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Young Australians, illness and education

Report on the national database project

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The Victoria Institute Building Better Learning

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YOUNG AUSTRALIANS, ILLNESS AND EDUCATION

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Final Report

APRIL 2015

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Acknowledgements

Ronald McDonald House Charities (RMHC) has demonstrated unparalleled commitment to improving the educational outcomes of students with chronic illness throughout Australia. The charity has supported 6,000 students recovering from serious health conditions to remain engaged with their education. RMHC provided substantial financial and in-kind support through its Ronald McDonald Learning Program (RMLP). The study was jointly funded through the Victoria University 'Out of Cycle' grant scheme that aims to foster and develop long-term research partnerships. Victoria University and The Victoria Institute co-funded this project with RMHC. The preparation of this report was also supported by the Australian Government's Collaborative Research Network (CRN) program.

The project was conceptualised in 2011 when Tracey Webster, RMLP National Learning Program Manager and Anita Neville, RMLP National Operations and Victorian State Manager discussed the database they had recently established with Julie White. Dr Iris Dumenden, Research Officer, VU helped develop the idea into a proposal. The project was also supported in its development phase by staff at the VU Research Office and The Victoria Institute. Debbie Krapywnyj and Stanley Koh provided valuable practical assistance at the proposal phase. Associate Professor Deborah Zion, Chair of the VU Human Research Ethics Committee assisted with navigation through ethical concerns.

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This final report was prepared with the assistance of Hendrik Jacobs, Communications Officer at The Victoria Institute.

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About

The Victoria Institute

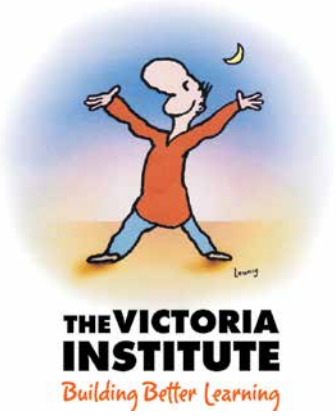
The Victoria Institute was established in 2011 under the leadership of Professor Roger Slee. It is a research-intensive unit focused on impact and influence, particularly in the areas of educational reform and inclusive practices.

Well placed within Victoria University, The Victoria Institute has social justice as a key focus. Our researchers work collaboratively with a range of government departments, policy makers, philanthropic organisations and community groups.

The Victoria Institute operates with the explicit intention of improving educational experiences and outcomes for all.

Our targeted research program aims to build better learning and greater participation and success for students from diverse and disadvantaged backgrounds as well as those who are disengaged or excluded. This includes the group of young people targeted by this particular project, who have significant health conditions that can affect their participation and success in education.

The Victoria Institute is connected with the College of Education and works in association with The Mitchell Institute and the Centre for International Research on Education Systems.



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Abbreviations

ABS — Australian Bureau of Statistics
ARC — Australian Research Council
AIHW — Australian Institute of Health and Welfare
CALD — Culturally and linguistically diverse
EDL — Education Liaison
IEO — Index of education and occupation
IER — Index of economic resources
IRSAD — Index of relative socio-economic advantage and disadvantage
IRSD — Index of relative socio-economic disadvantage
RMLP — Ronald McDonald Learning Program
SEIFA — Socio-economic indexes for areas
SES — Socio-economic status

Executive Summary

Australia's health system faces many challenges related to chronic and complex health conditions. Major advances in biomedicine mean that children and young people are now surviving conditions that would have meant early death just a short time ago. This has major implications for Australia's education systems.

A troubling side effect of this success in medicine is the number of children and young people who manage their chronic health conditions, but who can easily remain overlooked in education. In many ways this is a new frontier for teachers, schools and education systems. Never before have so many students been present in our classrooms, who have survived major health challenges, but who are not yet systematically supported to thrive in education.

This report provides a detailed summary of education, health and demographic information about Australian children and young people who live with significant health conditions. This study closely examined an important national database of 2360 such individuals.

This study is contextualised within recent international literature from the fields of education, medicine, oncology, public health, paediatric nursing, psychology, counselling, psychiatry and social policy. Socio-economic indexes developed by the Australian Bureau of Statistics were employed in the analysis of data.

As Australian government figures are not available about these young people as an educational cohort, the major purpose of this study was to provide an empirical base for policy recommendation and further investigation. An important secondary aim of the study was to contribute to the growing body of evidence about pressing educational issues related to these children and young people. Concern about the education of this group is expected to escalate as this cohort of Australian students continues to expand, due to advances in biomedicine.

Recommendations

1. To systematically identify students enrolled in Australian schools who have health conditions.
2. To identify students with health conditions as a collective educational cohort, rather than individual young people who are isolated medical aberrations.
3. To retrieve and analyse data related to school absence from education system databases for (a) student stays in hospital, (b) students who spend periods of time at home recuperating, and (c) students with patterns of frequent or sporadic absences due to health conditions.
4. To develop and publish government policy and guidelines to explain the legal entitlement to reasonable adjustment for students with health conditions.
5. To provide practical assistance to schools that explain the legal obligations to support students with health conditions.

6. To establish guidelines and procedures for schools regarding assistance for students with health conditions.

7. To establish a comprehensive checklist for use by families, teachers and health professionals that supports clear communication and monitoring of (a) the effects of the student's health condition on their learning, and (b) reasonable adjustment measures.

8. To develop a system to monitor Australian students with health conditions.

9. To use the RMLP database as a quality resource for further research, particularly about students with cancer and their education.

10. To undertake research into the connections between: (a) social determinants of health, (b) Australian SES data, and (c) the education of students with health conditions.

ORIENTATION TO THIS STUDY AND THE REPORT 1

This chapter outlines the context, focus and purpose of this study as well as an overview of each chapter. Background information about the partner organisation, Ronald McDonald Learning Program (RMLP) whose database was investigated in this project is also found here.

1.1 The Research Focus

The primary aim of this study was to develop empirical evidence about young people in Australia with serious and continuing health conditions and their education. Government figures about these young people, as a growing and substantial cohort of students, has not previously been available, making this study significant. A key purpose for undertaking this research was to build evidence to influence Departments of Education and school-level practice in Australia.

This study builds upon the ARC Linkage project (LP0669735), *Keeping Connected: Identity, Social Connection and Education for Young People Living with Chronic Illness* (Yates et al., 2010) on which Julie White was a Chief Investigator. The major component of that study was a longitudinal ethnographic study of the lives of 31 students who lived with serious ongoing health conditions. That study revealed a series of issues these young people face in relation to identity, education and school life, as well as related challenges faced by their families. However as an ethnographic study, the project did not produce larger scale empirical data – of the type that might compel governments to act.

Key contextual understandings underpinning this study:

- The number of young people in Australian schools with serious ongoing health conditions has increased dramatically over the past decade, with significant improvements in medicine leading to substantially increased rates of survival for a range of conditions. This means that many more children attend school and will live well into adulthood.
- Education leads to essential social and economic outcomes for young people and society and is as important for students with health conditions, as it is for others.
- Young people with serious ongoing health conditions (and their parents) frequently face significant communication difficulties with schools.
- Students with serious health conditions can also face difficulties connecting socially at school and bullying has been reported as widespread.
- Government Departments of Education do not monitor these students either individually or as a cohort.
- It is anticipated that these students will not be identified or included in the 2015 Federal Government count of Australian students with disability in education.

- Government Departments of Education have developed policy but only for extreme cases where students cannot attend regular schools.
- Children and young people with health conditions are entitled to 'reasonable adjustment' and support within their schools under national disability legislation in Australia, but knowledge about this in families and within education is low.
- There has been little research about the education of children and young people with serious ongoing health conditions.

The Ronald McDonald Learning Program (RMLP) is a national philanthropic program that provides short-term support for children with serious ongoing health conditions who have been associated with paediatric hospitals and missed significant periods of school. Like many philanthropic programs, the Learning Program developed because no adequate education service existed for this growing number of students. The program provides practical support for young people to return to school and participate in education.

It should be noted here that the majority of Australian students who live with serious health conditions do not participate in this program and are not represented in the RMLP database. However, as figures about ***students*** with health conditions are not available in Australia, this project provides an important starting point for longer-term research that identifies numbers of students in each state and territory with health conditions, existing educational needs and provision as well as gaps and requirements in system and school level educational support.

This report outlines the systematic analysis undertaken of the RMLP database and contextualises the study within the international literature. Demographic information contained in the database has been closely examined. Conclusions, and recommendations have been developed directly from this analysis and from the wider research context.

1.2 The Ronald McDonald Learning Program (RMLP)

From the beginning of the program in NSW in 1998 with 10 students, RMLP currently has 1086 students, and has provided educational support to 6,000 students since 1998. The program currently employs 794 qualified teachers as tutors, with education coordinators in 16 locations around Australia (see Figure 4.12.4). All the Australian states, the Australian Capital Territory and Northern Territory have programs.

The Ronald McDonald Learning Program comprises of several interrelated strands.

1.2.1 Tuition

The core program involves 40 weekly individual tuition sessions with a qualified and experienced teacher, funded and organised by RMLP in negotiation with the child's family and school. The aim of this tuition is to assist students to re-enter school after a period of absence, due to illness or injury. Individual learning plans are developed after psychometric assessment and other services, such as speech and occupational therapy, which are provided free of charge.

