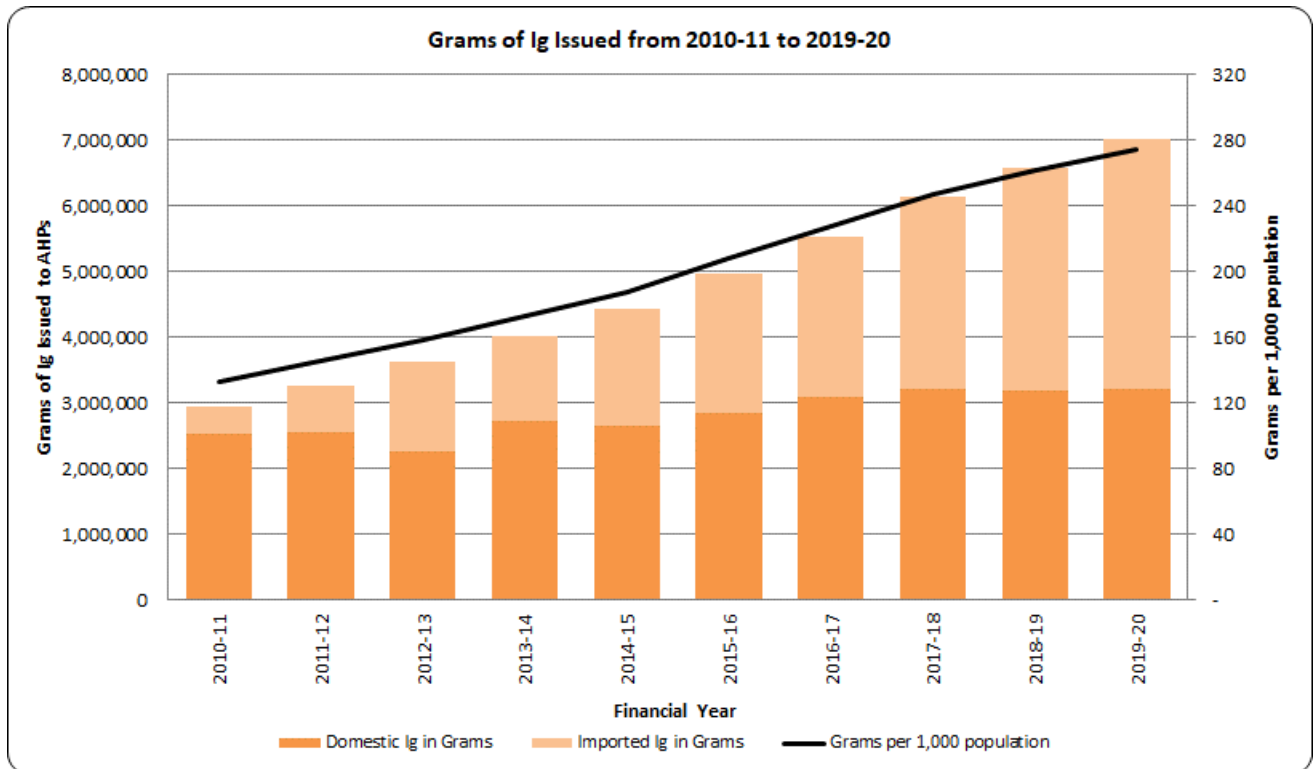


Figure 3: Ten-year trend in issues of Ig

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

Over the past 10 years the Australian Capital Territory (ACT) and the Northern Territory (NT) have been growing at an average of 14 per cent.

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

	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
2010-11	11%	10%	16%	-4%	10%	8%	7%	28%	<b>11%</b>
2011-12	11%	7%	16%	9%	6%	1%	47%	17%	<b>11%</b>
2012-13	11%	13%	11%	9%	7%	-6%	21%	12%	<b>11%</b>
2013-14	10%	11%	12%	15%	6%	14%	1%	12%	<b>11%</b>
2014-15	9%	11%	12%	7%	12%	8%	8%	8%	<b>10%</b>
2015-16	14%	10%	14%	11%	17%	2%	36%	3%	<b>12%</b>
2016-17	14%	11%	8%	10%	18%	4%	6%	7%	<b>11%</b>
2017-18	11%	12%	10%	5%	9%	21%	23%	13%	<b>11%</b>
2018-19	9%	8%	4%	7%	5%	8%	0%	19%	<b>7%</b>
2019-20	4%	7%	7%	7%	16%	9%	-11%	18%	<b>7%</b>
<b>Average last 10 years</b>	<b>10%</b>	<b>10%</b>	<b>10%</b>	<b>8%</b>	<b>11%</b>	<b>7%</b>	<b>14%</b>	<b>14%</b>	<b>10%</b>

## FINANCIAL TRENDS

Total expenditure on Ig (excluding plasma for fractionation) in 2019-20 was \$364.3 million, an increase of \$22.8 million (6.7 per cent) over 2018-19 (**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.

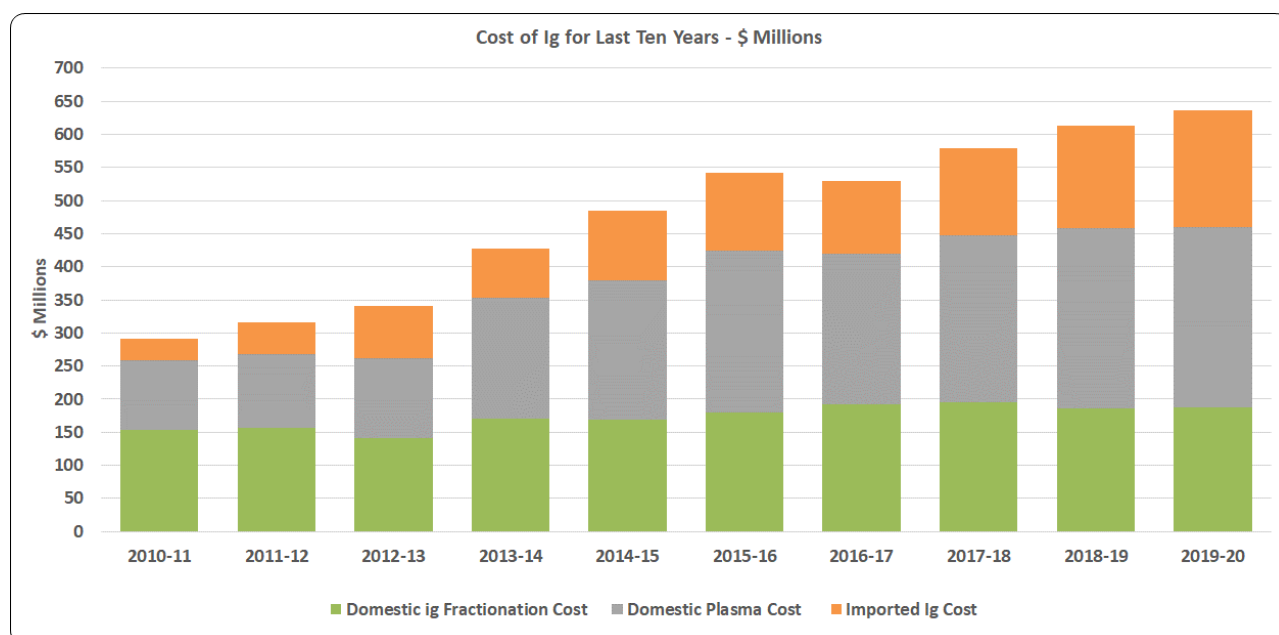
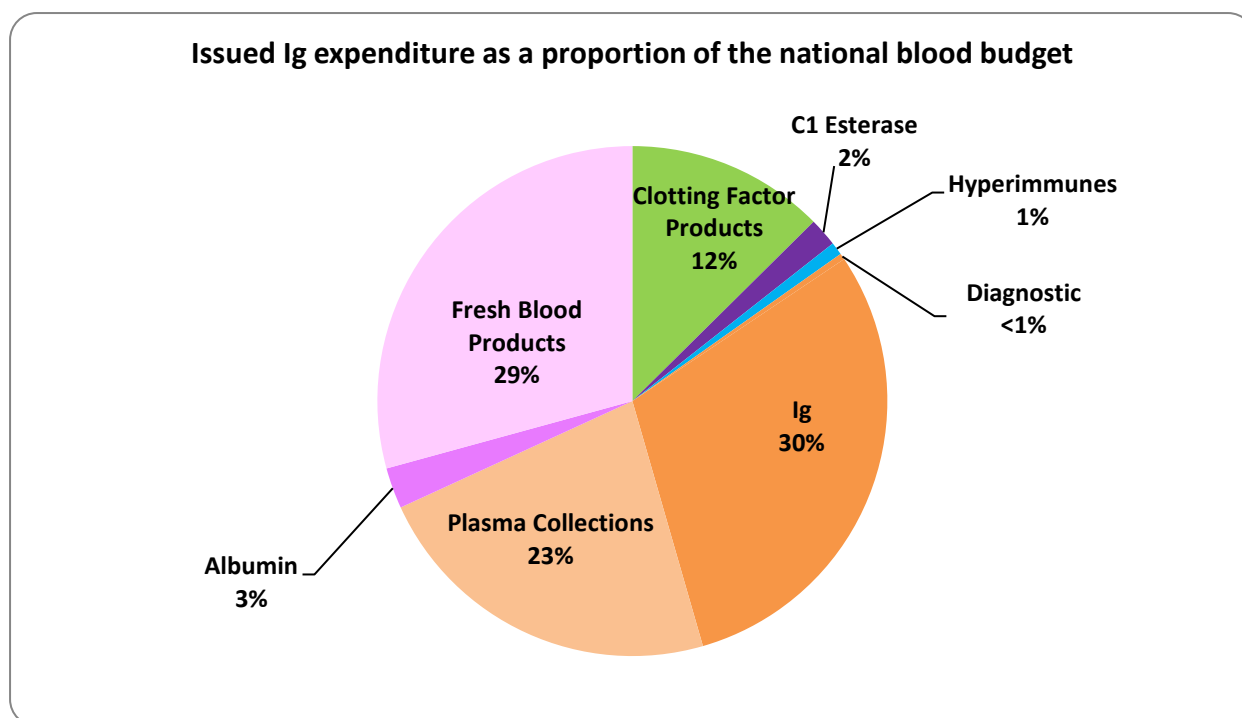


Figure 4: Ten-year trend in expenditure on Ig

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 30 per cent of the total budget for blood and blood products. Combined with expenditure for plasma for fractionation, Ig accounts for 53 per cent of the total blood budget, at a total expenditure of \$637.1 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 2019-20, 46 per cent was manufactured domestically and 54 per cent was imported from overseas (see **Table 5: Issues of domestic Ig compared with imported Ig**).

The increase in product importation from 2018-19 was about 12 per cent. Domestic supply is driven by the amount of plasma for fractionation collected in Australia, which increased by 9 per cent in 2019-20 over 2018-19. Intragam 10 (IVIg) and Evogam (SCIg) were Ig products manufactured domestically in 2019-20.

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 2019-20.

Table 5: Issues of domestic Ig compared with imported Ig

			NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Domestic Ig	Intragam 10	g	1,172,020	651,473	820,073	144,755	235,265	53,108	9,245	59,810	<b>3,145,748</b>
	Evogam	g	22,730	16,886	20,668	10,486	4,557	770	866	1,833	<b>78,796</b>
	<b>Total Domestic</b>	<b>g</b>	<b>1,194,750</b>	<b>668,359</b>	<b>840,741</b>	<b>155,241</b>	<b>239,822</b>	<b>53,877</b>	<b>10,111</b>	<b>61,643</b>	<b>3,224,544</b>
Imported Ig	<b>Total Imported</b>	<b>g</b>	<b>1,271,453</b>	<b>893,429</b>	<b>962,552</b>	<b>200,964</b>	<b>246,988</b>	<b>96,085</b>	<b>17,784</b>	<b>96,380</b>	<b>3,785,633</b>
<b>Ig Cost excluding the cost of plasma for fractionation</b>		\$(m)	\$128.8	\$80.6	\$93.8	\$18.4	\$25.5	\$7.6	\$1.4	\$8.1	\$364.3
<b>Proportion of domestic to imported Ig</b>		g%	48%	43%	47%	44%	49%	36%	36%	39%	<b>46%</b>

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	846,317	401,604	312,351	129,106	162,231	34,435	10,111	61,643	1,957,799
	Private	g	348,433	266,755	528,389	26,135	77,591	19,442	-	-	1,266,745
	<b>Total Domestic</b>	<b>g</b>	<b>1,194,750</b>	<b>668,359</b>	<b>840,741</b>	<b>155,241</b>	<b>239,822</b>	<b>53,877</b>	<b>10,111</b>	<b>61,643</b>	<b>3,224,544</b>
Imported Ig	Public	g	1,019,155	576,086	460,248	172,914	191,312	65,211	17,784	96,220	2,598,928
	Private	g	252,299	317,343	502,304	28,050	55,676	30,874	-	160	1,186,705
	<b>Total Imported</b>	<b>g</b>	<b>1,271,453</b>	<b>893,429</b>	<b>962,552</b>	<b>200,964</b>	<b>246,988</b>	<b>96,085</b>	<b>17,784</b>	<b>96,380</b>	<b>3,785,633</b>
Total Ig	Public	g	1,865,472	977,690	772,599	302,020	353,543	99,646	27,895	157,863	,556,726
	Private	g	600,732	584,098	1,030,693	54,185	133,267	50,316	-	160	2,453,450
	<b>Total Ig</b>	<b>g</b>	<b>2,466,203</b>	<b>1,561,787</b>	<b>1,803,292</b>	<b>356,205</b>	<b>486,809</b>	<b>149,962</b>	<b>27,895</b>	<b>158,023</b>	<b>7,010,176</b>
Ig as portion of National	Public	g%	41%	21%	17%	7%	8%	2%	1%	3%	100%
	Private	g%	24%	24%	42%	2%	5%	2%	0%	0%	100%
	<b>Total Ig</b>	<b>g%</b>	<b>35%</b>	<b>22%</b>	<b>26%</b>	<b>5%</b>	<b>7%</b>	<b>2%</b>	<b>1%</b>	<b>2%</b>	<b>100%</b>
	<b>% of Population</b>		<b>32%</b>	<b>26%</b>	<b>20%</b>	<b>7%</b>	<b>11%</b>	<b>2%</b>	<b>1%</b>	<b>2%</b>	<b>100%</b>
Grams Per 1,000 Population	Public		231.0	148.5	150.4	169.5	131.3	178.3	112.7	354.1	178.6
	Private		74.4	88.7	200.7	30.4	49.5	90.0	-	0.4	96.1
	<b>Total Ig</b>		<b>305.4</b>	<b>237.2</b>	<b>351.1</b>	<b>199.9</b>	<b>180.7</b>	<b>268.3</b>	<b>112.7</b>	<b>354.5</b>	<b>274.7</b>

Note: Excludes Norfolk Island



# Patient demographics

## PATIENT NUMBERS

Immunoglobulin was dispensed to 20,587 patients under the national blood arrangements during 2019-20, including 7,324 new patients. This represents about one per cent increase in the number of patients since 2018-19. A summary of new and total patient numbers is provided in **Figure 6**.

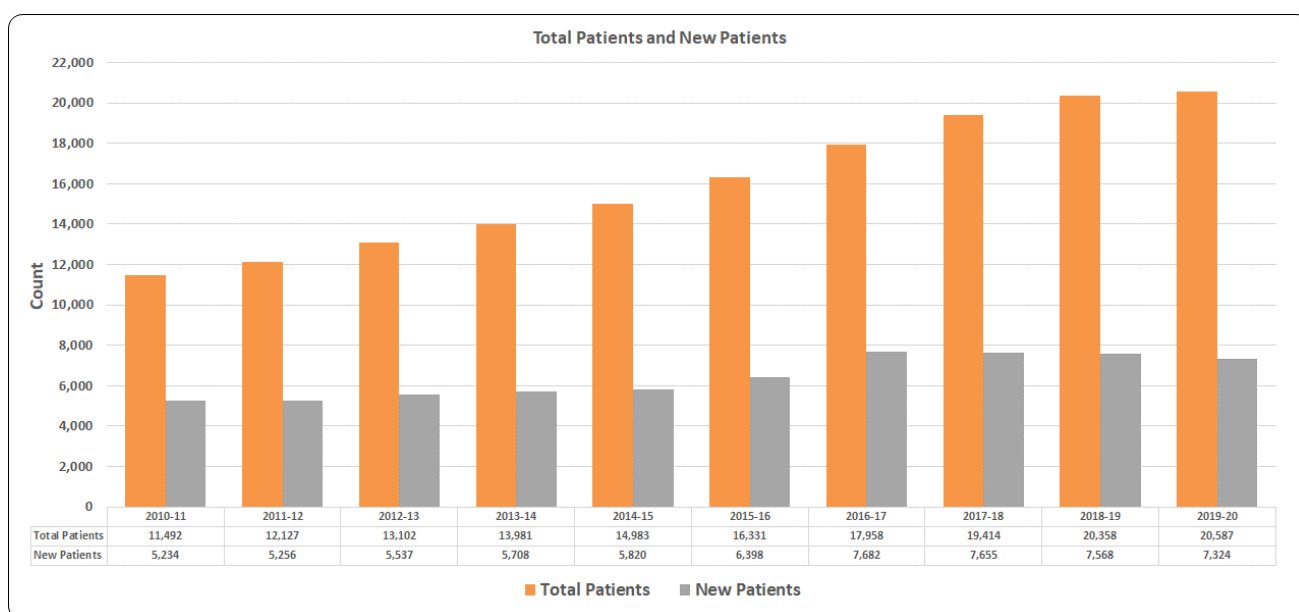


Figure 6: New and total patients for the last 10 years

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.