RMLP's Tuition Program caters for young people who have missed at least 40 days of school as a result of an acute or chronic illness or trauma. It is provided for young people who are eligible to be enrolled in a mainstream classroom and have experienced illness or trauma. Young people with an intellectual disability

or condition such as Down syndrome or autism, are not eligible for this program as they have other avenues of educational support (Ronald McDonald Learning Program).

1.2.2 Education Coordinators - Communication

A team of education coordinators is employed to assist communication between the young people, parents, program tutors and schools. The education coordinators take initial referrals and enquiries, organise assessments to be undertaken, find a suitable teacher in a child's locality to be the tutor and monitor progress by maintaining communication with tutors, parents and schools.

1.2.3 Education Liaison Between Hospital, Family and School

In response to a clearly identified and urgent need, the RMLP has implemented a new initiative to provide an education liaison service, to assist students with their education after they leave the hospital and before they are able to return to school. This has involved the employment of experienced teachers with significant expertise and basing them in Australian paediatric hospitals. These coordinators undertake the important liaison work between family, school and hospital, that is not undertaken by government funded hospital special schools or education services associated with paediatric hospitals.

1.2.4 Information for Parents

RMLP also provides information for parents including advice about advocacy in schools, important resources and points of contact. This information is provided on the program website and in the form of booklets.

1.2.5 Information for Teachers

Another aspect of the RMLP is the accredited teacher professional development course (EDMed) that introduces teachers to issues related to students with serious health conditions and how curriculum can be modified and adapted to include greater participation of the individual young people in the regular class programs. This professional learning program is regularly conducted free of charge for whole school groups and teams in schools in all Australian states and territories; in government, Catholic and independent sectors. To support this professional learning program, teachers who attend are given a detailed manual. Both components of the EDMed program serve to introduce teachers to issues involved in accommodating these students into classrooms.

The EDMed program is also offered to pre-service teacher education courses in universities via lectures and workshops. This is also provided freely and frequently.

1.3 The RMLP Database

The RMLP database is the source of the data for this research project. It contains individual records for each student accepted either for the Tuition Program or the Education Liaison Program as well as referrals made by parents, health professionals, hospital school teachers, or classroom teachers.

The database is a specifically modified version of Telosa's Exceed software suite, designed for fundraising by non-profit organisations (Telosa Software, 2014). This version of the software was developed for use by Ronald McDonald Houses around the world, and has been further modified for use by Australia's Ronald McDonald Learning Program. RMLP developed the National Information System, with the Exceed database forming a central part of the system, in 2010 (Ronald McDonald Learning Program, 2014). Records were first entered into the database on 26th May 2011.

The database includes information related to students, their families, tutors, other professionals and schools. Standard forms have been used to gather the national information, which is entered into the database. A key form is the student intake form, completed by parents or guardians in conjunction with the Education Coordinator.

When RMLP education coordinators make contact with the parents, tutors, or schools, information about these communications are entered into the database. The database therefore contains both a record of information related to each student and their family and a record of actions relating to the student.

This project looked only at de-identified demographic data relating to students and their families and did not access or analyse data related to the comments or actions of education coordinators, parents, tutors, or students. This was due to the limited permission gained from the University Ethics Committee that raised concerns (see section 1.5).

In addition to student information entered into the database from the student intake forms, some student information had also been entered into the database when a parent or hospital staff member contacted RMLP to establish individual eligibility or make referrals.

For this project, data from the initial phases of the intake process was analysed along with the other student records. Exceptions included student records that had been closed with no evidence of the student ever starting in the program, or where no address details had been entered or there was no evidence of contact with the student, parents or guardians. More details on student records that were excluded from this analysis are provided in section 3.2 Data preparation.

1.4 Research Purpose

The major purpose of this small study was to establish an empirical base to support the continuing development of the larger research agenda regarding school aged children and young people who live with significant health challenges.

During the planning and proposal phases of this study, three overarching research questions were used as a guide for the study.

1. What do children and young people, their parents, teachers and clinicians report about their learning as they transition repeatedly between hospital, home and school?
2. What enables children and young people with chronic illness to succeed in schooling?
3. What factors and processes shape these students' trajectories and what recommendations can be proposed for improved practices?

These questions were deliberately broad to retain the focus on what is known from the literature and from the earlier study (Yates et al., 2010) about the education of this cohort. It was not intended that these questions would be directly answered, but that they would assist the research team to retain focus on the larger research program about education regarding these students. Of specific interest is the extent to which:

- teachers, schools and education systems acknowledge the challenges these students face;
- these students' entitlement to inclusion and participation in school is recognised and supported;

- education systems take responsibility to support and advise schools about implementing Australian legislative requirements regarding 'reasonable adjustment' for these students.

The database at the centre of this project does not contain information about the majority of those Australian children and young people who live with serious health conditions. However, the wider research context that informed the design of this study, particularly the review of recent international literature consistently points to widespread concern about the education of these students.

The RMLP database is significant as it is the first Australian source of national data about this cohort that was developed for ***educational*** purposes. Further it provides empirical evidence about the education of children and young people with health conditions.

1.5 Ethics Approval

Because of the potentially sensitive focus of a study related to Australian children and young people with health challenges, the initial application for approval was submitted to the full Human Research Ethics Committee (HREC) at Victoria University.

The concerns raised by that committee did not relate to the records of the children or their families, but focused on three other concerns:

1. a general negative concern about database research, which it viewed as problematic and likened to 'fishing' exercises;

2. the lack of specificity contained in the initial HREC application and subsequent amendments that related to:

    a. the nature of the contents of the database;

    b. the proposed analytical process;

3. that reports written by teachers contained in the database did not have the informed consent of those teachers for these reports to be used for research purposes; and that retrospective consent could not be obtained.

The lead researcher had not yet established familiarity with the database, beyond a general understanding, in the belief that HREC approval was required prior to access. The second researcher had not yet been appointed to work on the study. Therefore, clear knowledge about the exact contents of the database at the centre of the study was not yet known. This was something of a 'chicken and egg' conundrum, with the lead researcher being unwilling to commit to any particular analytical approach, as it was not yet known what would be the most appropriate.

The teachers who wrote the reports were employees of the Ronald McDonald Learning Program whose reports were prepared while they operated as program tutors. The argument was forwarded that these were not classroom teachers and this data should be included in the study, without success. It was subsequently discovered that the majority of these reports had not been entered into the database, so it turned out to be a moot point.

After several discussions between the lead researcher and the chair of the HREC, the decision was taken to focus the study on demographic information and to clearly locate the study within the research literature.

At first this limitation seemed detrimental to the study, but over time it became a strength. The employment of creativity was required to determine how best the extensive demographic data, contained within the database, could be analysed to produce useful knowledge about children and young people with chronic illness. The early challenge to the study by the HREC had an unintentional effect of ensuring clarity and focus.

1.6 Overview of the Project and Report

There were five key phases of the project:

1. Contextualisation: Research literature from a range of fields was scanned to assist with the contextualisation of this study. (Chapter 2)

2. Defining the scope and data preparation:
Identifying the scope of the study required familiarity with database contents, investigation of analytical options, extraction and preparation of data for analysis (Chapter 3).

3. Investigation of demographic information: Student records in the database were analysed, aggregated and presented in summary form (Chapter 4).

4. Investigation of socio-economic status factors: SES data was examined, using Australian Bureau of Statistics data to investigate how information in the database compares with what is known about factors associated with socio-economic status in Australia (Chapter 5).

5. Analysis workshop: Questions and comments were raised during the intensive two-day analysis workshop that brought together the researchers and key individuals from the RMLP program (See Chapter 3). These discussions prompted further investigation of the data, which has been incorporated into three sections of this report (Chapters 4, 5 and 6).

RESEARCH ABOUT CHILDREN WITH SERIOUS HEALTH CONDITIONS AND EDUCATION

2

This chapter provides an overview of prior research about children with serious health conditions and education.

2.1 Prior Research

2.1.1 Introduction

Thirty years ago, Gortmaker and Sappenfield (1984) anticipated the social changes that would evolve as medical advances dramatically increased the numbers of children surviving and surviving longer with a range of serious and chronic illnesses, including cancer and cystic fibrosis. In this widely cited article, the difficulty and importance of obtaining data about the prevalence of chronic childhood conditions, is raised. Data is important, they argue, to enable thoughtful planning to support these children across diverse communities, especially as any given community will usually have only a small number of children with a particular condition.

Since that publication, a steady stream of academic articles has been published reporting on research projects about children and adolescents with health conditions. Some have focused on: quality of life (Berntsson, Berg, Brydolf, & Hellström, 2007; Koot & Wallander, 2014); psychosocial impacts (Blum 1992; Eiser, 1993; Morad, Kandel, Hyam, & Merrick, 2004; Sawyer, Drew, Yeo, & Britto, 2007) and transition to adulthood (Gortmaker, Perrin, Weitzman, Homer, & Sobol, 1993; Stam, Hartman, Deurloo, Groothoff, & Grootenhuis, 2006). There have also been a small number of research projects directly relating to the education of these children and young people. Most of these relate to children with a particular condition, most commonly cancer, (Donnan, 2011; Katz, Rubinstein, Hubert, & Blew, 1989; Rynard, Chambers, Klinck, & Gray, 1998). And some projects relate to the education of children with health conditions as a group (Bradley-Klug et al., 2013; Clay, Cortina, Harper, Cocco, & Drotar, 2004; Daly, 2013; Fowler, Johnson, & Atkinson, 1985; Kaffenberger, 2006; Mukherjee, Lightfoot, & Sloper, 2000; M. Weitzman, 1986; West, Denzer, Wildman, & Anhalt, 2013; Yates et al., 2010). Research focused on inclusion of children with disabilities in schools also occasionally talks explicitly about children with chronic health conditions (Slee, 2011).