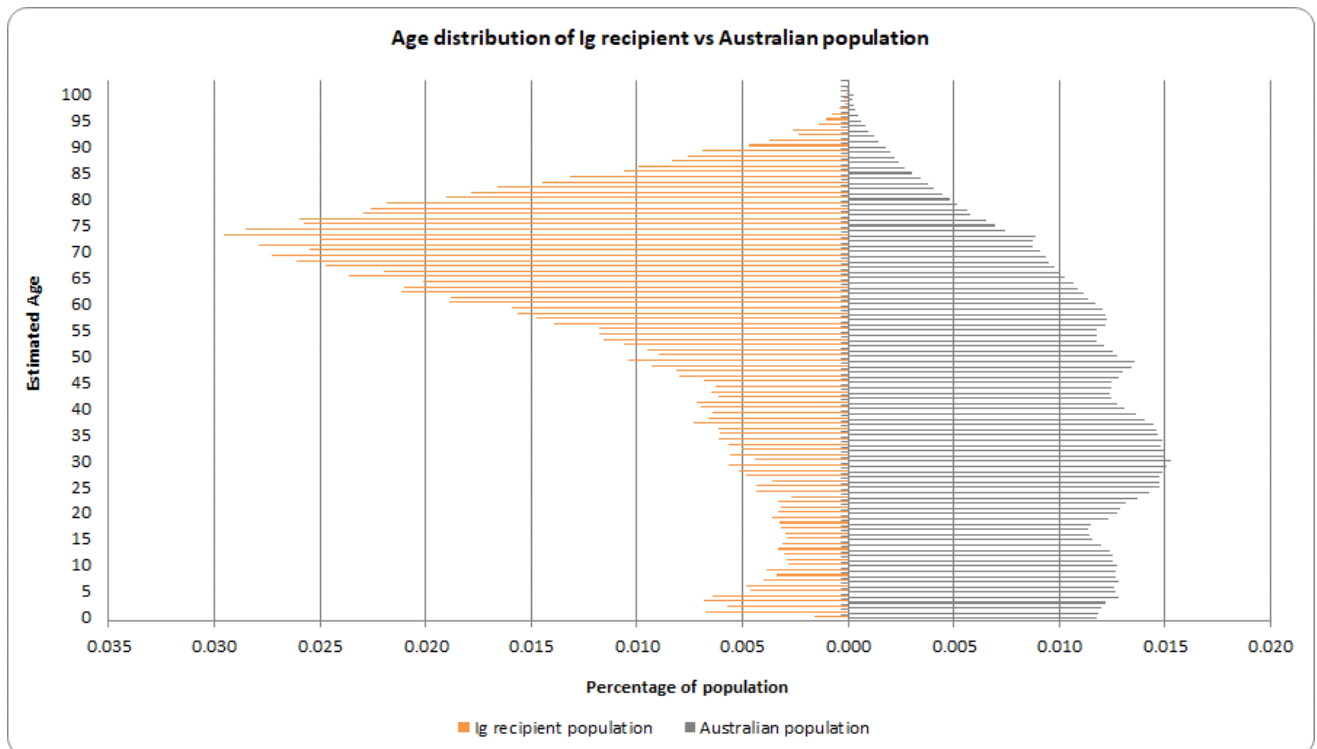
Table 7: Patient numbers by state and territory

	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
<b>2018-19</b>									
Patient Counts	7,648	4,678	4,953	1,188	1,193	410	115	394	20,358
New Patients	2,905	1,926	1,477	511	471	143	51	145	7,568
Population	8,038,047	6,528,913	5,050,660	1,743,445	2,605,843	531,850	245,703	423,229	25,172,336
Proportion of Population	31.9%	25.9%	20.1%	6.9%	10.4%	2.1%	1.0%	1.7%	100.0%
Patients per 1,000 Population	0.95	0.72	0.98	0.68	0.46	0.77	0.47	0.93	0.81
<b>2019-20</b>									
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
% Change in Patients	-1.7%	3.1%	3.1%	-2.3%	11.3%	8.5%	-13.0%	8.4%	1.1%
% Change in New Patients	-8.3%	-2.5%	3.2%	-14.7%	13.8%	11.2%	-27.5%	-1.4%	-3.2%

## AGE AND WEIGHT

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

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



**Figure 7: Patient age relative to Australian average**

*Note: The above figure calculations relate only to 2019-20 patients.*

**Figure 7** compares the age of Ig recipients in Australia in 2019-20 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 weights, since not all patients have their weight recorded, and for those that do, the weight recorded may not be recent.

<sup>1</sup> ABS 3101

<sup>2</sup> World Health Organization, [Ageing and health \(who.int\)](https://www.who.int)

**OFFICIAL**

**Table 8** shows the number of distinct patients and the average weight by age ranges for patients with dispenses in 2019-20.

**Table 8: Patient numbers and average weight by age range**

Age Range	Patient Counts	Average Weight (kg)	Treatment Episodes	Grams Dispensed
0-4	657	13	2,275	22,445
5-9	390	25	2,674	36,429
10-14	312	46	3,046	64,703
15-17	193	63	1,991	55,621
18-19	142	69	1,331	37,162
20-29	854	74	9,153	272,148
30-39	1,275	77	14,246	440,302
40-49	1,598	81	19,940	641,791
50-59	2,764	82	33,629	1,072,788
60-69	4,741	81	56,575	1,739,994
70-79	5,127	78	58,434	1,746,129
80-89	2,269	73	23,717	660,158
90 or more	265	68	2,548	63,720
<b>Total</b>	<b>20,587</b>	<b>77</b>	<b>229,559</b>	<b>6,853,389</b>

# Ig Dispenses

## IG DISPENSES BY CRITERIA CATEGORY

The Criteria classifies medical conditions into 4 categories (previously chapters) 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* (previously Chapter 5). Refer to **Appendix D** for further information.

**Table 9: Ig grams dispensed by criteria category**

Category	2015-16	2016-17	2017-18	2018-19	2019-20
Has an established therapeutic role	4,223,866	4,620,916	5,081,838	5,406,598	5,760,834
Has an emerging therapeutic role	535,596	645,636	721,766	792,821	908,889
Has application in exceptional circumstances only	216,927	220,122	271,817	246,231	181,777
Use is not supported	5	741	288	453	1,890
Other		96	25		
<b>Total</b>	<b>4,976,394</b>	<b>5,487,511</b>	<b>6,075,733</b>	<b>6,446,102</b>	<b>6,853,389</b>

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, Haematology 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 2015-16, there has been a 39 per cent increase in Ig issues for neurological conditions, compared with a 44 per cent increase for haematological conditions, and a 47 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 2019-20.

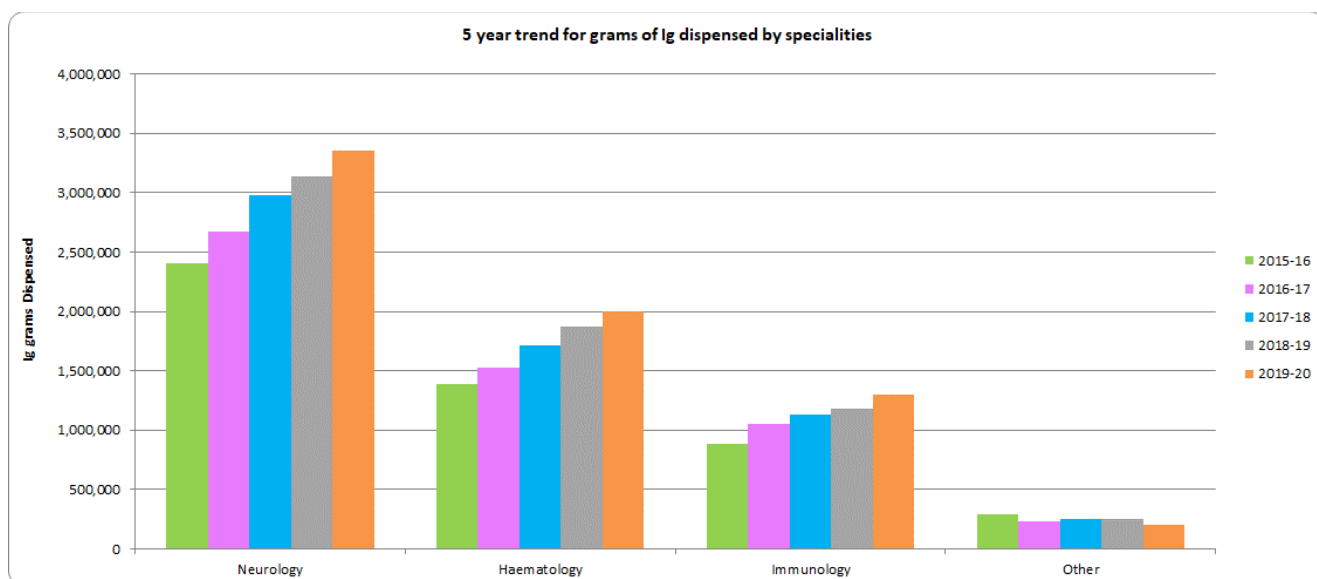


Figure 8: Grams of Ig dispensed by speciality

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, about 34 per cent of Western Australia’s (WA’s) Ig patients were haematology patients, using around 19 per cent of the state’s total Ig issue in 2019-20. By comparison, nationally, 40 per cent of patients were haematology patients, using 29 per cent of the national Ig issue – a significantly different ratio of patients to Ig use, as compared to WA. The reason for this inter-state and territory variation is unknown, but it may represent differences in clinical practice, differing disease profiles in the patient populations, variable access to alternative therapies, or differences due to the availability of specialist services across Australia.

Table 10: Ig grams dispensed by Speciality and state and territory for 2019-20

Specialities	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Dermatology*	12,703	10,368	15,478	-	3,390	1,820	-	2,620	<b>46,378</b>
Haematology	650,070	419,280	600,467	147,079	89,211	53,712	6,656	30,146	<b>1,996,618</b>
Immunology	512,147	282,728	285,985	58,472	100,672	21,079	4,032	38,586	<b>1,303,701</b>
Neurology	1,186,275	716,772	875,594	136,344	278,968	61,697	15,745	83,494	<b>3,354,888</b>
Transplant Medicine*	22,060	92,763	16,875	2,930	4,550	11,250	633	745	<b>151,805</b>
<b>Total</b>	<b>2,383,254</b>	<b>1,521,910</b>	<b>1,794,398</b>	<b>344,825</b>	<b>476,791</b>	<b>149,557</b>	<b>27,065</b>	<b>155,590</b>	<b>6,853,389</b>

\*Included as Other in Figure 8

Table 11: Patients dispensed Ig by speciality and state and territory for 2019-20

Specialities	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Dermatology*	18	18	17	-	5	<5	-	<5	<b>&lt;70</b>
Haematology	2,828	1,874	2,201	628	449	216	34	107	<b>8,222</b>
Immunology	1,831	1,065	959	210	375	83	24	125	<b>4,595</b>
Neurology	2,718	1,601	1,892	308	483	125	39	187	<b>7,229</b>
Transplant Medicine*	170	304	59	16	22	22	<5	5	<b>&lt;600</b>
<b>Total</b>	<b>7,518</b>	<b>4,824</b>	<b>5,106</b>	<b>1,161</b>	<b>1,328</b>	<b>&lt;450</b>	<b>&lt;105</b>	<b>&lt;430</b>	<b>20,587</b>

\*Included as Other in Figure 8

Table 12: New patients dispensed Ig by speciality and state and territory for 2019-20

Specialities	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Dermatology*	8	13	<5	-	<5	-	-	<5	<35
Haematology	1,169	788	655	266	221	85	12	39	3,214
Immunology	473	396	280	45	122	21	8	30	1,369
Neurology	897	558	554	118	183	45	15	69	2,415
Transplant Medicine*	136	137	39	8	12	9	<5	<5	345
<b>Total</b>	<b>2,665</b>	<b>1,878</b>	<b>1,524</b>	<b>436</b>	<b>536</b>	<b>159</b>	<b>&lt;40</b>	<b>&lt;148</b>	<b>7,324</b>

\*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 57 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 2019-20 (24 per cent), closely followed by chronic inflammatory demyelinating polyneuropathy (CIDP) (22 per cent). Primary immunodeficiency diseases (PID) with antibody deficiency accounted for 10 per cent of total Ig use.

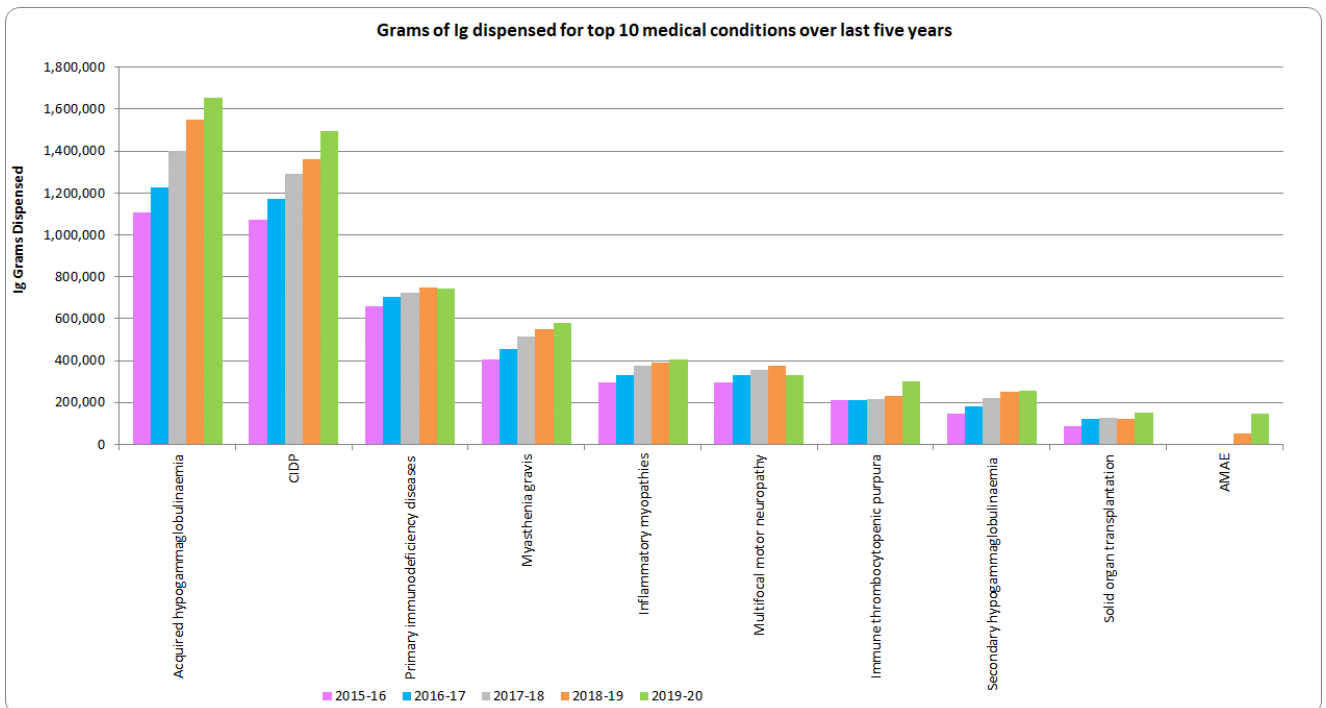


Figure 9: Grams of Ig dispensed by top 10 medical conditions

The top 10 medical conditions by state and territory for 2019-20 is presented in **Table 13**.