Australian reviews of the literature on children with chronic illness and their education, have noted the lack of research about education for children with a chronic illness or serious ongoing health condition (Jackson, 2012; Shiu, 2001).

Along with investigating the impact of serious health conditions on young people's lives, there are investigations into the effect of socio-economic status (SES) on young people's health (Barr, Britton, Smyth, & Fogarty, 2011; Cassedy et al., 2013; Gortmaker et al., 1993; Heaney et al., 2002; Minnick, Boynton, Ndirangu, & Furth, 2010; Orton, Kendrick, West, & Tata, 2014; Schechter, Shelton, Margolis, & Fitzsimmons, 2001; Stokes, Ashby, & Clapperton, 2001; Wong et al., 2014; Yu et al., 2014), and conversely the impacts of having a child with a serious health condition or disability on the SES of the family (Maguire, 2011; Saunders, 2006). Others have looked at the situation for single parents of children with a serious health condition (Brown et al., 2008; McLachlan, Gilfillan, & Gordon, 2013; White, 2014; Yates et al., 2010), and for the families of children with a serious health condition (Maguire, 2011; Thompson & Raezer, 1998).

2.1.2 Conceptualising the Field

Three key issues that have arisen in conceptualising the field are:

- Defining 'chronic illness' – Who is in? And who is out?
- Counting – how many students are affected; and
- Determining whether students with chronic illness can be considered as a group, rather than separated into medical conditions.

Defining Chronic Illness

A range of terms are used when talking about health conditions, which reflects in part, different conceptualisations and definitions. Terms include: chronic health condition (Ireys, 2001); ongoing health condition (Stein, Bauman, Westbrook, Coupey, & Ireys, 1993); long-term illness (Berntsson et al., 2007); and 'child and adolescent disability' (Morad et al., 2004).

This study has mostly used the term 'health conditions' but 'chronic illness', 'ongoing health conditions', 'serious health conditions', and the like are also used throughout. 'Health conditions' is used to include all groups and all conditions. Because the focus here is on the ***education*** of young people, whether their conditions occur within a defined period, e.g. cancer, or over a lifetime, e.g. cystic fibrosis, or is the result of accident or trauma, is not the central issue.

Ireys (2001) provides a useful categorisation and explanation of two key approaches to conceptualising the boundaries of chronic health conditions; a list-based approach and a non-categorical or functional approach.

A list-based approach would involve determining a list of conditions to be included. Controversy inevitably arises over what conditions should be on the list. Should mild asthma be included, for example? As Ireys (2001) notes, this approach becomes problematic because of the large number (200+) of chronic conditions in childhood and adolescence. Ireys (2001) also raises the important point that some children and young people live for long periods of time with serious ongoing health problems before an accurate diagnosis is made (p. 124). For example, this is common with autoimmune conditions. However, with a list-based approach, they would be excluded.

The non-categorical, generic or functional approach, looks at the 'meaningful consequences of a health condition' (Ireys, 2001, p. 124), rather than the diagnosis or name of the condition. Does the child experience limitations in some way as a result of their condition? Or do they require medical or other health-related services to sustain their functioning capacity?

The non-categorical approach emerges from the:

> *...common clinical observation that a particular diagnosis conveys little about the psychological and social functioning of a child or family … (and) virtually every diagnostic group has a wide variability in health status at any one point in time (Ireys, 2001, pp. 125-126).*

There can be as much variation within a diagnostic group as between different diagnostic groups (Ireys, 2001) which makes it appropriate to consider young people with chronic health conditions as a cohort rather than in terms of separate diagnoses, especially when thinking about their schooling and education. Each child will be affected differently and their situation will vary at different times. The understandings of the non-categorical approach highlight the need to communicate directly with each young person, rather than make assumptions about their lives based on diagnostic categories.

Studies using the non-categorical, generic or functional approach, often determine the amount of time a condition lasts to qualify as chronic. These can range from at least 3 months in duration (Gortmaker et al., 1993; Newacheck & Taylor, 1992) to least 12 months in duration (Morad et al., 2004; Sawyer et al., 2007). The range of terms listed at the start of this section to define chronic illness, indicate another significant area of ambiguity in positioning chronic illness. Should health conditions be differentiated from physical impairments or intellectual disabilities? Some authors make no differentiation using the terms interchangeably (Morad et al., 2004), while the Australian Institute of Health and Welfare (2012), clearly distinguishes between chronic conditions, (e.g. diabetes, cancer and asthma) and disability (e.g. stroke, head injury, physical, intellectual and psychological disabilities).

While the Ronald McDonald Learning Program (RMLP) database does list student health conditions, that organisation's approach to assessing students for program eligibility is based on a categorical or functional approach, rather than a list based approach, as explained in section 1.2 of this report. Records in this database indicate that a wide range of conditions are included.

There is ambiguity about where young people with chronic health conditions fit in education. Teachers of these students are no clearer. A significant factor is the lack of visibility of their condition. As the large Australian study 'Keeping Connected' noted, a key social goal for young people is to fit in to regular school (Yates et al 2010) which can play out in terms of not asking for assistance, nor being offered services and assistance that they might need and for which they are eligible (White et al., 2014). Jackson (2012, p. 544) describes the ambiguity this way:

> *One of the challenges for students with chronic illness is whether or not their condition fits into the definitions of disability… the usual distinctions between diagnoses of illness and disability becomes blurred in this situation, 'because illness implies a particular temporal relation – you get sick, you get well'.*

Chronic illness for adults is a growing and complex specialist field within health and living with chronic illness impacts significantly on individuals in many different ways. The Australian Chronic Illness Alliance (2014), through its definition, assists in conceptualising some of the issues faced by children and young people who have challenging health conditions and are attempting to learn and progress at school. Chronic illness for that organisation is:

> *…an illness that is permanent or lasts a long time. It may get slowly worse over time. It may lead to death, or it may finally go away. It may cause permanent changes to the body. It will certainly affect the person's quality of life.*

Deciding how to *define* a chronic health condition also becomes important, when trying to estimate the numbers of Australian students with such health conditions.

Counting - How Many are Affected?

A range of different studies have offered dramatically different estimates of the number of children affected by chronic health conditions, depending on definitions used, and methods of study used. Gortmaker and Sappenfield (1984), cite five different studies, finding rates from 10% - 20%. And a few years later, Newacheck and Taylor (1992), cite seven different studies finding rates of 5% to over 30%. A more recent Australian study (Sawyer et al., 2007), used the following definition that identified 12% of people younger than 18 years with a chronic condition.

> *Children with special health care needs are those who 'have or are at increased risk for a chronic physical, developmental, behavioural or emotional condition and who also require health and related services of a type or amount beyond that required by children generally'*
>
> (McPherson et al., 1998, cited in Sawyer, 2007, p.1482).

As an exercise, White (2015) employed Sawyer et al.'s (2007) estimate of 12% of the school-aged population (based on American data) who live with chronic health conditions, together with Australian Bureau of Statistics national figures of school enrolment, resulting in the startling figure of 437,462 Australian students that could be in the chronic illness category. While this requires substantial further work, it does point to the paucity of accurate Australian information, particularly within education, and the importance of definition and data in discussions about children and young people with health conditions.

Individual Illnesses?

Many studies examine the impact of particular illnesses for children, families or schools, and these usually emerge from specialist medical units or research fields. There is nevertheless a growing recognition of the usefulness of considering the needs and experiences of children with chronic health conditions and their families, as a group (Gortmaker et al., 1993), and this particularly applies within education.

Ireys (2001) cites Pless and Pinkerton's (1975, p.2) summary of the argument, which is worth reiterating here:

> *The chronicity of the illness and the impact that it has on the child, his [sic] parents, and his siblings, is more significant than the specific character of the disorder, be it diabetes, cerebral palsy, haemophilia, etc. in other words there are certain problems common to all chronic illness over and above particular challenges posed by individual needs.*

As White (forthcoming) points out, the important 'quality of life research' from the field of public health provides valuable assistance for conceptualisation here.

2.1.3 Socio-economic Status

> *People with long-term health conditions are one of the groups most likely to experience deep and persistent disadvantage (McLachlan et al., 2013, p. 136).*

This statement from the Australian government's productivity commission is just one amongst a plethora of studies and reports, showing that disadvantage is connected with poorer health and with disability. In a review of studies about children with disabilities and their families, Morad et al. (2004), noted that in addition to experiencing work uncertainty, sleep disturbance and financial burdens, "Families with a disabled child were also more likely to be living below the poverty line" (Morad et al., 2004).