**Table 13: Grams dispensed by states and territories and medical condition for 2019-20**

Specialities	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Acquired hypogammaglobulinaemia	541,160	351,789	511,459	107,347	67,091	48,769	4,426	20,641	<b>1,652,680</b>
CIDP	562,941	305,051	393,737	41,872	123,316	33,797	5,748	28,089	<b>1,494,548</b>
Primary immunodeficiency diseases	325,822	143,301	147,319	40,566	45,847	12,400	3,099	26,240	<b>744,595</b>
Myasthenia gravis	177,155	146,150	167,172	15,468	56,478	4,763	735	13,298	<b>581,216</b>
Inflammatory myopathies	132,708	80,789	78,678	34,928	45,025	8,233	6,040	19,865	<b>406,265</b>
Multifocal motor neuropathy	107,041	74,636	83,410	21,498	28,340	4,770	1,365	7,873	<b>328,932</b>
Immune thrombocytopenic purpura	113,968	62,898	93,265	4,153	15,233	7,569	360	4,172	<b>301,617</b>
Secondary hypogammaglobulinaemia	80,558	52,608	67,795	31,278	15,675	3,865	1,460	3,765	<b>257,003</b>
Solid organ transplantation	22,060	92,763	16,875	2,930	4,550	11,250	633	745	<b>151,805</b>
AMAE	52,645	26,010	54,898	4,630	4,975	2,050	165	3,015	<b>148,388</b>
<b>Total</b>	<b>2,116,056</b>	<b>1,335,993</b>	<b>1,614,607</b>	<b>304,667</b>	<b>406,529</b>	<b>137,465</b>	<b>24,030</b>	<b>127,701</b>	<b>6,067,048</b>

## Ig Dispenses - IVIg and SCIg

In March 2013, the Jurisdictional Blood Committee (JBC) approved the introduction of SCIg under the national blood arrangements. In 2019-20 the SCIg products supplied by the NBA are:

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

In addition to the clinical and diagnostic criteria for access to 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 2019-20, the medical conditions that SCIg can be used to treat are:

- primary immunodeficiency diseases with antibody deficiency,
- specific antibody deficiency,
- acquired hypogammaglobulinaemia secondary to haematological malignancies, or post-haemopoietic stem cell transplantation (HSCT),
- secondary hypogammaglobulinaemia unrelated to haematological malignancies, or post-haemopoietic stem cell transplantation (HSCT), and
- chronic inflammatory demyelinating polyneuropathy (CIDP) (added from 1 August 2019).

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 for 2019-20. **Tables 16-17** show the patient numbers and grams dispensed by SCIg medical condition, and by state and territory for 2019-20.

**Table 14: Patients dispensed by SCIg/IVIg, medical conditions and product for 2019-20**

Medical Condition	IVIg					SCIg		Total
	Flebogamma 5%	Flebogamma 10%	Gamunex 10%	Intragam 10	Privigen 10%	Evogam	Hizentra	
Acquired-hypogammaglobulinaemia	44	255	26	4,665	1,321	41	486	<b>6,432</b>
Chronic inflammatory demyelinating polyneuropathy	149	427	22	802	1,422	-	92	<b>2,712</b>
Primary immunodeficiency diseases	35	16	<5	1,585	73	236	504	<b>2,211</b>
Secondary hypogammaglobulinaemia	33	63	5	795	265	32	128	<b>1,233</b>
Specific antibody deficiency	<5	5	-	288	25	35	85	<b>407</b>



Table 15: Grams dispensed by SCIg/IVIg, medical conditions and product for 2019-20

Medical Condition	IVIg			SCIg		
	Imported IVIg	Intragam 10	Privigen 10%	Evogam	Hizentra	Total
Acquired-hypogammaglobulinaemia	61,079	1,165,590	303,135	8,078	114,799	<b>1,652,680</b>
Chronic inflammatory demyelinating polyneuropathy	280,412	418,630	761,470	-	34,036	<b>1,494,548</b>
Primary immunodeficiency diseases	19,060	503,565	19,465	51,116	151,370	<b>744,595</b>
Secondary hypogammaglobulinaemia	20,676	188,925	53,905	8,289	29,823	<b>301,617</b>
Specific antibody deficiency	3,096	79,425	5,850	6,359	20,503	<b>115,233</b>

Table 16: Patients dispensed by SCIg medical conditions, and state and territory for 2019-20

Products	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Acquired-hypogammaglobulinaemia	121	164	92	88	35	20	2	11	<b>524</b>
Chronic inflammatory demyelinating polyneuropathy	27	16	29	-	<5	7	-	12	<b>&lt;97</b>
Primary immunodeficiency diseases	271	189	139	54	44	9	<5	27	<b>728</b>
Secondary hypogammaglobulinaemia	47	31	59	<5	12	8	-	<5	<b>&lt;160</b>
Specific antibody deficiency	49	17	22	13	15	<5	<5	<5	<b>&lt;125</b>

Table 17: Grams dispensed by SCIg medical conditions, and state and territory for 2019-20

Products	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Acquired-hypogammaglobulinaemia	26,614	38,139	25,964	19,559	4,358	5,074	208	2,961	<b>122,877</b>
Chronic inflammatory demyelinating polyneuropathy	11,009	4,065	15,004	-	80	2,804	-	1,074	<b>34,036</b>
Primary immunodeficiency diseases	77,977	45,906	43,495	12,931	8,965	3,293	1,387	8,532	<b>202,486</b>
Secondary hypogammaglobulinaemia	11,538	5,567	16,565	368	2,310	1,442	-	322	<b>38,112</b>
Specific antibody deficiency	11,027	3,526	6,198	2,325	2,615	224	35	912	<b>26,862</b>

## Ig Issued – NHlg

In 2013-14, due to the introduction of SCIg as discussed above, demand for NHlg reduced significantly by about 19 per cent. CSL Behring produces NHlg 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 NHlg further declined in 2014-15 by 78 per cent because of implementation of the NHlg policy outlining the national position on access and use under the national blood arrangements.

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 IVlg and SCIg are both contraindicated. Normal human Ig access rules are detailed on the NBA website at <https://www.blood.gov.au/NHlg>.

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

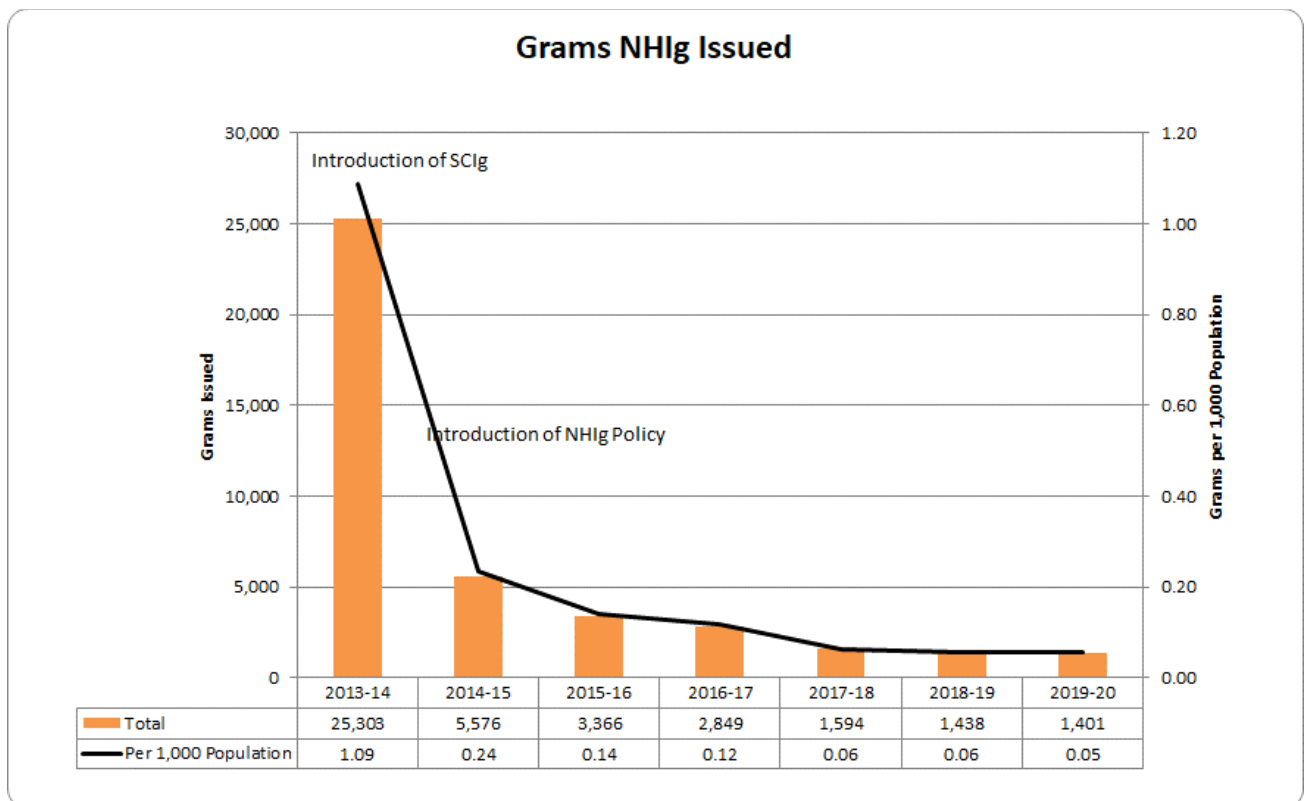


Figure 10: NHlg grams issued and grams issued per 1,000 population

# Appendices

## APPENDIX A – BACKGROUND

### Funding for Ig

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

### The Criteria

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

Version 3 of the Criteria was published in October 2018, replacing the *Criteria for the Clinical Use of Intravenous Immunoglobulin in Australia – Second Edition* which was introduced in August 2012.

Eligibility criteria were updated to align with new evidence and best clinical practice, along with other improvements to aid prescribers. Version 3 of the Criteria also reflects earlier updated access arrangements for SCIg and NHlg.

Although the Version 3 of the Criteria was introduced in October 2018, some patients continued under existing authorisations until their scheduled review for some conditions, while others transitioned on 22 October 2018. 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. Clinicians are required to seek authorisation to access government funded Ig for their patients through BloodSTAR. In seeking authorisation, clinicians must provide information to establish that the request in BloodSTAR meets the Criteria. For ongoing conditions, the Criteria may specify review criteria to be applied for reviewing the patient to determine whether access to funded Ig can continue.

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

## 2. Direct order and other supply arrangements

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

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

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

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

### 2019-20 Activities

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

The NBA Ig Governance Program continued its work throughout **2019-20** 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 Australian governments,
- 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 **2019-20** period, the program focused on the key activities listed below:

- Continued support for BloodSTAR and multiple enhancements, including the implementation of SCIg dosing functionality, with systems releases implemented in October 2019 and March 2020.
- Progressive changes to the *Criteria for the Clinical Use of intravenous immunoglobulin in Australia* were published in August 2019, October 2019 and March 2020.
- Continued implementation of the *National Immunoglobulin Program Performance Improvement Strategy 2019-20 to 2021-22*.
- Continued engagement with the program's network of committees to inform the work of the National Ig Governance program.
- Finalisation of the first Health Technology Assessment (HTA) for Ig for the treatment of acquired hypogammaglobulinaemia secondary to haematological malignancies or post-haemopoietic stem cell transplantation. Medical Services Advisory Committee (MSAC) advised that no immediate changes were required to the eligibility criteria, but that there should be more research to determine the specific patient groups and best-practice Ig use for greatest benefit.
- Publishing a selected set of Ig usage data on a regular monthly basis on the NBA website.

- Access to SCIg was provided for chronic inflammatory demyelinating polyneuropathy (CIDP), following approval in August 2019, pending the outcomes of the HTA evaluating the use of Ig in the treatment of CIDP.

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

The National Blood Authority received 3 prestigious awards in recognition of the work of the National Immunoglobulin Governance Program, including the Prime Minister's 2019 Silver Award for Public Sector Excellence. These awards acknowledge the work of NBA staff in collaboration with a diverse group of stakeholders to develop improved arrangements for the appropriate use of this precious and costly blood product.

## AWARDS FOR EXCELLENCE

The NBA has ensured the uninterrupted supply of immunoglobulin (Ig) products in Australia since 2004. The continuous and increasing demand for Ig has presented challenges for supply security and affordability. The NBA met these challenges by developing the National Immunoglobulin (Ig) Governance Program and BloodSTAR, a national online management and reporting system. Together, the program and BloodSTAR delivered an integrated, dynamic, rules-based system that is based on revised criteria for the clinical use of Ig in Australia.

The program is the first of its kind in the world, bringing together a number of disparate processes with new approaches to improve the use of high cost Ig products made from blood plasma.

In 2019 the National Blood Authority received three prestigious awards that recognised this work. These awards acknowledge the work of NBA staff in collaboration with a diverse group of stakeholders to develop improved arrangements for the appropriate use of this precious and costly blood product.

### 2019 Prime Minister's Award

The Prime Minister's Silver Award for Excellence in Public Sector Management was awarded to the NBA for developing and implementing Australia's National Immunoglobulin Governance Program. Awarded by the Institute of Public Administration Australia (IPAA), this achievement recognises Australia's National Immunoglobulin Governance Program as an innovative initiative to improve the use and management of government-funded Ig through nationally coordinated health sector governance arrangements.



L to R: Dr Steven Kennedy PSM, Secretary of the Treasury and IPAA ACT President, the Hon Ben Morton MP, Assistant Minister to the Prime Minister and Cabinet, Mr Cahill, Ms Cameron, Ms Wall, Ms Roberts, Mr Stone.

The award was presented by the Hon Ben Morton MP, Assistant Minister to the Prime Minister and Cabinet, and Dr Steven Kennedy PSM, Secretary of the Treasury and IPAA ACT President, at a ceremony at Parliament House in Canberra on 13 November 2019.

### 2019 Australian Business Awards for Business Innovation and Supply Chain Management

The Australian Business Awards are an annual comprehensive awards program which recognises organisations that demonstrate the core values of business innovation, product innovation, technological achievement and employee engagement via a set of established business and product award categories.

In 2019, the NBA received two Australian Business Awards. The Award for Business Innovation recognised the implementation of the National Immunoglobulin Governance Program as an innovative solution for new and existing business needs.

The Australian Business Award for Supply Chain Management was awarded in recognition of outstanding results achieved through the National Immunoglobulin Governance Program for excellence in supply chain management.

## 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
HTA	Health Technology Assessment
IDMS	Integrated Data Management System
Ig	Immunoglobulin products including IVIg and SCIg
IVIg	Intravenous immunoglobulin
JBC	Jurisdictional Blood Committee
MSAC	Medical Services Advisory Committee
NBA	National Blood Authority
NHIg	Normal human immunoglobulin
NIGAC	National Immunoglobulin Governance Advisory Committee
NSQHS	National Safety and Quality Health Service
NSW	New South Wales
NT	Northern Territory
PID	Primary Immunodeficiency Diseases
QLD	Queensland
SA	South Australia
SCIg	Subcutaneous Immunoglobulin
STARS	Supply Tracking Analysis Recording System
TAS	Tasmania
VIC	Victoria
WA	Western Australia

## Glossary of terms

Term	Description
<b>Blood products</b>	Products manufactured from human blood
<b>Lifeblood</b>	The Australian Red Cross Lifeblood
<b>Condition</b>	<p>Clinical conditions are categorised according to the quality of the available evidence and whether immunoglobulin treatment is considered beneficial</p> <p>Specific conditions (previously known as primary diagnosis) within a medical condition (previously 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</p>
<b><i>Criteria for the Clinical use of immunoglobulin in Australia (the Criteria)</i></b>	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
<b>Direct Orders</b>	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 <i>Criteria for the Clinical Use of Ig in Australia</i>
<b>Fractionation</b>	A manufacturing process that separates blood plasma into specific protein fractions
<b>Imprest stock</b>	Health provider orders product for stock that is maintained at a certain level and held at their site
<b>Intravenous immunoglobulin</b>	An immunoglobulin product derived from donated human plasma that is administered intravenously
<b>Jurisdiction</b>	Any of the parties to the Australian National Blood Agreement, being the Australian Government and all state and territory governments
<b>Minimum Product Inventory</b>	The minimum inventory of Ig held by CSL Behring to meet contract obligations
<b>National Blood Agreement</b>	The Agreement signed by all Australian governments in 2003 that sets out the objectives for governments for the management of the Australian blood sector
<b>National blood arrangements</b>	Arrangements, including funding arrangements, established under the National Blood Agreement
<b>National CSL Reserve</b>	The reserve of inventory of Ig that CSL Behring manages on behalf of the NBA for contingency purposes
<b>Normal immunoglobulin</b>	An immunoglobulin product derived from human plasma that is administered by intramuscular injection (as opposed to intravenous or sub-cutaneous injection)
<b>Plasma</b>	The liquid part of the blood containing antibodies and other proteins
<b>Speciality</b>	Classification of the conditions according to the clinical speciality, previously discipline

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



## APPENDIX C – CONDITIONS MAPPING TABLE

Specific Condition Name - New	Medical Condition Name - New	Specific Condition Name	Medical Condition Name	Speciality	Chapter	Version
Acquired bleeding disorder, other coagulation factors (Prothrombin, factor V, factor VII, factor X, factor XI, and factor XIII)	Coagulation factor inhibitors			Haematology	7	3
Acquired haemophilia A	Coagulation factor inhibitors			Haematology	7	3
Acquired haemophilia B	Coagulation factor inhibitors			Haematology	7	3
Acquired von Willebrand syndrome	Coagulation factor inhibitors			Haematology	7	3
Acute leukaemia	Acquired-hypogammaglobulinaemia — haematological malignancy or post HSCT			Haematology	5	3
Anti-neutrophil cytoplasmic antibody (ANCA) (PR3 or MPO)-positive idiopathic rapidly progressive glomerulonephritis	Anti-neutrophil cytoplasmic antibody (ANCA) associated vasculitis			Immunology	7	3
Ataxic sensory neuronopathy	Sjögren's syndrome			Neurology	7	3
Atypical rolandic epilepsy	Childhood epileptic encephalopathy			Neurology	7	3
Autoimmune haemolytic anaemia	Autoimmune haemolytic anaemia (AIHA)			Haematology	6	3
Autoimmune neutropenia	Autoimmune neutropenia			Haematology	7	3
Autoimmune retinopathy	Autoimmune retinopathy (AIR)			Immunology	7	3
Autonomic neuropathy	Sjögren's syndrome			Neurology	7	3
Bullous Pemphigoid	Bullous pemphigoid			Immunology	6	3
Catastrophic anti-phospholipid syndrome	Catastrophic anti-phospholipid syndrome (CAPS)			Immunology	7	3
Chronic Immune thrombocytopenic purpura (ITP)	Immune thrombocytopenic purpura (ITP) — adult			Haematology	5	3
Chronic inflammatory demyelinating polyneuropathy (CIDP)	Chronic inflammatory demyelinating polyneuropathy (CIDP)	Chronic inflammatory demyelinating polyneuropathy	Chronic inflammatory demyelinating polyneuropathy (CIDP)	Neurology	5	2
Chronic inflammatory demyelinating polyneuropathy (CIDP)	Chronic inflammatory demyelinating polyneuropathy (CIDP)			Neurology	5	3

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Specific Condition Name - New	Medical Condition Name - New	Specific Condition Name	Medical Condition Name	Speciality	Chapter	Version
Chronic lymphocytic leukaemia (CLL)	Acquired-hypogammaglobulinaemia — haematological malignancy or post HSCT	Chronic lymphocytic leukaemia	Acquired hypogammaglobulinaemia — haematological malignancy and post HSCT	Haematology	5	2
Chronic lymphocytic leukaemia (CLL)	Acquired-hypogammaglobulinaemia — haematological malignancy or post HSCT			Haematology	5	3
Cicatrical pemphigoid (CP)	Cicatrical pemphigoid (CP) or Mucous Membrane Pemphigoid (MMP)			Dermatology	6	3
Combined immunodeficiency generally less profound than SCID (e.g. thymoma)	Primary immunodeficiency diseases (PID)			Immunology	5	3
Combined immunodeficiency with associated or syndromal features (e.g. Wiskott Aldrich syndrome; ataxia telangiectasia)	Primary immunodeficiency diseases (PID)			Immunology	5	3
Common variable immunodeficiency disease (CVID)	Primary immunodeficiency diseases (PID)	Common variable immunodeficiency disease (CVID)	Primary immunodeficiency diseases (PID) with antibody deficiency	Immunology	5	2
Confirmed autoimmune congenital heart block in a fetus	Autoimmune congenital heart block			Immunology	7	3
Confirmed autoimmune congenital heart block in a neonate	Autoimmune congenital heart block			Immunology	7	3
Dermatomyositis (DM)	Inflammatory myopathies: polymyositis, dermatomyositis and necrotising autoimmune myopathy	Dermatomyositis	Inflammatory myopathies: polymyositis (PM), dermatomyositis (DM) and inclusion body myositis (IBM)	Neurology	5	2
Dermatomyositis (DM)	Inflammatory myopathies: polymyositis, dermatomyositis and necrotising autoimmune myopathy			Neurology	5	3
Diabetic amyotrophy	Diabetic amyotrophy			Neurology	8	3
Drug-induced pemphigus foliaceus	Pemphigus foliaceus (PF)			Immunology	6	3
Encephalitis associated with antibodies to AMPA receptor	Antibody mediated autoimmune encephalitis (AMAE)			Neurology	6	3
Encephalitis associated with antibodies to CASPR2	Antibody mediated autoimmune encephalitis (AMAE)			Neurology	6	3

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Specific Condition Name - New	Medical Condition Name - New	Specific Condition Name	Medical Condition Name	Speciality	Chapter	Version
Encephalitis associated with antibodies to GABA (A or B) receptor	Antibody mediated autoimmune encephalitis (AMAE)			Neurology	6	3
Encephalitis associated with antibodies to glycine receptor	Antibody mediated autoimmune encephalitis (AMAE)			Neurology	6	3
Encephalitis associated with antibodies to LGI1	Antibody mediated autoimmune encephalitis (AMAE)			Neurology	6	3
Encephalitis associated with antibodies to NMDA receptor	Antibody mediated autoimmune encephalitis (AMAE)			Neurology	6	3
Encephalitis associated with antibodies to VGKC	Antibody mediated autoimmune encephalitis (AMAE)			Neurology	6	3
Endemic pemphigus foliaceus	Pemphigus foliaceus (PF)			Immunology	6	3
Eosinophilic granulomatosis with polyangiitis (Churg-Strauss Syndrome)	Anti-neutrophil cytoplasmic antibody (ANCA) associated vasculitis			Immunology	7	3
Epidermolysis bullosa acquisita	Epidermolysis bullosa acquisita			Immunology	7	3
Evans syndrome - with significant Immune thrombocytopenic purpura (ITP) - adult	Immune thrombocytopenic purpura (ITP) — adult			Haematology	5	3
Evans syndrome child - with significant ITP	Immune thrombocytopenic purpura (ITP) — in children 15 years and younger			Haematology	6	3
Evans Syndrome with significant AIHA	Autoimmune haemolytic anaemia (AIHA)			Haematology	6	3
Existing patient - authorisation for IgG subclass deficiency	Specific antibody deficiency (SAD)			Immunology	6	3
Existing patient - authorisation for IgG subclass deficiency	Specific antibody deficiency (SAD)			Immunology	6	3
Fetal alloimmune thrombocytopenia (FAIT)	Fetal and neonatal alloimmune thrombocytopenia (FNAIT)			Haematology	5	3
Granulomatosis with polyangiitis (Wegener Granulomatosis)	Anti-neutrophil cytoplasmic antibody (ANCA) associated vasculitis			Immunology	7	3
Graves ophthalmopathy	Graves ophthalmopathy (GO)			Immunology	7	3
Guillain–Barré Syndrome (GBS)	Guillain–Barré syndrome (GBS)	Guillain–Barré syndrome	Guillain–Barré syndrome (GBS)	Neurology	5	2
Guillain–Barré Syndrome (GBS)	Guillain–Barré Syndrome (GBS)			Neurology	5	3

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Specific Condition Name - New	Medical Condition Name - New	Specific Condition Name	Medical Condition Name	Speciality	Chapter	Version
Guillain–Barré Syndrome (GBS) variants	Guillain–Barré Syndrome (GBS)			Neurology	5	3
Haemolytic disease of the fetus	Haemolytic disease of the fetus (HDF)			Haematology	7	3
Haemophagocytic lymphohistiocytosis	Haemophagocytic lymphohistiocytosis			Haematology	6	3
Heart and kidney transplant	Solid organ transplantation			Transplant Medicine	6	3
Heart and lung transplant	Solid organ transplantation			Transplant Medicine	6	3
Heart transplant	Solid organ transplantation			Transplant Medicine	6	3
Hyperhaemolysis syndrome	Hyperhaemolysis syndrome			Haematology	7	3
Hypogammaglobulinaemia following B cell depletion therapy	Secondary hypogammaglobulinaemia (including iatrogenic immunodeficiency)			Immunology	6	3
Hypogammaglobulinaemia following Solid organ transplantation	Secondary hypogammaglobulinaemia (including iatrogenic immunodeficiency)			Immunology	6	3
Idiopathic opsoclonus-myooclonus ataxia	Opsoclonus-myooclonus ataxia (OMA)			Neurology	6	3
IgA paraproteinaemic demyelinating neuropathy	Chronic inflammatory demyelinating polyneuropathy (CIDP)			Neurology	5	3
IgA pemphigus foliaceus	Pemphigus foliaceus (PF)			Immunology	6	3
IgG paraproteinaemic demyelinating neuropathy	Chronic inflammatory demyelinating polyneuropathy (CIDP)			Neurology	5	3
Existing patient - authorisation for IgG subclass deficiency	Specific antibody deficiency (SAD)	IgG subclass deficiency (existing authorisation)	Specific antibody deficiency (SAD)	Immunology	6	2
IgM paraproteinaemic demyelinating neuropathy	IgM paraproteinaemic demyelinating neuropathy			Neurology	6	3

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Specific Condition Name - New	Medical Condition Name - New	Specific Condition Name	Medical Condition Name	Speciality	Chapter	Version
Inclusion body myositis	Inflammatory myopathies: polymyositis, dermatomyositis and necrotising autoimmune myopathy	Inclusion body myositis	Inflammatory myopathies: polymyositis (PM), dermatomyositis (DM) and inclusion body myositis (IBM)	Neurology	5	2
Inclusion Body Myositis (IBM)	Inclusion Body Myositis (IBM)			Neurology	5	3
ITP - child - chronic	Immune thrombocytopenic purpura (ITP) — in children 15 years and younger			Haematology	6	3
ITP - child - newly diagnosed	Immune thrombocytopenic purpura (ITP) — in children 15 years and younger			Haematology	6	3
ITP - child - persistent	Immune thrombocytopenic purpura (ITP) — in children 15 years and younger			Haematology	6	3
Kawasaki disease	Kawasaki disease			Immunology	5	3
Kidney transplant	Solid organ transplantation			Transplant Medicine	6	3
Lambert–Eaton myasthenic syndrome	Lambert–Eaton myasthenic syndrome (LEMS)			Neurology	5	3
Landau Kleffner syndrome	Childhood epileptic encephalopathy			Neurology	7	3
Lennox-Gastaut syndrome	Childhood epileptic encephalopathy			Neurology	7	3
LETMs	Neuromyelitis optica spectrum disorders (NMOSD)			Neurology	7	3
Limbic encephalitis, nonparaneoplastic	Limbic encephalitis — nonparaneoplastic	Limbic encephalitis, nonparaneoplastic	Limbic encephalitis — nonparaneoplastic	Neurology	7	2
Liver and kidney transplant	Solid organ transplantation			Transplant Medicine	6	3
Liver transplant	Solid organ transplantation			Transplant Medicine	6	3
Lung transplant	Solid organ transplantation			Transplant Medicine	6	3
Lymphoproliferative syndromes (e.g. XLP1, XLP2, CD27 def)	Primary immunodeficiency diseases (PID)			Immunology	5	3
Macrophage activation syndrome	Haemophagocytic lymphohistiocytosis			Haematology	6	3

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Specific Condition Name - New	Medical Condition Name - New	Specific Condition Name	Medical Condition Name	Speciality	Chapter	Version
Memory B cell deficiency secondary to haemopoietic stem cell transplantation (HSCT)	Acquired-hypogammaglobulinaemia — haematological malignancy or post HSCT			Haematology	5	3
Microscopic polyangiitis	Anti-neutrophil cytoplasmic antibody (ANCA) associated vasculitis			Immunology	7	3
Monophasic acute disseminated encephalomyelitis (ADEM)	Acute disseminated encephalomyelitis (ADEM)			Neurology	6	3
Mucous Membrane Pemphigoid (MMP)	Cicatricial pemphigoid (CP) or Mucous Membrane Pemphigoid (MMP)			Dermatology	6	3
Multifocal motor neuropathy with or without persistent conduction block	Multifocal motor neuropathy (MMN)	Multifocal motor neuropathy with or without persistent conduction block	Multifocal motor neuropathy (MMN)	Neurology	5	2
Multifocal motor neuropathy with or without persistent conduction block	Multifocal motor neuropathy (MMN)			Neurology	5	3
Multiphasic acute disseminated encephalomyelitis (ADEM)	Acute disseminated encephalomyelitis (ADEM)			Neurology	6	3
Multiple myeloma (MM)	Acquired-hypogammaglobulinaemia — haematological malignancy or post HSCT	Multiple myeloma	Acquired hypogammaglobulinaemia — haematological malignancy and post HSCT	Haematology	5	2
Multiple myeloma (MM)	Acquired-hypogammaglobulinaemia — haematological malignancy or post HSCT			Haematology	5	3
Myasthenia gravis (MG)	Myasthenia gravis (MG)			Neurology	5	3
Myocarditis in children	Myocarditis in children			Immunology	8	3
Necrotising autoimmune myopathy (NAM)	Inflammatory myopathies: polymyositis, dermatomyositis and necrotising autoimmune myopathy			Neurology	5	3
Neonatal alloimmune thrombocytopenia (NAIT)	Fetal and neonatal alloimmune thrombocytopenia (FNAIT)			Haematology	5	3
Neonate with haemochromatosis	Neonatal haemochromatosis (NH)			Haematology	5	3
Newly Diagnosed Immune thrombocytopenic purpura (ITP)	Immune thrombocytopenic purpura (ITP) — adult			Haematology	5	3

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Specific Condition Name - New	Medical Condition Name - New	Specific Condition Name	Medical Condition Name	Speciality	Chapter	Version
NMOSD–AQP4 ab positive	Neuromyelitis optica spectrum disorders (NMOSD)			Neurology	7	3
NMOSD–MOG ab positive	Neuromyelitis optica spectrum disorders (NMOSD)			Neurology	7	3
NMOSD–seronegative	Neuromyelitis optica spectrum disorders (NMOSD)			Neurology	7	3
Non-Hodgkin lymphoma (NHL)	Acquired-hypogammaglobulinaemia — haematological malignancy or post HSCT	Non-Hodgkin lymphoma	Acquired hypogammaglobulinaemia — haematological malignancy and post HSCT	Haematology	5	2
Non-Hodgkin lymphoma (NHL)	Acquired-hypogammaglobulinaemia — haematological malignancy or post HSCT			Haematology	5	3
Other Haematological malignancy	Acquired-hypogammaglobulinaemia — haematological malignancy or post HSCT			Haematology	5	3
Other Hypogammaglobulinaemia unrelated to haematological malignancies or haemopoietic stem cell transplantation (HSCT)	Secondary hypogammaglobulinaemia (including iatrogenic immunodeficiency)			Immunology	6	3
Other primary immunodeficiency	Primary immunodeficiency diseases (PID)	Other primary immunodeficiency	Primary immunodeficiency diseases (PID) with antibody deficiency	Immunology	5	2
Other Haematological malignancy	Acquired-hypogammaglobulinaemia — haematological malignancy or post HSCT	Other relevant haematological malignancies	Acquired hypogammaglobulinaemia — haematological malignancy and post HSCT	Haematology	5	2
Other transplant	Solid organ transplantation			Transplant Medicine	6	3
Paediatric acute neuropsychiatric disorders (PANS)	PANDAS/PANS			Neurology	7	3
Paediatric autoimmune neuropsychiatric disorder (PANDAS)	PANDAS/PANS			Neurology	7	3
Painful small fibre neuropathy	Sjögren’s syndrome			Neurology	7	3
Pancreas and kidney transplant	Solid organ transplantation			Transplant Medicine	6	3