In recent years a burgeoning body of research has examined connections between low socio-economic status and poor health or disability. Evidencing this trend, the Australian Institute for Health and Welfare (AIHW), examines the impact of socioeconomic factors, as a matter of course, when investigating trends for different illnesses and health conditions (Australian Institute of Health and Welfare, 2012; Australian Institute of Health and Welfare & Australasian Association of Cancer Registries, 2012).

The association of low socio-economic status and poorer health is many faceted. For example:

- Children from families with a lower socio-economic status are more likely to be injured (Orton et al., 2014; Stokes et al., 2001), and more likely to have some health conditions, including congenital heart conditions (Yu et al., 2014) and epilepsy (Heaney et al., 2002).
- Children from families with a lower socio-economic status die earlier and have more complications from various conditions, including cancer (Australian Institute of Health and Welfare, 2012), cystic fibrosis (Barr et al., 2011) and kidney disease (Minnick et al., 2010; Wong et al., 2014).
- There are barriers to access to health services for people from lower socioeconomic status in Australia (Katterl, 2011).
- Families with a child who has a chronic health condition can face additional financial challenges because of this (Morad et al., 2004). Reporting on Australia's *Keeping Connected* project, Yates et al. (2010, p. 52) comment:

> *Parents also report other challenges which emerged in tandem with the young person's ill health. For example, financial pressures as a result of parents (usually mothers) having to limit their hours of paid work in order to cater for the specific and unpredictable needs of their un-well son or daughter.*

There has also been some research into how socio-economic status impacts on education for children and young people with chronic health conditions. Gortmaker et al. (1993) found that the success of young people with chronic health conditions, as they transitioned to adulthood, was more strongly linked to their socio-economic status in childhood, than to their health condition. A recent Australian study (Goldfeld, O'Connor, Quach, Tarasuik, & Kvalsvig, 2014) also notes the importance of SES in relation to serious childhood illness and education.

The social determinants of health are of particular interest:

> *The social determinants of health are the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels. The social determinants of health are mostly responsible for health inequities - the unfair and avoidable differences in health status seen within and between countries. (World Health Organisation, 2013)*

This also applies to education. What are the social determinants of health and education for this cohort of Australian students?

2.1.4 Single Parents

The pressures on families resulting from a child with a chronic health condition are multiplied in a single parent household. Drawing from Yates et al. (2010), a recent poster presentation outlining key concerns, noted:

> *For example, if a parent, generally a mother, needs to be available to take her child to regular and emergency medical appointments, then this might restrict the work she is able to do, and the hours she can work. If she is single parenting, then this might cause significant financial hardship, and the family might need to move to more outer suburban areas, in order to find af-*

fordable accommodation. Moving may require changing schools, or travelling further to school, and also living further from medical care, which in turn increases the time needed to attend medical appointments, (and the time taken off work and school) and the travel expense (White et al., 2014).

While Brown et al. (2008), in a review article, did not find evidence that having a child with a chronic illness, leads to higher rates of divorce, Morad et al. (2004) reports on a large study in the USA, including data from over 5000 children with disabilities and nearly 25,000 without disabilities, which found that "mothers of children with disabilities are more likely to be divorced, separated or never married and unemployed" (p. 24). Clearly more research is needed in this area.

In a unique review of research about single parents of children with a chronic illness, Brown et al. (2008) makes reference to the substantial literature on the association between chronic illness, financial difficulty and low socioeconomic status, and to the literature on the emotional and practical stresses and impacts on these families, which often fall particularly heavily on mothers. Reference is also made in this review to the plentiful research on lone parenting and in particular lone mothering. However these researchers reported being shocked that they did not locate *any* research studies on single parents with a child with a chronic illness or disability, and strongly advocated for the importance of such research. `

2.1.5 Education

Much research about children with chronic health conditions, makes mention of the difficulties associated with education. Some studies investigate school absences that result from chronic illness; school re-entry (especially for young people with cancer), or teacher perceptions. However, there is little research that explicitly investigates education for these children. In particular, very little Australian research exists about this issue.

Fields of research - The research into education and children with chronic health conditions that does exist, originates from a number of fields, including:

- Medical and public health
    - ◊ School absence rates and achievement for children with a chronic illness (Fowler et al., 1985; Newacheck & Taylor, 1992; M. Weitzman, 1986; Michael Weitzman, Walker, & Gortmaker, 1986);
    - ◊ Educational needs of children surviving cancer (Marks, Sheinfeld Gorin, & McAuliffe, 2008).
- Paediatric nursing
    - ◊ School re-entry (Kliebenstein & Broome, 1999)
- Psychology and psychiatry
    - ◊ School psychologists looking at communication between health practitioners and schools (Bradley-Klug et al., 2013);
    - ◊ Education outcomes for particular illnesses (Smith, Patterson, Szabo, Tarazi, & Barakat, 2013);
    - ◊ Teacher's experience and perceptions of children with chronic illness (Clay et al., 2004; West et al., 2013);
    - ◊ School change (Walsh & Chenneville, 2013);
    - ◊ School re-entry (Sexson & Madan-Swain, 1993).

- School counsellors
    - ◊ Supporting children with chronic illness in schools (Kaffenberger, 2006).
- Oncology departments – sometimes multidisciplinary teams
    - ◊ School reintegration programs following cancer treatment (Katz et al., 1989; Katz, Varm, Rubenstein, Blew, & Hubert, 1992; Rynard et al., 1998);
    - ◊ Issues around education for children with cancer (Donnan, 2011).
- Social policy
    - ◊ Inclusion of students with chronic health conditions (Mukherjee et al., 2000);
    - ◊ Listening to young people's views about support in school (Lightfoot, Wright, & Sloper, 1999)
- Children's hospitals
    - ◊ For example looking at educational needs and issues (Shiu, 2001).
- Education
    - ◊ The Keeping Connected project - listening to young people with a chronic illness about identity and education, and to their parents (White, 2014; Yates et al., 2010);
    - ◊ Policy gaps (Ashton & Bailey, 2004; White, 2015);
    - ◊ School change (Thies & McAllister, 2001);
    - ◊ The importance of relationships at school (Dockett, 2004);
    - ◊ Parent and teacher recommendations (Shiu, 2004b);
    - ◊ Inclusion (Jackson, 2012; Shiu, 2004a; Tait, 2012);
    - ◊ Equity in educational outcomes (Shiu, 2008);
    - ◊ Support in schools (St Leger, 2012);
    - ◊ Identifying children's educational needs (Thies, 1999).

Repeated themes that emerge from the literature:

- Communication is mentioned repeatedly (Daly, 2013; Jackson, 2012; White, 2014; Yates et al., 2010). "The issue of communication is prevalent in the literature discussing the special educational needs of students with chronic illness. Over 50% of the documents studied discussed ways that communication contributes, whether positively or negatively, to student engagement and student success in the classroom" (Jackson, 2012, p. 547). Some explore the potential technologies offer for communication (e.g. Wilkie, 2012) while others are enthusiastic about technologies being used in paediatric hospitals (Nisselle, Hanns, Green, & Jones, 2012). However, few contextualise discussion of technology within actual education programs or pay attention to associated curriculum and pedagogical issues.
- The importance of communicating directly with students, and not making assumptions about their needs. For example: assuming that their needs are the same as those of others with the same condition, and recognizing that their needs may change from day to day or month to month (Jackson, 2012; Yates et al., 2010).
- Along with communication, is the idea of collaboration between teachers, parents, students, health professionals, school nurses and school counsellors (Ainscow, 2012; Bradley-Klug et al., 2013; Daly, 2013; West et al., 2013).
- The lack of policy for students with a chronic illness in Australia, leads to inequities (Ashton &

Bailey, 2004; Donnan, 2011; White, 2014, 2015). These students are frequently not recognised within school and system level disability policy and programs, despite legal frameworks indicating otherwise. As the mother of one child with cancer comments: "Unfortunately I feel that my son has slipped through the cracks as he is not labelled with any disability, but really he now has a hidden disability" (Donnan, 2011, p. 15). The lack of policy and guidance also leads to these young people being poorly accommodated in education. The *Keeping Connected* project concluded, "the kinds of support they get from school can seem haphazard or inappropriate" (Yates et al., 2010, p. 142).

- Lack of Australian research (Jackson, 2012; Shiu, 2001). "As an Australian teacher and researcher, a point of interest is that there appears to be little Australian research on the education of students with chronic illness" (Jackson, 2012, p. 549).
- The importance of remaining connected to friends and to school life (Dockett, 2004; Jackson, 2012; Lightfoot et al., 1999; Yates et al., 2010).
- School absence - the levels and impact of the absence (Donnan, 2011; Fowler et al., 1985; Jackson, 2012; Lightfoot et al., 1999; Weitzman, 1986; Weitzman et al., 1986).
- Striving to conform, to fit in with one's peer group, appear 'normal', do normal teenage things (Jackson, 2012; Sawyer et al., 2007; Shiu, 2001; White, 2014; Yates et al., 2010).
- Attending school when not fully well, in pain, suffering treatment side effects (for example cognitive effects can occur several years after treatment for cancer), with low energy, or tiredness (for example asthma can lead to lack of sleep at night), or part-time. It may be important for a variety of reasons for the young person to be in school, including social connection, even when it is difficult for them. However to what extent are they able to learn, be consistent, do homework, focus? And they may have different priorities with different levels of energy. See for example Berland (2009); French (2001); Jackson (2012); Lightfoot et al. (1999); Marks et al. (2008); Shiu (2001) and Yates et al. (2010).
- The lack of visible indicators to alert teachers to student difficulties, e.g., "The effects of pain and fatigue on academic capacity are not always obvious to teachers and other school staff" (Jackson, 2012, p.545) and may even be kept hidden, as students strive to fit in with their peers, and avoid ostracism (Yates et al., 2010).
- Low teacher expectations. On the one hand, teachers may fail to accommodate students when they do not realise the impact of the illness, or are not aware that there is one. Conversely, when teachers are aware of a student's health condition, they may have overly low expectations (Bessell, 2001; White, 2014).
- Bullying is regularly reported as a difficulty.(Lightfoot et al., 1999; Mukherjee et al., 2000; Yates et al., 2010). "Often, the response of peers is to ostracise or ignore the student living with chronic illness" (Jackson, 2012, p. 546).