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Specific Condition Name - New	Medical Condition Name - New	Specific Condition Name	Medical Condition Name	Speciality	Chapter	Version
Paraneoplastic associated breast cancer	Opsoclonus-myoclonus ataxia (OMA)			Neurology	6	3
Paraneoplastic associated neuroblastoma	Opsoclonus-myoclonus ataxia (OMA)			Neurology	6	3
Paraneoplastic associated other tumour type	Opsoclonus-myoclonus ataxia (OMA)			Neurology	6	3
Paraneoplastic associated small cell lung cancer	Opsoclonus-myoclonus ataxia (OMA)			Neurology	6	3
Paraneoplastic cerebellar degeneration	Paraneoplastic cerebellar degeneration			Neurology	8	3
Paraneoplastic pemphigus foliaceus	Pemphigus foliaceus (PF)			Immunology	6	3
Paraneoplastic Subacute Sensory Neuropathy	Paraneoplastic Subacute Sensory Neuropathy			Neurology	8	3
Pemphigus herpetiformis	Pemphigus foliaceus (PF)			Immunology	6	3
Pemphigus vulgaris	Pemphigus vulgaris (PV)			Dermatology	6	3
Persistent Immune thrombocytopenic purpura (ITP)	Immune thrombocytopenic purpura (ITP) — adult			Haematology	5	3
Polymyositis (PM)	Inflammatory myopathies: polymyositis, dermatomyositis and necrotising autoimmune myopathy	Polymyositis	Inflammatory myopathies: polymyositis (PM), dermatomyositis (DM) and inclusion body myositis (IBM)	Neurology	5	2
Polymyositis (PM)	Inflammatory myopathies: polymyositis, dermatomyositis and necrotising autoimmune myopathy			Neurology	5	3
Possible Common variable immune deficiency (CVID) - below normal serum IgG but normal serum IgA level	Primary immunodeficiency diseases (PID)			Immunology	5	3
Post-haemopoietic stem cell transplantation	Acquired-hypogammaglobulinaemia — haematological malignancy or post HSCT	Post-haemopoietic stem cell transplantation	Acquired hypogammaglobulinaemia — haematological malignancy and post HSCT	Haematology	5	2
Post-transfusion purpura (PTP)	Post-transfusion purpura (PTP)			Haematology	6	3
Pregnant woman with previous fetal loss	Neonatal haemochromatosis (NH)			Haematology	5	3
Pure red cell aplasia – associated B19 infection	Pure red cell aplasia (PRCA)			Haematology	7	3



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Specific Condition Name - New	Medical Condition Name - New	Specific Condition Name	Medical Condition Name	Speciality	Chapter	Version
Pure red cell aplasia – autoimmune mediated	Pure red cell aplasia (PRCA)			Haematology	7	3
Pyoderma Gangrenosum	Pyoderma Gangrenosum (PG)			Immunology	7	3
Rasmussen encephalitis	Rasmussen encephalitis			Neurology	7	3
Recurrent acute disseminated encephalomyelitis (ADEM)	Acute disseminated encephalomyelitis (ADEM)			Neurology	6	3
Relapsing remitting multiple sclerosis	Multiple sclerosis (MS – RMMS)			Neurology	7	3
Scleromyxedema – skin and systemic disease	Scleromyxedema			Immunology	7	3
Scleromyxedema – skin involvement only	Scleromyxedema			Immunology	7	3
Secondary hypogammaglobulinaemia (excluding haematological malignancies)	Secondary hypogammaglobulinaemia (including iatrogenic immunodeficiency)	Secondary hypogammaglobulinaemia (excluding haematological malignancies)	Secondary hypogammaglobulinaemia (including iatrogenic immunodeficiency)	Immunology	6	2
Sensorimotor axonal neuropathy	Sjögren’s syndrome			Neurology	7	3
Sepsis	Sepsis			Immunology	8	3
Sero-negative autoimmune encephalitis	Antibody mediated autoimmune encephalitis (AMAE)			Neurology	6	3
Sero-negative limbic encephalitis	Antibody mediated autoimmune encephalitis (AMAE)			Neurology	6	3
Severe combined immunodeficiency (SCID)	Primary immunodeficiency diseases (PID)			Immunology	5	3
Severe reduction in all Ig isotypes with decreased or absent B-cells (e.g. XLA def)	Primary immunodeficiency diseases (PID)			Immunology	5	3
Severe reduction in at least two Ig isotypes with low/normal B-cells (e.g. CVID)	Primary immunodeficiency diseases (PID)			Immunology	5	3
Severe reduction in serum IgG and IgA with normal/elevated IgM (e.g. CD40L def)	Primary immunodeficiency diseases (PID)			Immunology	5	3
Sjögren’s syndrome	Sjögren’s syndrome	Sjögren’s syndrome	Sjögren’s syndrome	Immunology	7	2
Specific antibody deficiency	Specific antibody deficiency (SAD)			Immunology	6	3
Staphylococcal TSS	Toxic shock syndrome			Immunology	6	3
Stevens–Johnson syndrome / toxic epidermal necrolysis overlap (SJS/TEN)	Toxic epidermal necrolysis / Stevens–Johnson syndrome			Immunology	6	3
Stiff person syndrome	Stiff person syndrome			Neurology	5	3
Streptococcal TSS	Toxic shock syndrome			Immunology	6	3

OFFICIAL

Specific Condition Name - New	Medical Condition Name - New	Specific Condition Name	Medical Condition Name	Speciality	Chapter	Version
Subacute sensory neuropathy	Paraneoplastic neurological syndromes	Subacute sensory neuropathy	Paraneoplastic neurological syndromes	Neurology	7	2
Susac syndrome	Susac syndrome			Neurology	7	3
Suspected autoimmune encephalitis	Antibody mediated autoimmune encephalitis (AMAE)			Neurology	6	3
Suspected autoimmune limbic encephalitis	Antibody mediated autoimmune encephalitis (AMAE)			Neurology	6	3
Systemic capillary leak syndrome	Systemic Capillary leak syndrome			Immunology	7	3
Thymoma-associated hypogammaglobulinaemia (Goods Syndrome)	Secondary hypogammaglobulinaemia (including iatrogenic immunodeficiency)			Immunology	6	3
Toxic epidermal necrolysis (TEN)	Toxic epidermal necrolysis / Stevens–Johnson syndrome			Immunology	6	3
Transient hypogammaglobulinaemia of infancy	Primary immunodeficiency diseases (PID)			Immunology	5	3
West syndrome	Childhood epileptic encephalopathy			Neurology	7	3
X-linked agammaglobulinaemia	Primary immunodeficiency diseases (PID)	X-linked agammaglobulinaemia	Primary immunodeficiency diseases (PID) with antibody deficiency	Immunology	5	2

APPENDIX D – DATASET OF IG SUPPLY BY STATE/TERRITORY 2019-20

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
<b>Has an established therapeutic role (previously Chapter 5)</b>										
Acute leukaemia	Patients	157	98	57	18	26	6		<5	350
	Average Age	46	46	49	7	55	49		53	46
	Average Weight	63	71	73	21	82	65		99	68
	Grams	17,592	14,351	10,289	688	5,277	1,209		325	49,729
	Grams/Episode	22	18	23	7	19	25		22	20
	Grams per 1,000 Population	2	2	2	0	2	2		1	2
Chronic Immune thrombocytopenic purpura (ITP)	Patients	147	123	108	30	59	8	<5	6	481
	Average Age	59	62	58	70	59	45	23	47	59
	Average Weight	81	77	82	81	82	86	51	96	81
	Grams	26,353	15,730	20,783	3,850	10,503	908	978	1,545	80,648
	Grams/Episode	45	46	31	52	55	57	75	52	42
	Grams per 1,000 Population	3	2	4	2	4	2	4	3	3
Chronic inflammatory demyelinating polyneuropathy (CIDP)	Patients	1,053	564	724	166	76	56	11	58	2,656
	Average Age	64	64	63	61	63	62	52	60	63
	Average Weight	83	85	85	84	82	88	79	83	84
	Grams	553,638	303,991	383,832	122,296	40,804	32,652	5,748	27,354	1,470,313
	Grams/Episode	42	43	27	44	42	38	54	45	37
	Grams per 1,000 Population	69	46	75	69	15	58	23	61	58
Chronic lymphocytic leukaemia (CLL)	Patients	629	394	408	107	115	43	12	27	1,703
	Average Age	73	74	73	73	72	74	66	74	73
	Average Weight	77	77	79	76	79	82	88	77	78
	Grams	162,997	106,309	121,568	22,293	29,014	12,361	2,358	8,385	465,285
	Grams/Episode	27	25	23	24	26	27	33	28	25
	Grams per 1,000 Population	20	16	24	13	11	22	10	19	18
Combined immunodeficiency generally less profound than SCID (e.g. thymoma)	Patients	18	16	6	6	<5	<5	<5	<5	<66
	Average Age	49	29	44	64	11	60	60	36	41
	Average Weight	57	46	75	73	33	107	108	111	60
	Grams	5,051	3,456	2,633	1,875	357	700	150	528	14,748

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams/Episode	22	16	23	31	11	50	50	24	21
	Grams per 1,000 Population	1	1	1	1	0	1	1	1	1
Combined immunodeficiency with associated or syndromal features (e.g. Wiskott Aldrich syndrome; ataxia telangiectasia)	Patients	10	15	11	<5	<5		<5	<5	<56
	Average Age	19	27	16	27	8		13	36	21
	Average Weight	45	58	37	60	19		26	60	46
	Grams	2,622	2,918	2,678	813	115		178	660	9,983
	Grams/Episode	19	18	13	20	8		9	18	16
	Grams per 1,000 Population	0	0	1	0	0		1	1	0
Common variable immunodeficiency disease (CVID)	Patients	21	5	<5	<5	<5			<5	<46
	Average Age	61	65	67	73	55			47	62
	Average Weight	74	74	60	56	85			94	76
	Grams	1,055	183	25	45	145			55	1,508
	Grams/Episode	28	10	25	22	21			28	22
	Grams per 1,000 Population	0	0	0	0	0			0	0
Dermatomyositis (DM)	Patients	92	64	56	18	18	<5	<5	9	<267
	Average Age	49	46	54	46	51	50	51	46	50
	Average Weight	69	72	76	79	66	70	69	73	73
	Grams	30,375	24,396	24,375	8,730	6,835	1,520	215	4,053	100,498
	Grams/Episode	32	44	24	34	36	56	27	40	32
	Grams per 1,000 Population	4	4	5	5	3	3	1	9	4
Evans syndrome - with significant Immune thrombocytopenic purpura (ITP) - adult	Patients	<5	<5	<5	<5	<5				<25
	Average Age	47	40	44	82	77				49
	Average Weight	94	65	72	66	80				77
	Grams	940	470	590	335	80				2,415
	Grams/Episode	47	47	23	48	40				37
	Grams per 1,000 Population	0	0	0	0	0				0
Fetal alloimmune thrombocytopenia (FAIT)	Patients	<5	<5	<5		<5				<20
	Average Age	36	32	31		34				34
	Average Weight	74	61	85		70				73
	Grams	5,193	2,210	2,218		55				9,675
	Grams/Episode	82	50	57		55				66

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams per 1,000 Population	1	0	0		0				0
Guillain–Barré Syndrome (GBS)	Patients	210	132	112	35	27	15	<5	15	545
	Average Age	53	56	53	50	53	54	35	38	53
	Average Weight	82	80	79	85	81	76	94	78	81
	Grams	34,453	20,543	18,230	5,750	3,963	2,385	680	2,395	88,398
	Grams/Episode	34	39	21	36	36	45	38	61	32
	Grams per 1,000	4	3	4	3	1	4	3	5	3
Guillain–Barré Syndrome (GBS) variants	Patients	74	63	43	17	7	5		<5	<215
	Average Age	57	53	56	56	47	53		53	55
	Average Weight	77	76	75	81	93	86		64	77
	Grams	10,448	9,093	6,050	2,315	1,068	725		575	30,273
	Grams/Episode	30	41	19	31	34	52		96	30
	Grams per 1,000 Population	1	1	1	1	0	1		1	1
IgA paraproteinaemic demyelinating neuropathy	Patients	6	<5	6						<17
	Average Age	79	71	65						70
	Average Weight	75	67	100						89
	Grams	2,820	325	4,620						7,765
	Grams/Episode	41	25	44						42
	Grams per 1,000 Population	0	0	1						0
IgG paraproteinaemic demyelinating neuropathy	Patients	20	<5	13	<5	<5	<5		<5	<58
	Average Age	71	83	75	52	64	81		71	72
	Average Weight	79	76	85	72	66	79		81	80
	Grams	6,483	735	5,285	1,020	1,068	1,145		735	16,470
	Grams/Episode	34	27	29	31	43	31		37	32
	Grams per 1,000 Population	1	0	1	1	0	2		2	1
Inclusion body myositis	Patients					<5				<5
	Average Age					76				76
	Average Weight					61				61
	Grams					100				100
	Grams/Episode					25				25
	Grams per 1,000 Population					0				0

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Inclusion Body Myositis (IBM)	Patients	45	51	40	<5	14	<5		6	<168
	Average Age	73	72	70	75	70	75		70	71
	Average Weight	82	84	82	62	74	66		79	81
	Grams	15,938	26,384	19,210	668	6,585	810		2,465	72,059
	Grams/Episode	36	42	26	35	34	27		33	34
	Grams per 1,000 Population	2	4	4	0	2	1		6	3
Kawasaki disease	Patients	135	117	73	31	9	7	<5	<5	<382
	Average Age	3	4	4	3	5	1	4	1	4
	Average Weight	18	17	18	16	20	11	26	12	18
	Grams	5,645	4,865	3,090	1,133	348	195	293	70	15,638
	Grams/Episode	30	30	15	31	29	18	29	23	25
	Grams per 1,000 Population	1	1	1	1	0	0	1	0	1
Lambert–Eaton myasthenic syndrome	Patients	9	5	9	<5			<5	<5	<38
	Average Age	60	67	60	70			81	75	62
	Average Weight	69	76	81	76			66	65	76
	Grams	3,735	3,795	4,490	925			130	720	13,795
	Grams/Episode	31	59	19	44			26	60	30
	Grams per 1,000 Population	0	1	1	1			1	2	1
Lymphoproliferative syndromes (e.g. XLP1, XLP2, CD27 def)	Patients	6	<5		<5	<5	<5			<26
	Average Age	35	28		12	16	43			30
	Average Weight	73	75		33	54	60			67
	Grams	1,995	500		29	163	158			2,843
	Grams/Episode	26	11		2	13	23			18
	Grams per 1,000 Population	0	0		0	0	0			0
Memory B cell deficiency secondary to haemopoietic stem cell transplantation (HSCT)	Patients	125	75	111	11	36	9		7	367
	Average Age	49	51	58	54	55	54		42	54
	Average Weight	69	70	74	70	77	85		55	72
	Grams	22,294	14,035	29,775	2,290	7,703	2,948		810	79,855
	Grams/Episode	24	21	20	24	22	35		20	22
	Grams per 1,000 Population	3	2	6	1	3	5		2	3
	Patients	219	116	123	49	44	12	7	27	589

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Multifocal motor neuropathy with or without persistent conduction block	Average Age	59	57	59	62	60	62	56	60	59
	Average Weight	78	81	81	82	83	81	86	88	81
	Grams	132,708	80,789	78,678	45,025	34,928	8,233	6,040	19,865	406,265
	Grams/Episode	45	50	30	52	52	37	73	64	44
	Grams per 1,000 Population	16	12	15	25	13	15	24	45	16
Multiple myeloma (MM)	Patients	584	369	463	71	111	50	<5	16	1,646
	Average Age	71	69	71	70	69	69	62	68	70
	Average Weight	78	81	77	83	86	82	104	78	79
	Grams	143,741	93,433	128,567	14,081	27,609	13,998	720	4,257	426,404
	Grams/Episode	28	25	22	25	25	30	36	25	25
	Grams per 1,000 Population	18	14	25	8	10	25	3	10	17
Myasthenia gravis (MG)	Patients	403	327	353	113	50	14	<5	29	1,266
	Average Age	62	63	62	63	64	54	43	58	62
	Average Weight	81	81	84	81	82	78	83	82	82
	Grams	177,155	146,150	167,172	56,478	15,468	4,763	735	13,298	581,216
	Grams/Episode	35	40	24	36	34	35	22	42	32
	Grams per 1,000 Population	22	22	33	32	6	9	3	30	23
Necrotising autoimmune myopathy (NAM)	Patients	57	41	47	24	16	<5	<5	5	<200
	Average Age	66	64	63	52	65	57	58	65	62
	Average Weight	79	80	82	80	68	98	88	54	79
	Grams	20,855	20,493	18,753	13,995	7,265	2,990	1,150	1,135	86,635
	Grams/Episode	35	47	22	40	35	64	52	25	34
	Grams per 1,000 Population	3	3	4	8	3	5	5	3	3
Neonatal alloimmune thrombocytopenia (NAIT)	Patients	8	10	<5	5	<5				<33
	Average Age	26	-	30	33	28				26
	Average Weight	62	3	60	76	45				56
	Grams	2,910	43	713	2,993	948				7,605
	Grams/Episode	71	3	26	77	43				53
	Grams per 1,000 Population	0	0	0	2	0				0
Neonate with haemochromatosis	Patients	<5	<5	<5	<5					<20
	Average Age	21	-	-	-					5