2.1.6 Previous Research Directly Related to this Project

The Keeping Connected Project and Related Research

This project builds on the *Keeping Connected: Identity, social connection and education for young people living with chronic illness* ARC project. That project produced a research report (Yates et al., 2010) as well as a report for the young people who participated in the project (Walker, Ferguson, & Drew, 2009). A series of articles by the researcher team were included in a special issue of the *International Journal of Inclusive Education*, Volume 18, Issue 3, 2014. Julie White, one of the authors of this report, was also a chief investigator on the *Keeping Connected* project.

SCOPING AND PREPARATION: WORKING WITH THE DATABASE

3

This chapter provides an overview of the methodological literature related to database research and an overview of the data preparation and scoping work undertaken for the *Young Australians, illness and education: National database project*.

3.1 Knowledge Discovery in Databases

Over recent decades databases have been created and used in many areas of service provision including health, social welfare and education. There has also been an increased interest in accessing these databases for research purposes (D'Arcy, Holman, Bass, Rouse, & Hobbs, 1999; Jick et al., 2003; Lane, Stain, Kelly, Lewin, & Higginbotham, 2008; Manns et al., 2001; Merceron & Yacef, 2003; Stanley, Croft, Gibbins, & Read, 1994; Tamblyn, Lavoie, Petrella, & Monette, 1995). While ensuring the validity of data in databases is important for research, this is not straightforward, as outlined below. Researchers have developed a range of approaches to assist with data validity.

The General Practice Research Database in the UK, for example, requires all medical practices to work to guidelines and to undertake ongoing training for data entry. Importantly, medical practices that have not entered data consistently, are excluded from using this research database (Jick et al., 2003).
The process of exploring the contents of databases is sometimes referred to as 'data mining'. However as Fayyad, Piatetsky-Shapiro, and Smyth (1996) explain, it is more useful to consider data mining to be just one step in a larger overall process:

> In our view, *knowledge discovery in databases (KDD)* refers to the overall process of discovering useful knowledge from data, and data mining refers to a particular step in this process … The additional steps in the KDD process, such as data preparation, data selection, data cleaning, incorporation of appropriate prior knowledge, and proper interpretation of the results of mining, are essential to ensure that useful knowledge is derived from the data (p. 39).

Data 'cleaning' refers to the identification of mistakes and anomalies in the data. Keeping data clean is a serious and perennial problem, highlighted in chapter titles of the book, *Exploratory Data Mining and Data Cleaning*, which includes sections titled: "Cautionary tales" and "Taming the data" (Dasu & Johnson, 2003). In their article, "A Taxonomy of Dirty Data", Kim, Choi, Hong, Kim, and Lee (2003), explain in detail the range of ways that dirty data can arise, and what can be done about it. They summarise saying, "broadly, dirty data include missing data, wrong data, and non-standard representations of the same data" (p. 81). These problems can arise in a range of ways including:

- Errors made in entering the data into the database;
- Different people using the same fields differently, or using different ways of representing the same data;
- Through issues resulting from the transfer of data from one computer system to another; and
- As a result of problems that occur during the extraction of data from a database.

As Charles Lawoko, an experienced data analyst consultant explained, "More than 50% of consulting time is usually spent on cleaning data" (personal communication, March 24th, 2014).

The following sections report on the process of discovering knowledge in the RMLP database. Outlined here are methodological decisions made during the project and some of the limitations that were encountered in the research processes.

3.2 Scoping the Project

Following University Ethics Committee approval, a number of decisions were made about what would be analysed and how this analysis would be undertaken. That is the focus of this section. The overall purpose of contributing to knowledge about young people with chronic illness and education in Australia, remained uppermost in the analytic processes of the study that involved:

- Familiarisation with the contents of the database. Involvement of the partners from RMLP was important to understand how the data fields were used, including differences in usage in different state offices, and also to understand anomalies in the data.
- Discussions between the researchers and the partners from RMLP about analysis to be undertaken, including consideration of:
    - ◊ Demographic records;
    - ◊ Connections between database contents and SES;
    - ◊ Investigation of patterns in service delivery;
    - ◊ Information in the records related to parents and other relatives;
- Attention was paid to the ways in which data could be extracted. Due to the structure of the database and the form of the existing extraction programs, it was not possible, within the project time and resource limits, to analyse data related to the patterns of tutoring sessions.
- Investigating different ways of representing and understanding the data, including:
    - ◊ Use of mapping applications to identify student locations based on postcodes from the database;
    - ◊ Use of Australian Bureau of Statistics (ABS) data to produce maps based showing SES in different postcode areas;
    - ◊ Use of ABS data to investigate the relationship between SES and other demographic factors related to young people in the database;
    - ◊ Use of ABS and Australian Institute of Health and Welfare (AIHW) data to compare our results with general Australian population findings where possible.

3.2 Data Preparation

Data preparation refers to the work involved to prepare the data for analysis. While the researchers carried out the main preparatory work, involvement of the partners from RMLP was important to understand how the data had been entered and filed.

Data Extraction Process

The first step was to extract the data for all the students and their family members, which was not a straightforward process.

After a series of test extractions, the data for analysis was extracted from the database on 14th April 2014. The extraction had 8531 records, including students, parents, siblings and other family members.

During data cleaning (see below) some records were removed, leaving 8508 records. Of these, 2360 were student records. Most of the analyses subsequently undertaken were in relation to these student records.

Data Selection, Labelling and Re-coding

As discussed in section, 3.1 Knowledge Discovery in Databases, data preparation and cleaning, can be expected to take more time than the actual data analysis, and that was the case for this project.

Because of the detailed nature of this work, this report provides an indication of the decisions made in preparing the data for analysis.

- Deciding which items may be useful to include for analysis.
    - ◊ There are 240 potential items of data for each student. Some of these data fields are not used for RMLP students, some are occasionally used and some are regularly or always used.
    - ◊ It was important to identify each item correctly and then decide which items may be useful for analysis and therefore clearly labelled, prepared and ‘cleaned’.
    - ◊ Items to be deleted were identified during this process.
- Correct labelling of the data.
    - ◊ When data is extracted from the database into a spreadsheet, the labels for the data are not always clear to those less familiar with the database.
- Converting data into different formats.
    - ◊ The database contains dates of birth, but not ages at program entry. A decision was made to calculate the age of each student at the time of entry of their data into the database, using their date of birth.
    - ◊ Alphanumeric codes are used in the database to identify student participation in different programs and other statuses. For example a student could be identified as an Education Liaison Program student, a Tuition Program student, a student who has moved through both programs, or a deceased student. These codes were allocated labels for ready identification in graphs. The codes were also grouped, so that student records could be identified in different groupings, such as all active students in any program.

- ◊ Alphanumeric codes are used to identify illnesses, periods of time away from school, referral sources, whether students speak English at home and many other issues. Each code was allocated a label for display in graphs. In some instances the decision was made to re-code some variables (like specific conditions) into groups, to allow for a range of different analyses and the development of accessible graphs.

- Parent/Guardian Addresses

  - ◊ Identification was made of student records where only a mother or only a father was listed, or where the parents lived at different addresses.

  - ◊ Other codes were assigned to students in each of these situations, and in a few less common situations, such as a student not living with either parent, to allow for analysis based on these factors.

Data Cleaning

This process required a range of actions, including:

- Identification and correction of as many data entry errors as possible. Prior to 14th April, RMLP staff in each state office were asked to amend these data entry problems in their student records.

  - ◊ Liaison between the researchers and RMLP partners to assist with identification and correction of data entry errors found during test data extractions.

  - ◊ Prior to the final data extraction on 14th April, RMLP staff in each state office were asked to amend data entry problems in their student records.

- Excluding records from the analysis occurred for example:

  - ◊ When student records did not have an address, and/or did not have a parent or guardian entered these records were individually checked. These were mostly initial referrals from hospital-based staff.

  - ◊ Occasional errors were made in data entry, leading to duplicated records or other anomalies. Each of these, when identified through data scanning, was individually checked, and deleted from the master spreadsheet when appropriate.

  - ◊ When student records where closed ('exited'), with no evidence of having entered the Tuition or Education Liaison Program, these student records were deleted from the master spreadsheet.

- Amending suburb, postcode and state:

  - ◊ Where a student address did not have a postcode or state listed, and it had been determined that this was a genuine student record, if the suburb was listed, the postcode and state was entered. If the suburb was not listed, the school address was used to identify the postcode and state.

  - ◊ The database allows for several different addresses (e.g. home, office, postal), for any person in the database including a student, parent or sibling. Different education coordinators developed different ways of using the address fields which, together with data entry errors, led to confusing address records as the student's regular home address was the primary one for analysis. This was resolved through a combination of techniques.

- Correcting spelling errors and consolidating terms used for languages other than English. For example:

- ◊ Spelling errors or spelling a language with or without an initial capital letter identifies them as separate languages.
- ◊ Calling the same language different things identifies them as separate languages, e.g. Filipino and Tagalog.
- ◊ Listing two additional languages. When a student had two additional languages listed, this initially appeared in graphs, as if it was one new language. A new field was created to allow for listing the first and second additional language separately.

- Amending date errors:
  - ◊ When a non-existent date was identified in the database, usually a date of birth, that date had to be removed before the data could be analysed in SPSS, the statistical analysis package.
- Identifying and removing or amending invalid codes entered in various fields.

While these errors seem insignificant in the day-to-day use of the database, they became important when analysis of the data was attempted. Small anomalies such as an upper rather than a lower case letter or an extra space inadvertently added, can lead to items being treated separately during analysis, so accurate data entry is important.

ANALYSING THE RMLP STUDENT RECORDS 4

This chapter presents the first stage of what was learned by analysing the RMLP database records. Where it is important, information is provided about data and data cleaning, prior to presenting each section of analysis.

The Analysis Workshop

Integral to the overall process of data analysis was the two-day workshop conducted at The Victoria Institute at the midpoint of the project. This workshop, attended by the researchers and key national and research personnel from RMLP, provided the opportunity to view, discuss and question the graphs and charts produced at this point from the database. Through this process, RMLP staff were able to offer explanations, anecdotes and possibilities for various patterns in the data, based on extensive knowledge of the sector, their own programs and the database they had created. Many thoughtful and helpful questions were raised that informed the subsequent focus of the study during this workshop.

Chapter 4, together with Chapter 5 that examines SES factors, incorporates a number of those explanations, and addresses a number of the questions posed at that workshop. However, a number of questions are yet to be addressed in future research.

Chapter 4 is organised into the following sections:

1. Student numbers
2. Types of students and relatives in the database
3. How students find out about RMLP - Referral source
4. Health condition
5. Gender and Health condition
6. School absence
7. School absence and Health condition
8. Age and School year level
9. Aboriginal and Torres Strait Islander
10. Language spoken at home
11. School sector
12. Location of students

4.1 Student Numbers

The records in the database were entered over a period of 2.5 years. Records began to be entered into the database from 26th May 2011 with records from Victoria, followed by other RMLP state offices during October 2011. The data analysed for this project was extracted from the database on 14th April 2014.

After deletion of anomalies and cleaning processes, 2360 student records remained. All of these records have a postcode, but some of the records are not complete, so not all analyses include all the students. Where relevant, the number of students used to create each graph, has been included.

The number of students participating in the programs, and who therefore have records in the database, is affected by a number of factors. The key factor relates to levels of funding RMLP receives in each year which impacts on how many Teachers and education coordinators can be employed. This in turn affects how many students can be accepted into the program at any time.

So how does the number of students in the RMLP database, compare with the number of students who live with a chronic health condition in Australia? Using existing data, we can only make estimates and this depends very much on the standpoint taken while making this estimate. As explained in section 2.1.2, 'Conceptualising the Field', the figures used, depend very much on both the definition of chronic health condition employed and whether a categorical or non-categorical approach is employed.

Australian researchers, Sawyer et al. (2007), provide some useful figures, particularly for application within education, which is our main interest here. White's (2015) exercise, using Sawyer et al.'s estimate that at least 12% of students live with chronic illness combined with figures about Australian student enrolments is confronting. Noting the estimate that:

> *...at least 12% of young people live with a chronic health condition (Sawyer et al., 2007, p. 1481), I undertook a simple exercise that resulted in a quite startling figure. Official student enrolment numbers showed that just over three and a half million students (3,545,519) are enrolled in Australian schools (Australian Bureau of Statistics, 2014). Applying Sawyer et al.'s (2007) minimum estimate of 12% to that, a figure of nearly half a million (437,462) school-aged students could be living with serious health challenges in Australia. While this has not been verified, and it should also be noted here that Sawyer et al. used American data for their estimates, interesting questions are nevertheless raised about how many Australian students have chronic illness, how this should be counted and what this means for education (White, 2015, p. 2).*

4.2 Affiliation Codes

Each student record entered into the RMLP database is given an 'affiliation code', to indicate if that person is a student, a parent, sibling, or a cohabiting relative of the student. There are separate affiliation codes for each parent. Mothers are assigned the 'Parent/Guardian' code and the father is assigned the 'Parent/Guardian2' code. When filling out the program entry form, parents have the opportunity to enter details for all people living in the household. All members of the household are frequently included, but this is not always the case. Therefore these records provide an approximation, rather than an accurate record of the families.

Affiliation codes are also used to identify various situations and types of students. For example they can indicate if a student has exited the program or died, or if the student is an Education Liaison (EDL). An EDL student receives advocacy assistance with education through a program employee liaising between medical staff, school and family. An EDL student may also join the RMLP Tuition Program when they are able to return to school.

A student record can be allocated more than one affiliation code. Sometimes this indicates a family circumstance that is not typical, for example where a sibling or other relative acts as guardian. For the purpose of this project, new affiliation codes have been created to describe these uncommon situations.

In the chart below (Figure 4.2.1), the existing codes are indicated in bold typeface, and codes created for this analysis, are indicated in regular typeface.

Recommendation for RMLP: That extra affiliation codes are created, to help clearly indicate some of these less common, but possibly significant records.

Figure 4.2.1 People in the RMLP Database

	Description	Count	Percent
ALP01	**Student/Prospective Student**	1106	13.00%
ALP014	Student with a sibling who is also a student	1	0.01%
ALP02	**Parent/Guardian**	2350	27.62%
ALP03	**Parent/Guardian2**	1567	18.42%
ALP04	**Sibling of Student**	2117	24.88%
ALP041	A sibling who is also a student	3	0.04%
ALP042	A sibling who is a parent/guardian	2	0.02%
ALP043	A sibling who is a parent/ guardian2	1	0.01%
ALP05	**Family Relative of Student**	102	1.20%
ALP053	Other Relative & Parent/Guardian	1	0.01%
ALP06	**Exited student**	1064	12.51%
ALP064	Exited Student with a sibling who is a student also	3	0.04%
ALP07	**RMLP Student & Education Liaison (EDL) student**	62	0.73%
ALP08	**EXITED Parent**	2	0.02%
ALP09	Exited RMLP & EDL student[1]	10	0.12%
EDL01	**Education Liaison (EDL) Student**	48	0.56%

1. At the time of writing this report, the code ALP09 has started being used in the RMLP database to indicate an 'Exited Parent/Guardian2'. However at the time of extracting data from the RMLP database in April 2014, the code ALP09 was not being used, and was added to the data being analysed, as explained above.

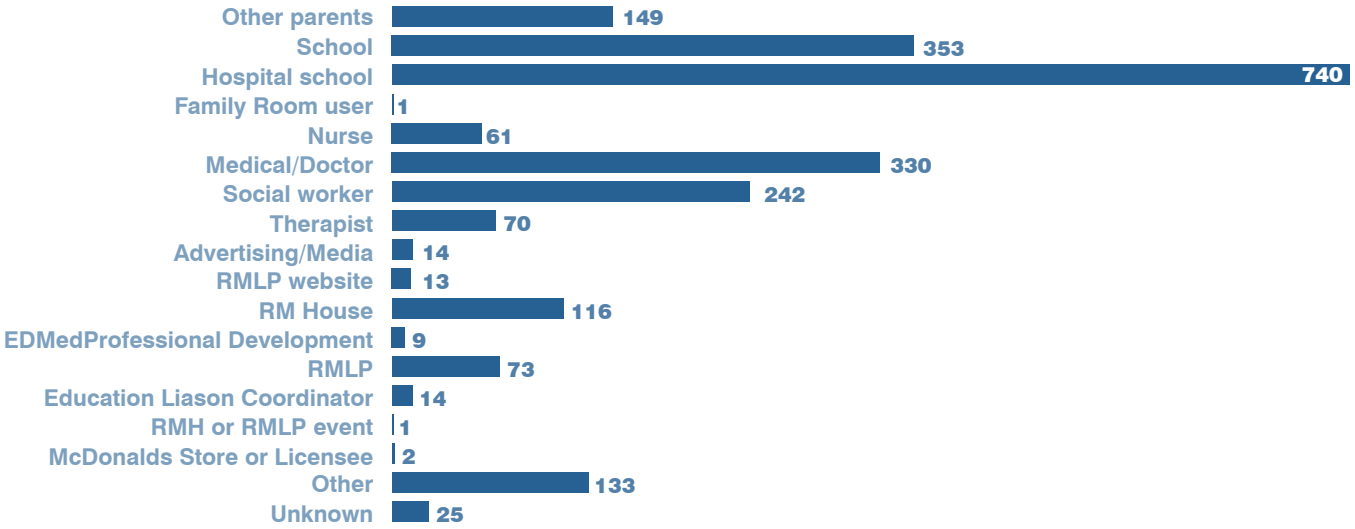
EDL08	**Exited EDL Student**	32	0.38%
EDL09	Deceased EDL Student	5	0.06%
XXX01	**Deceased child (actual)**	**29**	**0.34%**
XXX03	Deceased Parent	3	0.04%
TOTAL		**8508**	**100%**

4.3 Referral to the RMLP Program

Students, parents and guardians find out about RMLP program in a range of ways. A parent or guardian may have found out about the program through other parents or personal contacts and they may contact RMLP directly. Alternatively a hospital staff member, or someone from the student's school, may contact RMLP directly with a referral, and then RMLP staff follow up by contacting the parents. When a student is entered into the database, the source of the referral or the way the parent heard about the program, is entered (see Figure 4.3.1).