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Average Weight	49	1	4	2					13
	Grams	245	15	23	5					288
	Grams/Episode	49	3	2	5					13
	Grams per 1,000 Population	0	0	0	0					0
Newly Diagnosed Immune thrombocytopenic purpura (ITP)	Patients	223	205	187	51	82	15	<5	9	<777
	Average Age	58	61	59	47	57	62	34	57	58
	Average Weight	78	80	79	81	79	75	100	71	79
	Grams	29,828	22,730	24,968	6,035	13,438	1,790	180	1,195	100,163
	Grams/Episode	53	60	29	60	61	72	60	60	46
	Grams per 1,000 Population	4	3	5	3	5	3	1	3	4
Non-Hodgkin lymphoma (NHL)	Patients	614	419	637	97	152	63	8	18	1,986
	Average Age	70	68	69	67	69	69	57	62	69
	Average Weight	77	78	77	76	77	78	73	73	77
	Grams	152,415	109,399	191,330	22,972	33,692	16,427	1,348	4,464	532,047
	Grams/Episode	27	25	23	26	23	28	25	18	25
	Grams per 1,000 Population	19	17	37	13	13	29	5	10	21
Other Haematological malignancy	Patients	206	59	114	18	16	11		7	422
	Average Age	68	63	70	64	54	73		75	68
	Average Weight	76	77	74	85	73	82		89	76
	Grams	42,064	14,263	29,930	4,768	4,052	1,827		2,400	99,304
	Grams/Episode	27	22	20	27	25	29		29	24
	Grams per 1,000 Population	5	2	6	3	2	3		5	4
Other primary immunodeficiency	Patients	<5								<5
	Average Age	75								75
	Average Weight									
	Grams	55								55
	Grams/Episode	14								14
	Grams per 1,000 Population	0								0
Persistent Immune thrombocytopenic purpura (ITP)	Patients	113	107	102	31	41	8	<5	5	408
	Average Age	56	59	55	44	56	69	40	50	55
	Average Weight	74	80	82	70	82	99	57	88	79



OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams	23,438	13,678	21,455	5,455	7,258	1,168	303	1,025	73,778
	Grams/Episode	49	53	31	59	58	56	43	64	44
	Grams per 1,000 Population	3	2	4	3	3	2	1	2	3
Polymyositis (PM)	Patients	154	59	91	14	16	<5		8	340
	Average Age	63	63	58	57	73	93		60	61
	Average Weight	77	80	82	63	77	56		75	79
	Grams	55,811	29,748	40,283	5,615	7,298	260		2,685	141,699
	Grams/Episode	34	44	26	39	37	20		34	33
	Grams per 1,000 Population	7	5	8	3	3	0		6	6
Possible Common variable immune deficiency (CVID) - below normal serum IgG but normal serum IgA level	Patients	427	156	134	37	30	12	<5	29	812
	Average Age	58	48	57	46	51	50	23	52	55
	Average Weight	77	69	75	73	71	79	42	78	75
	Grams	144,470	45,509	43,886	10,741	8,631	3,048	270	10,371	266,926
	Grams/Episode	28	21	23	21	22	25	18	26	25
	Grams per 1,000 Population	18	7	9	6	3	5	1	23	10
Post-haemopoietic stem cell transplantation	Patients	<5								<5
	Average Age	64								64
	Average Weight									
	Grams	58								58
	Grams/Episode	29								29
	Grams per 1,000 Population	0								0
Pregnant woman with previous fetal loss	Patients	<5	<5		<5					<15
	Average Age	36	32		35					35
	Average Weight	77	75		80					76
	Grams	3,090	2,380		240					5,710
	Grams/Episode	42	74		80					52
	Grams per 1,000 Population	0	0		0					0
Severe combined immunodeficiency (SCID)	Patients	15	10	17	<5	<5	<5			<57
	Average Age	21	17	21	37	24	61			21
	Average Weight	48	38	46	110	77	76			47
	Grams	3,892	2,726	4,494	240	573	420			12,345

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams/Episode	25	18	13	40	19	23			18
	Grams per 1,000 Population	0	0	1	0	0	1			0
Severe reduction in all Ig isotypes with decreased or absent B-cells (e.g. XLA def)	Patients	37	33	23	10	10		<5	<5	<123
	Average Age	30	33	28	22	30		26	35	30
	Average Weight	68	66	61	59	62		50	79	65
	Grams	14,710	12,946	6,452	2,799	3,101		981	992	41,981
	Grams/Episode	29	24	22	20	20		30	23	25
	Grams per 1,000 Population	2	2	1	2	1		4	2	2
Severe reduction in at least two Ig isotypes with low/normal B-cells (e.g. CVID)	Patients	429	208	210	91	71	19	<5	41	1,055
	Average Age	50	48	50	44	50	40	60	44	49
	Average Weight	71	75	76	75	72	74	82	73	74
	Grams	147,372	72,471	81,661	29,056	24,449	7,760	1,495	13,634	377,899
	Grams/Episode	28	23	22	24	26	23	42	26	25
	Grams per 1,000 Population	18	11	16	16	9	14	6	31	15
Severe reduction in serum IgG and IgA with normal/elevated IgM (e.g. CD40L def)	Patients	18	8	19	<5	7	<5	<5		<67
	Average Age	27	40	53	80	46	53	63		44
	Average Weight	50	63	69	66	72	98	64		64
	Grams	4,528	2,455	5,491	245	2,975	235	25		15,954
	Grams/Episode	20	20	16	18	29	29	25		20
	Grams per 1,000 Population	1	0	1	0	1	0	0		1
Stiff person syndrome	Patients	44	9	23	5	<5	<5	<5	<5	<101
	Average Age	60	45	57	70	63	36	37	47	57
	Average Weight	77	73	83	74	74	62	61	69	78
	Grams	26,493	4,238	14,908	2,825	390	2,255	150	900	52,158
	Grams/Episode	46	50	29	30	28	43	30	30	38
	Grams per 1,000 Population	3	1	3	2	0	4	1	2	2
Transient hypogammaglobulinaemia of infancy	Patients	<5	<5		<5	<5	<5			<25
	Average Age	3	2		-	1	3			2
	Average Weight	14	10		4	11	11			12
	Grams	73	10		5	59	80			226
	Grams/Episode	5	5		3	3	4			4

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams per 1,000 Population	0	0		0	0	0			0
X-linked agammaglobulinaemia	Patients		<5							<5
	Average Age		36							36
	Average Weight		61							61
	Grams		128							128
	Grams/Episode		21							21
	Grams per 1,000 Population		0							0
	<b>Total for conditions where Ig has an established therapeutic role</b>	<b>Patients</b>	<b>6,185</b>	<b>3,765</b>	<b>4,228</b>	<b>1,048</b>	<b>1,004</b>	<b>367</b>	<b>80</b>	<b>343</b>
<b>Average Age</b>		<b>62</b>	<b>61</b>	<b>63</b>	<b>58</b>	<b>62</b>	<b>62</b>	<b>50</b>	<b>57</b>	<b>62</b>
<b>Average Weight</b>		<b>77</b>	<b>78</b>	<b>80</b>	<b>78</b>	<b>78</b>	<b>81</b>	<b>76</b>	<b>78</b>	<b>78</b>
<b>Grams</b>		<b>2,035,530</b>	<b>1,227,887</b>	<b>1,518,500</b>	<b>398,624</b>	<b>306,309</b>	<b>122,966</b>	<b>24,125</b>	<b>126,894</b>	<b>5,760,834</b>
<b>Grams/Episode</b>		<b>33</b>	<b>32</b>	<b>24</b>	<b>35</b>	<b>31</b>	<b>32</b>	<b>43</b>	<b>35</b>	<b>30</b>
<b>Grams per 1,000 Population</b>		<b>252</b>	<b>187</b>	<b>296</b>	<b>224</b>	<b>114</b>	<b>220</b>	<b>97</b>	<b>285</b>	<b>226</b>
<b>Has an emerging therapeutic role (previously Chapter 6)</b>										
Autoimmune haemolytic anaemia	Patients	27	25	27	9	10	<5	<5	<5	<113
	Average Age	58	60	62	60	65	50	52	59	60
	Average Weight	72	69	81	65	62	103	62	83	74
	Grams	4,340	2,978	7,795	1,125	1,865	740	620	85	19,548
	Grams/Episode	44	56	39	40	43	74	41	21	43
	Grams per 1,000 Population	1	0	2	1	1	1	3	0	1
Bullous Pemphigoid	Patients	8	18	11	7	<5			7	<56
	Average Age	77	73	63	59	67			63	67
	Average Weight	93	104	92	74	106			103	95
	Grams	2,990	10,010	10,460	2,983	1,090			2,705	30,238
	Grams/Episode	54	66	43	51	68			59	53
	Grams per 1,000 Population	0	2	2	2	0			6	1
Cicatrical pemphigoid (CP)	Patients	<5	<5	8	<5					<23
	Average Age	57	67	72	67					70
	Average Weight	78	76	81	89					81
	Grams	2,840	1,630	6,520	450					11,440
	Grams/Episode	62	54	23	75					32

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams per 1,000 Population	0	0	1	0					0
Drug-induced pemphigus foliaceus	Patients	<5								<5
	Average Age	71								71
	Average Weight	90								90
	Grams	180								180
	Grams/Episode	45								45
	Grams per 1,000 Population	0								0
Encephalitis associated with antibodies to AMPA receptor	Patients		<5	<5						<10
	Average Age		48	73						65
	Average Weight		54	70						65
	Grams		110	80						190
	Grams/Episode		110	40						63
	Grams per 1,000 Population		0	0						0
Encephalitis associated with antibodies to CASPR2	Patients	8	<5	<5		<5	<5			<28
	Average Age	58	75	43		72	75			57
	Average Weight	69	75	79		87	90			76
	Grams	3,575	675	1,665		345	455			6,715
	Grams/Episode	40	68	27		31	24			35
	Grams per 1,000 Population	0	0	0		0	1			0
Encephalitis associated with antibodies to GABA (A or B) receptor	Patients	<5	<5	5						<15
	Average Age	32	61	59						52
	Average Weight	98	53	92						93
	Grams	845	40	2,155						3,040
	Grams/Episode	35	20	34						34
	Grams per 1,000 Population	0	0	0						0
Encephalitis associated with antibodies to glycine receptor	Patients			7						7
	Average Age			50						50
	Average Weight			76						76
	Grams			2,270						2,270
	Grams/Episode			18						18
	Grams per 1,000 Population			0						0

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Encephalitis associated with antibodies to LGI1	Patients	8	<5	5		<5		<5	<5	<33
	Average Age	63	76	62		70		70	63	64
	Average Weight	71	100	84		66		83	64	76
	Grams	3,025	235	1,770		663		165	90	5,948
	Grams/Episode	34	39	21		24		33	30	27
	Grams per 1,000 Population	0	0	0		0		1	0	0
Encephalitis associated with antibodies to NMDA receptor	Patients	34	16	27	6	5	<5		<5	<98
	Average Age	40	28	38	24	34	39		61	37
	Average Weight	76	64	82	65	67	51		55	76
	Grams	7,980	3,478	7,033	645	638	360		150	20,283
	Grams/Episode	30	33	20	27	27	45		50	26
	Grams per 1,000 Population	1	1	1	0	0	1		0	1
Encephalitis associated with antibodies to VGKC	Patients	8	7	11	<5	<5				<36
	Average Age	52	69	46	64	27				51
	Average Weight	73	73	67	57	50				69
	Grams	2,300	1,478	3,160	715	100				7,753
	Grams/Episode	26	34	19	55	20				24
	Grams per 1,000 Population	0	0	1	0	0				0
Endemic pemphigus foliaceus	Patients		<5	<5						<10
	Average Age		46	59						56
	Average Weight		60	75						71
	Grams		240	480						720
	Grams/Episode		60	40						45
	Grams per 1,000 Population		0	0						0
Evans syndrome child - with significant ITP	Patients	<5	<5	<5		<5			<5	<25
	Average Age	13	8	13		14			1	12
	Average Weight	33	41	54		93			9	69
	Grams	13	40	108		345			20	525
	Grams/Episode	13	40	54		38			10	35
	Grams per 1,000 Population	0	0	0		0			0	0
	Patients	6	<5	<5				<5		<21

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Evans Syndrome with significant AIHA	Average Age	38	61	75				29		44
	Average Weight	63	65	80				60		65
	Grams	785	60	135				120		1,100
	Grams/Episode	49	15	34				17		35
	Grams per 1,000 Population	0	0	0				0		0
Existing patient - authorisation for IgG subclass deficiency	Patients	6	15	5	<5	<5	<5	<5		<46
	Average Age	67	66	53	73	67	72	31		65
	Average Weight	110	81	64	94	74	57	64		84
	Grams	2,518	5,148	893	845	1,008	470	25		10,906
	Grams/Episode	25	24	14	23	30	22	25		23
	Grams per 1,000 Population	0	1	0	0	0	1	0		0
Haemophagocytic lymphohistiocytosis	Patients	14	9	10	<5	<5				<43
	Average Age	42	30	56	41	67				47
	Average Weight	72	61	60	63	110				65
	Grams	1,990	895	1,590	473	200				5,148
	Grams/Episode	42	45	27	68	67				38
	Grams per 1,000 Population	0	0	0	0	0				0
Heart and kidney transplant	Patients			<5						<5
	Average Age			53						53
	Average Weight			79						79
	Grams			193						193
	Grams/Episode			8						8
	Grams per 1,000 Population			0						0
Heart and lung transplant	Patients	<5				<5				<10
	Average Age	40				16				20
	Average Weight	46				42				42
	Grams	5				35				40
	Grams/Episode	5				7				7
	Grams per 1,000 Population	0				0				0
Heart transplant	Patients	7	<5	7						<19
	Average Age	54	39	48						49

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Average Weight	76	39	78						77
	Grams	460	48	2,330						2,838
	Grams/Episode	12	24	19						18
	Grams per 1,000 Population	0	0	0						0
Hypogammaglobulinaemia following B cell depletion therapy	Patients	105	73	95	31	<5	9		<5	<323
	Average Age	55	48	58	52	17	70		63	54
	Average Weight	79	75	75	69	41	76		75	75
	Grams	25,161	13,716	25,781	7,329	470	2,292		1,023	75,771
	Grams/Episode	27	20	19	23	14	19		31	22
	Grams per 1,000 Population	3	2	5	4	0	4		2	3
Hypogammaglobulinaemia following Solid organ transplantation	Patients	144	97	59	5	<5	5		6	312
	Average Age	53	57	55	58	60	32		55	55
	Average Weight	68	68	74	74	79	67		71	70
	Grams	32,058	24,687	12,153	630	548	901		1,315	72,291
	Grams/Episode	24	23	15	19	30	24		28	22
	Grams per 1,000 Population	4	4	2	0	0	2		3	3
Idiopathic opsoclonus-myoclonus ataxia	Patients	8	<5	<5		<5				<23
	Average Age	23	12	6		46				27
	Average Weight	33	36	24		71				42
	Grams	1,063	193	165		1,785				3,205
	Grams/Episode	19	28	17		66				32
	Grams per 1,000 Population	0	0	0		1				0
IgA pemphigus foliaceus	Patients			<5						<5
	Average Age			55						55
	Average Weight			70						70
	Grams			505						505
	Grams/Episode			27						27
	Grams per 1,000 Population			0						0
IgM paraproteinaemic demyelinating neuropathy	Patients	29	16	22	5	<5	<5		<5	<87
	Average Age	76	73	66	80	63	70		55	71
	Average Weight	77	83	85	69	84	87		88	81