Of the 2360 student records analysed for this project, only 14 records did not include a referral source. It is notable that almost one third of the students (32%) found out about the program through a hospital school. The other common sources of finding out about the program are through their own school (15%), a medical professional or doctor (14%), or a social worker (10%). If all the health related sources except for the hospital school, that is 'medical / doctor', 'nurse', 'therapist' and 'social worker' are aggregated, 704 students (30%) enter the RMLP program through these health and medical related sources. If we add to that referrals from the hospital schools, then the figure is 1,444 students (66%) who enter the program through a hospital related source.

Figure 4.3.1 Sources of Program Referral



Considering some of the implications of these figures, especially the high numbers of students referred through hospital sources, several interconnected assumptions prove useful.

Hospital professionals are in regular direct connection with these young people, and so they are more likely to be aware both of their individual situations and of the issues they likely to be facing in general. This would also make them more likely to be interested in knowing about and remembering about the RMLP program.

They are in a position to notice the need, provide information and referral, and understand the importance of helping young people link back to their schools and ongoing education.

There are 9 paediatric hospitals around Australia, as well as hospitals with paediatric wards. This concentration of large numbers of sick children in a small number of hospitals and paediatric wards, means that awareness of the RMLP program that RMLP staff build among health professionals (including allied health) in these hospitals and with teachers in the hospital special schools, can lead to many program referrals.

Referrals from hospitals and hospital schools in particular, are likely to focus on students who spend large amounts of time in hospital. As will be discussed in other sections of this report, not all children who have chronic health conditions spend large amounts of time in hospital.

On the other hand, there are approximately 10,000 schools in Australia (Australian Bureau of Statistics, 2014b). Presumably each school will have only a small number of such children enrolled, who are either (a) attending school while managing their health conditions, (b) recuperating at home or (c) in hospital. Figures about these students are not available. So while RMLP informs school staff through the EDMed program, individual teachers or schools are unlikely to refer many students. RMLP as a philanthropic organisation cannot be expected to reach all the 10,000 Australian schools, but they can (and do) create good connections in the 9 Australian paediatric hospitals and wards around the country.

4.4 Health Condition

This section discusses the relative numbers of student with different health conditions in the database and implications for students and for research.

In the RMLP database health conditions are broken into 42 pre-defined health conditions (Figure 4.4.1). It is worth noting that many children also have secondary serious health issues, resulting from, or concurrent with the primary condition. These secondary conditions may be noted in the database notes, but are not coded within the current system, and have not been analysed for this report.

The most common type of health condition for students in the RMLP database is Leukaemia (418 students, 19.5%). When all types of cancer are taken as a group, this accounts for 44% (949) of the students (Figure 4.4.2).

Of the 2147 student who have a health condition (illness) listed, 396 (18.4%) fall into the ‘other’ category. Managers in the RMLP program explained that one reason for the large number of conditions being listed as ‘other’ is because doctors these days are giving more detailed diagnoses (for instance for type of cancer). Parents list this detailed diagnosis on the registration form, which does not match with any of the pre-defined health conditions in the database, so it gets slotted into ‘other’. Also included within the ‘other’ category, are immune system conditions, which are complex and varied.

After cancer, the next most common health condition in the database is trauma (grouping together general accidents, road accidents and burns) with 100 students. Following this are: epilepsy (89 students); cystic fibrosis (82 students); stroke (59 students); diabetes (48 students); ortho-congenital abnormalities (47 students); and asthma (44 students) (see Figures 4.4.1 & 4.4.2).

Figure 4.4.1 Student's Reported Primary Health Condition

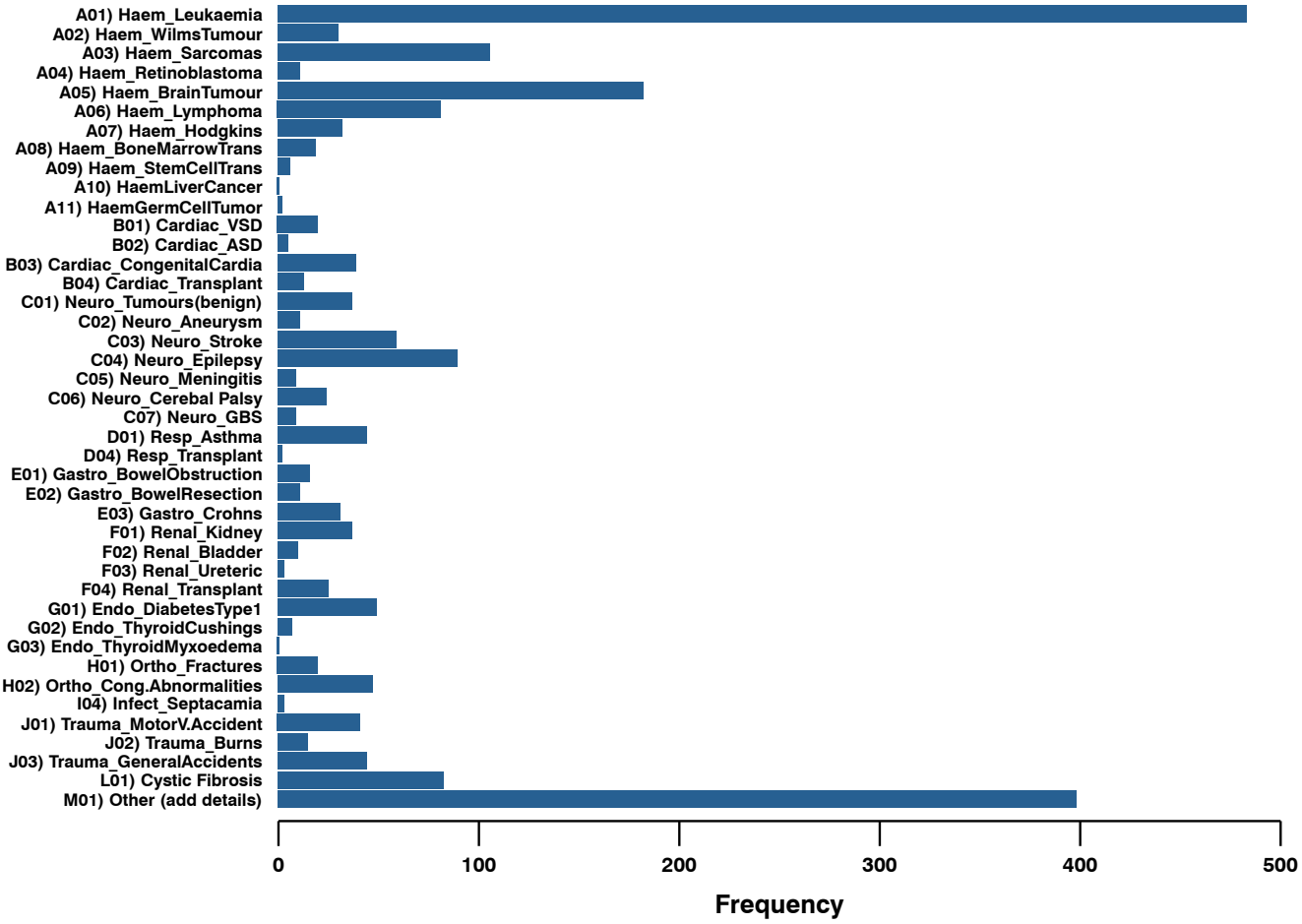
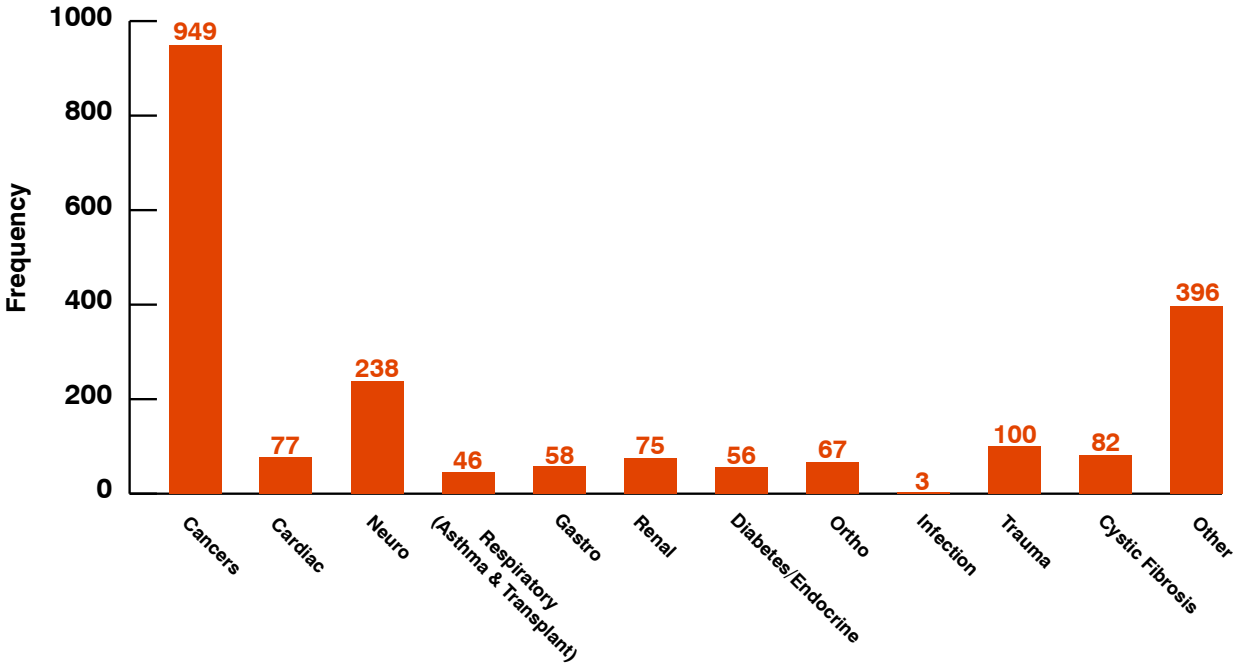