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams	12,515	5,020	11,555	2,993	1,170	1,778		385	35,415
	Grams/Episode	41	36	23	47	35	38		55	32
	Grams per 1,000 Population	2	1	2	2	0	3		1	1
ITP - child - chronic	Patients	<5	9	<5	6	<5	<5	<5		<35
	Average Age	5	7	5	11	11	7	3		7
	Average Weight	18	34	20	53	35	28	15		29
	Grams	143	666	425	520	160	55	28		1,996
	Grams/Episode	20	20	11	47	15	28	14		19
	Grams per 1,000	0	0	0	0	0	0	0		0
ITP - child - newly diagnosed	Patients	20	22	<5		<5			<5	<57
	Average Age	4	4	4		1			8	4
	Average Weight	17	20	21		8			35	18
	Grams	498	545	80		33			70	1,225
	Grams/Episode	15	18	20		7			70	17
	Grams per 1,000 Population	0	0	0		0			0	0
ITP - child - persistent	Patients	6	10	<5	<5	<5				<31
	Average Age	6	6	1	10	3				6
	Average Weight	21	27	7	55	16				27
	Grams	248	683	15	215	45				1,205
	Grams/Episode	21	23	8	54	15				24
	Grams per 1,000 Population	0	0	0	0	0				0
Kidney transplant	Patients	106	222	47	21	14	18	<5	5	433
	Average Age	46	51	53	46	41	44	48	62	50
	Average Weight	76	75	76	70	74	78	84	90	76
	Grams	14,535	73,835	13,488	4,410	2,755	10,555	633	745	120,955
	Grams/Episode	22	35	14	48	30	45	20	30	29
	Grams per 1,000 Population	2	11	3	2	1	19	3	2	5
Liver and kidney transplant	Patients	<5	<5	<5						<15
	Average Age	28	62	63						49
	Average Weight	54	53	50						53
	Grams	228	225	15						468



OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams/Episode	33	28	5						26
	Grams per 1,000 Population	0	0	0						0
Liver transplant	Patients	11	<5	<5						<21
	Average Age	26	41	54						39
	Average Weight	39	67	48						46
	Grams	1,513	183	310						2,005
	Grams/Episode	38	20	10						25
	Grams per 1,000 Population	0	0	0						0
Lung transplant	Patients	43	78	<5	<5	<5	<5			<151
	Average Age	49	54	30	59	59	48			52
	Average Weight	67	74	50	80	70	63			72
	Grams	5,235	17,798	540	140	140	695			24,548
	Grams/Episode	28	25	21	70	70	22			25
	Grams per 1,000 Population	1	3	0	0	0	1			1
Macrophage activation syndrome	Patients	<5	<5	<5	<5					<20
	Average Age	50	40	36	36					42
	Average Weight	61	90	89	53					73
	Grams	355	260	265	70					950
	Grams/Episode	39	130	33	23					43
	Grams per 1,000 Population	0	0	0	0					0
Monophasic acute disseminated encephalomyelitis (ADEM)	Patients	9	9	14	<5				<5	<42
	Average Age	34	21	29	5				5	27
	Average Weight	59	37	58	22				20	52
	Grams	825	615	1,678	100				20	3,238
	Grams/Episode	24	21	22	17				20	22
	Grams per 1,000 Population	0	0	0	0				0	0
Mucous Membrane Pemphigoid (MMP)	Patients	<5	5	<5	<5		<5		<5	<30
	Average Age	75	66	50	51		48		74	62
	Average Weight	79	89	80	88		71		85	85
	Grams	320	4,550	390	1,130		1,820		2,620	10,830
	Grams/Episode	53	86	30	33		140		69	69

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams per 1,000 Population	0	1	0	1		3		6	0
Multiphasic acute disseminated encephalomyelitis (ADEM)	Patients	<5	<5	<5						<15
	Average Age	78	47	31						49
	Average Weight	71	66	43						58
	Grams	900	830	485						2,215
	Grams/Episode	35	29	13						24
	Grams per 1,000 Population	0	0	0						0
Other Hypogammaglobulinaemia unrelated to haematological malignancies or haemopoietic stem cell transplantation (HSCT)	Patients	223	109	192	29	10	20	<5	9	587
	Average Age	63	59	61	48	58	53	67	62	60
	Average Weight	77	70	73	65	70	66	61	75	73
	Grams	55,315	24,108	54,503	6,619	3,106	4,346	360	1,499	149,855
	Grams/Episode	26	23	21	19	25	22	30	22	23
	Grams per 1,000 Population	7	4	11	4	1	8	1	3	6
Other transplant	Patients	<5								<5
	Average Age	56								56
	Average Weight	58								58
	Grams	10								10
	Grams/Episode	5								5
	Grams per 1,000 Population	0								0
Pancreas and kidney transplant	Patients	<5	<5							<10
	Average Age	38	44							42
	Average Weight	50	80							73
	Grams	75	675							750
	Grams/Episode	25	68							58
	Grams per 1,000 Population	0	0							0
Paraneoplastic associated breast cancer	Patients				<5					<5
	Average Age				71					71
	Average Weight				63					63
	Grams				125					125
	Grams/Episode				21					21
	Grams per 1,000 Population				0					0

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Paraneoplastic associated neuroblastoma	Patients	6	<5	<5			<5			<21
	Average Age	3	1	1			1			3
	Average Weight	19	10	13			10			17
	Grams	950	30	148			30			1,158
	Grams/Episode	16	10	7			6			13
	Grams per 1,000 Population	0	0	0			0			0
Paraneoplastic associated other tumour type	Patients		<5		<5					<10
	Average Age		80		1					53
	Average Weight		77		11					54
	Grams		390		43					433
	Grams/Episode		26		5					19
	Grams per 1,000 Population		0		0					0
Paraneoplastic associated small cell lung cancer	Patients	<5								<5
	Average Age	78								78
	Average Weight	64								64
	Grams	50								50
	Grams/Episode	25								25
	Grams per 1,000 Population	0								0
Paraneoplastic pemphigus foliaceus	Patients		<5			<5				<10
	Average Age		49			49				49
	Average Weight		50			50				50
	Grams		100			100				200
	Grams/Episode		50			25				33
	Grams per 1,000 Population		0			0				0
Pemphigus herpetiformis	Patients	<5								<5
	Average Age	59								59
	Average Weight	64								64
	Grams	720								720
	Grams/Episode	40								40
	Grams per 1,000 Population	0								0
Pemphigus vulgaris	Patients	15	9	8	<5					<37

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Average Age	54	39	64	69					57
	Average Weight	95	60	76	116					80
	Grams	9,543	4,188	8,568	1,810					24,108
	Grams/Episode	69	37	30	39					41
	Grams per 1,000 Population	1	1	2	1					1
Post-transfusion purpura (PTP)	Patients		<5	<5						<10
	Average Age		67	-						40
	Average Weight		73	7						46
	Grams		215	15						230
	Grams/Episode		72	8						46
	Grams per 1,000 Population		0	0						0
Recurrent acute disseminated encephalomyelitis (ADEM)	Patients	9	<5	8	<5				<5	<32
	Average Age	50	17	29	3				40	37
	Average Weight	71	64	50	12				116	63
	Grams	3,370	1,690	1,423	90				920	7,493
	Grams/Episode	29	46	18	11				102	30
	Grams per 1,000 Population	0	0	0	0				2	0
Secondary hypogammaglobulinaemia (excluding haematological malignancies)	Patients	6	<5	<5					<5	<21
	Average Age	60	63	62					30	59
	Average Weight	70	66	69						68
	Grams	210	23	85					35	353
	Grams/Episode	21	11	21					35	21
	Grams per 1,000 Population	0	0	0					0	0
Sero-negative autoimmune encephalitis	Patients	55	18	21	<5		<5			<104
	Average Age	49	54	52	32		67			51
	Average Weight	79	80	80	103		89			80
	Grams	15,985	5,168	6,690	1,105		265			29,213
	Grams/Episode	34	37	23	85		29			31
	Grams per 1,000 Population	2	1	1	1		0			1
Sero-negative limbic encephalitis	Patients	16	7	30			<5		<5	<63
	Average Age	60	68	48			43		69	51

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Average Weight	76	61	70			84		72	72
	Grams	4,160	1,040	9,445			910		570	16,125
	Grams/Episode	30	39	20			31		32	23
	Grams per 1,000 Population	1	0	2			2		1	1
Specific antibody deficiency	Patients	155	57	58	77	26	<5	<5	9	377
	Average Age	56	57	53	50	50	11	2	40	53
	Average Weight	70	73	76	70	59	63	14	77	71
	Grams	41,421	16,224	18,283	19,812	5,702	274	70	2,540	104,327
	Grams/Episode	24	23	20	21	20	23	3	29	22
	Grams per 1,000 Population	5	2	4	11	2	0	0	6	4
Staphylococcal TSS	Patients	9	15	<5	5				<5	<39
	Average Age	43	40	69	25				50	42
	Average Weight	80	64	92	64				100	75
	Grams	1,125	1,740	540	550				100	4,055
	Grams/Episode	42	102	108	79				100	71
	Grams per 1,000 Population	0	0	0	0				0	0
Stevens–Johnson syndrome / toxic epidermal necrolysis overlap (SJS/TEN)	Patients	17	16	<5	<5	<5			<5	<53
	Average Age	38	49	17	55	33			64	42
	Average Weight	64	72	71	55	101			88	70
	Grams	2,425	2,073	265	165	120			265	5,313
	Grams/Episode	53	55	22	55	40			38	49
	Grams per 1,000 Population	0	0	0	0	0			1	0
Streptococcal TSS	Patients	24	54	20	20	11	<5	<5	<5	<144
	Average Age	49	48	23	47	43	2	18	40	40
	Average Weight	75	75	61	89	82	12	75	43	72
	Grams	3,468	6,515	1,881	2,715	1,670	25	150	335	16,758
	Grams/Episode	105	78	28	85	111	25	150	84	71
	Grams per 1,000 Population	0	1	0	2	1	0	1	1	1
Suspected autoimmune encephalitis	Patients	64	53	46	9	12			8	191
	Average Age	43	52	49	36	58			40	47
	Average Weight	65	70	69	66	74			47	68

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams	10,930	10,145	9,888	845	1,740			1,630	35,178
	Grams/Episode	27	36	19	28	33			41	27
	Grams per 1,000 Population	1	2	2	0	1			4	1
Suspected autoimmune limbic encephalitis	Patients	24	16	31	<5	5	<5		<5	<91
	Average Age	60	48	42	64	73	84		71	48
	Average Weight	73	75	77	78	78	60		93	76
	Grams	3,845	3,643	10,743	1,665	1,145	60		575	21,675
	Grams/Episode	37	39	24	57	33	20		82	30
	Grams per 1,000 Population	0	1	2	1	0	0		1	1
Thymoma-associated hypogammaglobulinaemia (Goods Syndrome)	Patients	<5	<5	<5	<5	<5	<5		<5	<35
	Average Age	58	75	67	75	85	66		56	66
	Average Weight	64	56	73	72	76	79		64	67
	Grams	1,225	365	743	655	30	30		300	3,348
	Grams/Episode	26	21	21	23	30	30		25	24
	Grams per 1,000 Population	0	0	0	0	0	0		1	0
Toxic epidermal necrolysis (TEN)	Patients	5	<5	<5		<5				<20
	Average Age	53	53	69		66				58
	Average Weight	68	50	101		70				66
	Grams	635	250	200		440				1,525
	Grams/Episode	79	50	200		55				69
	Grams per 1,000 Population	0	0	0		0				0
<b>Total for conditions where Ig has an emerging therapeutic role</b>	<b>Patients</b>	<b>1,207</b>	<b>992</b>	<b>808</b>	<b>256</b>	<b>132</b>	<b>77</b>	<b>&lt;25</b>	<b>68</b>	<b>3,508</b>
	<b>Average Age</b>	<b>54</b>	<b>54</b>	<b>55</b>	<b>51</b>	<b>51</b>	<b>52</b>	<b>38</b>	<b>56</b>	<b>54</b>
	<b>Average Weight</b>	<b>73</b>	<b>73</b>	<b>74</b>	<b>71</b>	<b>67</b>	<b>73</b>	<b>58</b>	<b>77</b>	<b>73</b>
	<b>Grams</b>	<b>284,900</b>	<b>249,445</b>	<b>239,901</b>	<b>60,970</b>	<b>27,445</b>	<b>26,061</b>	<b>2,170</b>	<b>17,996</b>	<b>908,889</b>
	<b>Grams/Episode</b>	<b>28</b>	<b>30</b>	<b>21</b>	<b>27</b>	<b>29</b>	<b>33</b>	<b>22</b>	<b>39</b>	<b>26</b>
	<b>Grams per 1,000 Population</b>	<b>35</b>	<b>38</b>	<b>47</b>	<b>34</b>	<b>10</b>	<b>47</b>	<b>9</b>	<b>40</b>	<b>36</b>
<b>Has application in exceptional circumstances only (previously Chapter 7)</b>										
Acquired bleeding disorder, other coagulation factors (Prothrombin, factor V, factor	Patients			<5		<5				<10
	Average Age			71		70				71
	Average Weight			81		60				70

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
VII, factor X, factor XI, and factor XIII)	Grams			160		120				280
	Grams/Episode			80		60				70
	Grams per 1,000 Population			0		0				0
Acquired haemophilia A	Patients	<5				<5				<10
	Average Age	84				65				69
	Average Weight	60				119				104
	Grams	-				360				360
	Grams/Episode	-				60				45
	Grams per 1,000 Population					0				0
Acquired haemophilia B	Patients					<5				<5
	Average Age					68				68
	Average Weight					70				70
	Grams					630				630
	Grams/Episode					35				35
	Grams per 1,000 Population					0				0
Acquired von Willebrand syndrome	Patients	<5	<5	<5		5				<20
	Average Age	71	59	49		71				62
	Average Weight	54	97	93		69				75
	Grams	2,000	170	3,735		2,335				8,240
	Grams/Episode	45	43	57		51				52
	Grams per 1,000 Population	0	0	1		1				0
Anti-neutrophil cytoplasmic antibody (ANCA) (PR3 or MPO)-positive idiopathic rapidly progressive glomerulonephritis	Patients	<5	<5							<10
	Average Age	54	50							51
	Average Weight	84	200							161
	Grams	330	640							970
	Grams/Episode	66	64							65
	Grams per 1,000 Population	0	0							0
Ataxic sensory neuropathy	Patients	<5	<5			<5		<5		<20
	Average Age	67	59			47		47		63
	Average Weight	79	50			57		58		72
	Grams	1,055	150			165		170		1,540

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams/Episode	23	19			55		21		24
	Grams per 1,000 Population	0	0			0		1		0
Atypical rolandic epilepsy	Patients	<5	<5	7						<17
	Average Age	5	7	11						10
	Average Weight	20	29	33						31
	Grams	193	860	1,473						2,525
	Grams/Episode	14	24	11						14
	Grams per 1,000 Population	0	0	0						0
Autoimmune neutropenia	Patients	<5	<5	<5	<5				<5	<25
	Average Age	43	62	32	77				49	43
	Average Weight	59	84	80	74				70	70
	Grams	923	280	505	225				280	2,213
	Grams/Episode	29	47	22	75				56	32
	Grams per 1,000 Population	0	0	0	0				1	0
Autoimmune retinopathy	Patients		<5							<5
	Average Age		49							49
	Average Weight		95							95
	Grams		380							380
	Grams/Episode		63							63
	Grams per 1,000 Population		0							0
Autonomic neuropathy	Patients	<5				<5				<10
	Average Age	54				26				43
	Average Weight	57				92				70
	Grams	560				495				1,055
	Grams/Episode	23				35				28
	Grams per 1,000 Population	0				0				0
Catastrophic anti-phospholipid syndrome	Patients	<5	<5	<5				<5		<20
	Average Age	49	35	38				36		42
	Average Weight	98	75	83				78		88
	Grams	650	225	485				35		1,395
	Grams/Episode	38	32	30				35		34



OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams per 1,000 Population	0	0	0				0		0
Confirmed autoimmune congenital heart block in a fetus	Patients	<5								<5
	Average Age	33								33
	Average Weight	79								79
	Grams	80								80
	Grams/Episode	80								80
	Grams per 1,000 Population	0								0
	Confirmed autoimmune congenital heart block in a neonate	Patients		<5						
Average Age			-							-
Average Weight			3							3
Grams			5							5
Grams/Episode			5							5
Grams per 1,000 Population			0							0
Eosinophilic granulomatosis with polyangiitis (Churg-Strauss Syndrome)	Patients				<5		<5			,10
	Average Age				81		55			80
	Average Weight				62		90			63
	Grams				660		80			740
	Grams/Episode				22		80			24
	Grams per 1,000 Population				0		0			0
Epidermolysis bullosa acquisita	Patients		<5		<5					<10
	Average Age		40		72					59
	Average Weight		73		127					106
	Grams		1,980		1,600					3,580
	Grams/Episode		86		44					61
	Grams per 1,000 Population		0		1					0
Granulomatosis with polyangiitis (Wegener Granulomatosis)	Patients				<5					<5
	Average Age				49					49
	Average Weight				74					74
	Grams				435					435
	Grams/Episode				31					31
	Grams per 1,000 Population				0					0

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
Graves ophthalmopathy	Patients	<5		<5	<5					<15
	Average Age	69		59	54					58
	Average Weight	60		94	59					79
	Grams	85		1,060	510					1,655
	Grams/Episode	21		35	27					31
	Grams per 1,000 Population	0		0	0					0
Haemolytic disease of the fetus	Patients	5	<5	<5		<5		<5	5	<30
	Average Age	27	31	33		29		-	33	31
	Average Weight	69	75	57		99		3	81	71
	Grams	2,273	2,408	1,363		800		3	5,055	11,900
	Grams/Episode	69	57	18		100		3	62	49
	Grams per 1,000 Population	0	0	0		0		0	11	0
Hyperhaemolysis syndrome	Patients	<5								<5
	Average Age	71								71
	Average Weight	95								95
	Grams	135								135
	Grams/Episode	68								68
	Grams per 1,000 Population	0								0
Landau Kleffner syndrome	Patients	<5	<5	<5						<15
	Average Age	23	6	6						13
	Average Weight	79	20	22						43
	Grams	720	200	110						1,030
	Grams/Episode	48	13	12						26
	Grams per 1,000 Population	0	0	0						0
Lennox-Gastaut syndrome	Patients	<5	<5	<5				<5		<20
	Average Age	7	9	4				7		5
	Average Weight	22	25	19				21		20
	Grams	845	50	690				43		1,628
	Grams/Episode	33	10	9				43		15
	Grams per 1,000 Population	0	0	0				0		0
LETMs	Patients	5								5

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Average Age	63								635
	Average Weight	83								83
	Grams	1,435								1,435
	Grams/Episode	30								30
	Grams per 1,000 Population	0								0
Limbic encephalitis, nonparaneoplastic	Patients	<5								<5
	Average Age	19								19
	Average Weight									
	Grams	-								-
	Grams/Episode	-								-
	Grams per 1,000 Population									
Microscopic polyangiitis	Patients			<5	<5					<10
	Average Age			68	42					48
	Average Weight			66	55					58
	Grams			170	1,235					1,405
	Grams/Episode			19	43					37
	Grams per 1,000 Population			0	1					0
NMOSD–AQP4 ab positive	Patients	5			<5					<10
	Average Age	61			45					59
	Average Weight	59			40					57
	Grams	1,935			80					2,015
	Grams/Episode	31			16					30
	Grams per 1,000 Population	0			0					0
NMOSD–MOG ab positive	Patients	<5	5	<5	<5					<20
	Average Age	32	32	59	8					35
	Average Weight	59	58	92	26					62
	Grams	613	1,358	260	50					2,280
	Grams/Episode	28	27	17	10					25
	Grams per 1,000 Population	0	0	0	0					0
NMOSD–seronegative	Patients	24	<5	<5	<5	<5		<5		<49
	Average Age	49	15	41	38	19		18		42

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Average Weight	76	52	74	51	79		37		70
	Grams	6,707	2,163	495	823	160		75		10,422
	Grams/Episode	31	49	12	30	80		15		31
	Grams per 1,000 Population	1	0	0	0	0		0		0
Paediatric acute neuropsychiatric disorders (PANS)	Patients	11		15	<5					<31
	Average Age	12		12	17					12
	Average Weight	48		62	70					59
	Grams	6,450		7,348	1,223					15,020
	Grams/Episode	61		26	64					37
	Grams per 1,000 Population	1		1	1					1
Paediatric autoimmune neuropsychiatric disorder (PANDAS)	Patients	<5	<5	<5	<5					<20
	Average Age	10	15	12	11					12
	Average Weight	45	70	50	50					52
	Grams	575	548	1,100	100					2,323
	Grams/Episode	44	46	22	14					29
	Grams per 1,000 Population	0	0	0	0					0
Painful small fibre neuropathy	Patients	<5	<5			<5		<5	<5	<25
	Average Age	67	62			56		64	60	60
	Average Weight	80	65			72		80	81	76
	Grams	615	130			980		120	2,050	3,895
	Grams/Episode	32	19			32		60	68	44
	Grams per 1,000 Population	0	0			0		0	5	0
Pure red cell aplasia – associated B19 infection	Patients	6	<5	6	<5	<5			<5	<32
	Average Age	60	66	57	40	59			35	57
	Average Weight	93	61	80	73	75			58	80
	Grams	1,135	315	1,740	580	560			115	4,445
	Grams/Episode	54	35	26	73	56			115	38
	Grams per 1,000 Population	0	0	0	0	0			0	0
Pure red cell aplasia – autoimmune mediated	Patients	7	5	<5			<5		<5	<27
	Average Age	67	71	63			72		75	68
	Average Weight	75	67	76			94		59	73

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams	2,080	723	330			283		115	3,530
	Grams/Episode	55	60	110			141		58	62
	Grams per 1,000 Population	0	0	0			1		0	0
Pyoderma Gangrenosum	Patients	7	27	11	<5	<5	<5		<5	<64
	Average Age	51	58	69	43	41	72		31	60
	Average Weight	87	84	84	66	127	63		73	84
	Grams	2,755	21,040	6,750	1,530	800	65		400	33,340
	Grams/Episode	61	60	32	38	62	65		33	49
	Grams per 1,000 Population	0	3	1	1	0	0		1	1
Rasmussen encephalitis	Patients	12	5	5	<5	<5	<5		<5	<42
	Average Age	27	39	37	14	37	4		62	31
	Average Weight	66	55	66	53	110	21		65	64
	Grams	5,933	1,083	1,333	1,658	660	103		325	11,093
	Grams/Episode	35	24	14	41	44	26		22	29
	Grams per 1,000 Population	1	0	0	1	0	0		1	0
Relapsing remitting multiple sclerosis	Patients	21	6	<5					<5	<37
	Average Age	43	45	58					48	46
	Average Weight	79	73	82					62	78
	Grams	5,097	1,163	600					600	7,460
	Grams/Episode	29	33	15					38	28
	Grams per 1,000 Population	1	0	0					1	0
Scleromyxedema – skin and systemic disease	Patients	5	<5		<5	<5				<20
	Average Age	69	66		68	75				69
	Average Weight	76	55		75	60				67
	Grams	3,450	1,120		1,550	1,200				7,320
	Grams/Episode	49	20		53	43				40
	Grams per 1,000 Population	0	0		1	0				0
Scleromyxedema – skin involvement only	Patients	<5			<5	<5				<15
	Average Age	17			48	75				48
	Average Weight	64			80	53				74
	Grams	520			2,830	315				3,665

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams/Episode	65			48	29				47
	Grams per 1,000 Population	0			2	0				0
Sensorimotor axonal neuropathy	Patients	6	<5			<5		<5		<21
	Average Age	62	72			65		70		64
	Average Weight	77	57			67		81		74
	Grams	2,448	293			205		325		3,270
	Grams/Episode	39	23			26		36		35
	Grams per 1,000 Population	0	0			0		1		0
Sjögren's syndrome	Patients	<5								<5
	Average Age	75								75
	Average Weight									
	Grams	28								28
	Grams/Episode	28								28
	Grams per 1,000 Population	0								0
Subacute sensory neuropathy	Patients	<5								<5
	Average Age	69								69
	Average Weight									
	Grams	75								75
	Grams/Episode	25								25
	Grams per 1,000 Population	0								0
Susac syndrome	Patients	10	<5	11	<5	<5				<36
	Average Age	36	37	45	52	46				41
	Average Weight	95	64	88	64	83				85
	Grams	7,640	2,545	5,725	1,070	325				17,305
	Grams/Episode	45	35	31	30	36				37
	Grams per 1,000 Population	1	0	1	1	0				1
Systemic capillary leak syndrome	Patients	6	<5	<5	<5	<5			<5	<31
	Average Age	38	71	30	30	49			64	51
	Average Weight	77	79	47	82	78			72	76
	Grams	3,055	3,500	335	1,040	760			1,760	10,450
	Grams/Episode	36	53	28	80	58			88	50

OFFICIAL

Specific Condition		NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National
	Grams per 1,000 Population	0	1	0	1	0			4	0
West syndrome	Patients			<5						<5
	Average Age			5						5
	Average Weight			18						18
	Grams			228						228
	Grams/Episode			9						9
	Grams per 1,000 Population			0						0
	<b>Total for conditions where Ig application is in exceptional circumstances only</b>	<b>Patients</b>	<b>163</b>	<b>92</b>	<b>96</b>	<b>30</b>	<b>26</b>	<b>&lt;20</b>	<b>&lt;20</b>	<b>16</b>
<b>Average Age</b>		<b>43</b>	<b>48</b>	<b>35</b>	<b>46</b>	<b>58</b>	<b>36</b>	<b>47</b>	<b>45</b>	<b>43</b>
<b>Average Weight</b>		<b>73</b>	<b>71</b>	<b>67</b>	<b>70</b>	<b>78</b>	<b>53</b>	<b>60</b>	<b>76</b>	<b>71</b>
<b>Grams</b>		<b>62,392</b>	<b>43,325</b>	<b>35,993</b>	<b>17,198</b>	<b>10,870</b>	<b>530</b>	<b>770</b>	<b>10,700</b>	<b>181,777</b>
<b>Grams/Episode</b>		<b>39</b>	<b>46</b>	<b>25</b>	<b>41</b>	<b>46</b>	<b>66</b>	<b>29</b>	<b>58</b>	<b>37</b>
<b>Grams per 1,000 Population</b>		<b>8</b>	<b>7</b>	<b>7</b>	<b>10</b>	<b>4</b>	<b>1</b>	<b>3</b>	<b>24</b>	<b>7</b>
<b>Use is not supported (previously Chapter 8)</b>										
Diabetic amyotrophy	Patients		<5							<5
	Average Age		80							80
	Average Weight		83							83
	Grams		650							650
	Grams/Episode		33							33
	Grams per 1,000 Population		0							0
Myocarditis in children	Patients	<5								<5
	Average Age	-								-
	Average Weight	3								3
	Grams	8								8
	Grams/Episode	8								8
	Grams per 1,000 Population	0								0
Paraneoplastic cerebellar degeneration	Patients	<5								<5
	Average Age	50								50
	Average Weight	85								85
	Grams	155								155
	Grams/Episode	52								52

OFFICIAL

Specific Condition	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	National	
	0								0	
Paraneoplastic Subacute Sensory Neuropathy	Grams per 1,000 Population								0	
	Patients		<5						<5	
	Average Age		77						77	
	Average Weight		80						80	
	Grams		128						128	
	Grams/Episode		26						26	
	Grams per 1,000 Population		0						0	
Sepsis	Patients	<5	<5	<5		<5			<20	
	Average Age	20	60	-		76			54	
	Average Weight	135	90	3		100			88	
	Grams	270	475	5		200			950	
	Grams/Episode	270	59	5		100			79	
	Grams per 1,000 Population	0	0	0		0			0	
<b>Total where Ig use is not supported</b>	<b>Patients</b>	<b>&lt;5</b>	<b>6</b>	<b>&lt;5</b>	<b>-</b>	<b>&lt;5</b>	<b>-</b>	<b>-</b>	<b>&lt;21</b>	
	<b>Average Age</b>	<b>34</b>	<b>75</b>	<b>-</b>	<b>-</b>	<b>76</b>	<b>-</b>	<b>-</b>	<b>68</b>	
	<b>Average Weight</b>	<b>79</b>	<b>85</b>	<b>3</b>	<b>-</b>	<b>100</b>	<b>-</b>	<b>-</b>	<b>83</b>	
	<b>Grams</b>	<b>433</b>	<b>1,253</b>	<b>5</b>	<b>-</b>	<b>200</b>	<b>-</b>	<b>-</b>	<b>1,890</b>	
	<b>Grams/Episode</b>	<b>87</b>	<b>38</b>	<b>5</b>	<b>-</b>	<b>100</b>	<b>-</b>	<b>-</b>	<b>46</b>	
	<b>Grams per 1,000 Population</b>	<b>0</b>	<b>0</b>	<b>0</b>		<b>0</b>			<b>0</b>	
<b>Total</b>	<b>Patients</b>	<b>7,518</b>	<b>4,824</b>	<b>5,106</b>	<b>1,328</b>	<b>1,161</b>	<b>445</b>	<b>100</b>	<b>427</b>	<b>20,587</b>
	<b>Average Age</b>	<b>61</b>	<b>59</b>	<b>61</b>	<b>57</b>	<b>61</b>	<b>60</b>	<b>48</b>	<b>56</b>	<b>60</b>
	<b>Average Weight</b>	<b>77</b>	<b>77</b>	<b>79</b>	<b>77</b>	<b>77</b>	<b>79</b>	<b>73</b>	<b>78</b>	<b>77</b>
	<b>Grams</b>	<b>2,383,254</b>	<b>1,521,910</b>	<b>1,794,398</b>	<b>476,791</b>	<b>344,825</b>	<b>149,557</b>	<b>27,065</b>	<b>155,590</b>	<b>6,853,389</b>
	<b>Grams/Episode</b>	<b>33</b>	<b>32</b>	<b>24</b>	<b>34</b>	<b>31</b>	<b>32</b>	<b>39</b>	<b>37</b>	<b>30</b>
	<b>Grams per 1,000 Population</b>	<b>295</b>	<b>231</b>	<b>349</b>	<b>268</b>	<b>128</b>	<b>268</b>	<b>109</b>	<b>349</b>	<b>269</b>

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.



## APPENDIX E – SYSTEM SOURCE FOR TABLES AND FIGURES

Table 1: Ig growth for the last 5 years.....	IDMS
Table 1: Ig growth for the last 5 years .....	7
Table 2: Go live dates for BloodSTAR.....	9
Table 3: Grams recorded in the different systems held by the NBA .....	11
Table 4: Percentage change in grams issued compared to previous year over time by state and territory.....	13
Table 5: Issues of domestic Ig compared with imported Ig .....	15
Table 6: Issues of domestic Ig compared with imported Ig, and public versus private Australian Health Providers.....	16
Table 7: Patient numbers by state and territory .....	17
Table 8: Patient numbers and average weight by age range .....	19
Table 9: Ig grams dispensed by criteria category.....	20
Table 10: Ig grams dispensed by Speciality and state and territory for 2019-20 .....	21
Table 11: Patients dispensed Ig by speciality and state and territory for 2019-20 .....	21
Table 12: New patients dispensed Ig by speciality and state and territory for 2019-20.....	22
Table 13: Grams dispensed by states and territories and medical condition for 2019-20.....	23
Table 14: Patients dispensed by SCIg/IVIg, medical conditions and product for 2019-20 .....	24
Table 15: Grams dispensed by SCIg/IVIg, medical conditions and product for 2019-20.....	25
Table 16: Patients dispensed by SCIg medical conditions, and state and territory for 2019-20.....	25
Table 17: Grams dispensed by SCIg medical conditions, and state and territory for 2019-20.....	25
Figure 1: Snapshot .....	All
Figure 2: Per cent dispensed grams by medical condition.....	BloodSTAR
Figure 3: Ten-year trend in issues of Ig.....	IDMS
Figure 4: Ten-year trend in expenditure on Ig .....	IDMS
Figure 5: Ig expenditure as a proportion of the national blood budget.....	IDMS
Figure 6: New and total patients for the last 10 years.....	BloodSTAR
Figure 7: Patient age relative to Australian average.....	BloodSTAR
Figure 8: Grams of Ig dispensed by speciality .....	BloodSTAR
Figure 9: Grams of Ig dispensed by top 10 medical conditions .....	BloodSTAR
Figure 10: NHIg grams issued and grams issued per 1,000 population .....	IDMS
Appendix A: Background.....	All
Appendix B: Acronymns and Glossary .....	All
Appendix C: Conditions Mapping Table.....	BloodSTAR
Appendix D: Dataset of Ig Supply by State/Territory 2019-20.....	BloodSTAR