Figure 4.4.2 Student's Reported Primary Health Condition – Grouped



The proportion of children with different health conditions in the RMLP database does not indicate the proportion of children who have these conditions in the general population. Cancer, for example, is very uncommon among children in the Australian population, with a rate of 14 new cases per 100,000 children diagnosed each year, or 0.014% (Australian Institute of Health and Welfare, 2012). However database records indicate that 44% of the students in the RMLP programs have cancer.

On the other hand asthma is the most frequently reported long-term health condition; affecting 10%[2] of children aged 9 – 14 years (Australian Institute of Health and Welfare, 2012, p. 17). And cystic fibrosis, while uncommon, is still much more common than childhood cancer, with an incidence of about 1 in 2800, 0.036% of births in Australia (Bell et al., 2011). The database records indicate that students with asthma make up only 2% of its students and 3.8% of its students have cystic fibrosis.

The surprisingly high proportion of RMLP students with cancer, compared to asthma and cystic fibrosis, could be explained in a number of ways. Although cancer is very uncommon, it is very likely to involve extended hospital stays (Donnan, 2011) as well as long periods of recuperation at home. Asthma, on the other hand, is very common in Australia but rarely leads to significant periods of hospitalisation or extended school absence. Similarly, cystic fibrosis, while much more common than cancer, does not lead to extended stays in hospital beyond regular tune-ups. Nor does it usually involve long periods of school absence.

One might then be tempted to conclude that while the RMLP database does not indicate the proportions of children who have different health conditions in the general population, it might be indicative of the proportion of children who have different health conditions which impact significantly on their schooling. However this apparently simple explanation is problematic, and other complexities must be considered.

- Donnan (2011), in her report of a project funded by RMLP, notes that in a survey of 80 parents of Australian school children with cancer, 80% of these students had spent over 10 weeks and up to 2 years in hospital, with 45.6% of them spending over 6 months in hospital. Might it be that children with cancer tend to spend longer in hospital than children with some other health conditions, and are therefore more likely to come to the notice of the hospital school educators, who are a key source of RMLP referrals (see section 1.3)?
- Students with asthma or cystic fibrosis (as well as many other health conditions) could be absent from school for shorter periods of time, but with regularity over a long period (even over the entire 13 years of schooling) and so are easily overlooked.
- The Asthma Australia website reports that: “Asthma is a leading cause of absenteeism in school students, which in severe cases can cause them to fall behind in their work” (Asthma Australia). This finding is supported by studies on childhood asthma and school attendance cited in French (2001).
- As discussed in section 4.3, it appears likely that children whose health conditions impact on their schooling without extended stays in hospital, are less likely to be referred to RMLP, and their needs for accommodation with education, remain more invisible.

These issues require further investigation. Students with serious health conditions are often overlooked within their schools (White, 2014) and education departments do not monitor the progress of these students.

2. French (2001, p. 241), cites studies that found rates of 16 - 17% for childhood asthma in Australia.

And while children with cancer should, of course, receive excellent care, there are other health conditions that are overlooked, particularly in terms of education, and which are under-represented in the RMLP database.

RMLP Students with Cancer

The database contains records for at least 61% of school children diagnosed with cancer each year in Australia. This was calculated in the following way. The records in the database cover the three years from 2011 - 2013[3]. The table below (Figure 4.4.3) shows the Australian population for children aged 5-17 during those three years and then calculates that roughly 1544 children would have been diagnosed with cancer during that period. That is, 0.014% of the population in each year.

The RMLP database includes 949 children with cancer. This is 61% of the estimated 1544 children with cancer who could be in the database. Given that the RMLP database records examined for this project actually include less than 3 years of data, this makes the figure of 61% of the children with cancer, a conservative estimate.

Figure 4.4.3 Estimated Number of Children 5-17 Diagnosed with Cancer, 2011-2013

Year	Australian population of children aged 5 -17 years	Estimated number of children diagnosed with cancer aged 5 - 17 (0.014%)
2011	3,636,474	509
2012	3,675,013	515
2013	3,715,377	520
		1544

This figure of 61% (or more) is a substantial percentage of the children with cancer, which provides credibility for using the RMLP database for research into children with cancer and their education. It is important however, to also pay attention to the remaining and diverse 39%. Further research into the range of other illness and health conditions, would assist in building a clearer picture of those Australian children and young people that miss school in different ways.

4.5 Gender and Health Condition

There are slightly more males than females in the program (see Figure 4.5.1). ABS figures show that for every 100 girls born in Australia, 105 boys are born (Australian Bureau of Statistics, 2010, 2013a). However by the age of 30, the same number of males as females exist, because from conception onwards, males are more likely to die than females (Kraemer, 2000). The Australian Bureau of Statistics reports that:

> *Over the last two decades or so, the mortality rate for infant boys was consistently higher than that for infant girls, although both declined. Between 1991 and 2010, the male infant mortality rate decreased from 7.9 to 4.8 deaths per 1,000 live births, while the female infant mortality rate decreased from 6.3 to 3.4 deaths (Australian Bureau of Statistics, 2012d).*

3. In fact just over 2.5 years is probably a better estimate, because the data used in this report was extracted on 14th April 2014, and students started being entered into the database only gradually during 2011. On May 26th 2011 the first student records were entered, these students were from Victoria where the database was trialled first. No other states entered student records until 4th October 2011.

A likely explanation for there being slightly more males than females in the program would be the combination of more males being born, and males being more susceptible to various illness and accidents than females (Australian Bureau of Statistics, 2012d; Kraemer, 2000).

Figure 4.5.1 Student Gender

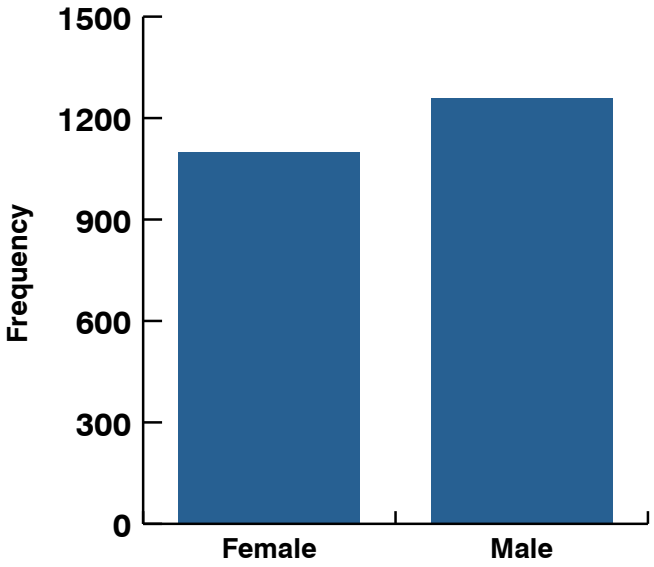


Figure 4.5.2 (on the following page) shows the number of students with different health conditions, by gender. For many, but not all conditions, boys are represented in higher numbers. For example it is not surprising, that there are more boys with fractures and various sorts of trauma, such as burns or motor vehicle accidents. The noticeable gender difference for leukaemia (and several other forms of cancer) mirrors findings for childhood cancer from the UK (Cancer Research UK, 2014) (see Figures 4.5.3 and 4.5.4). Strikingly, there are more girls in the program with cystic fibrosis than boys (Figure 4.5.2). The literature confirms that while equal number of males and females are born with cystic fibrosis, and while survival rates have increased dramatically, in many countries including Australia, girls still become sicker with cystic fibrosis, and die earlier than boys (Reid et al., 2011; Verma, Bush, & Buchdahl, 2005). So, data from the RMLP database mirrors what is known, in respect of gender and these types of health conditions, showing that a reasonably representative group entered the program.

Figure 4.5.2 Student Health Conditions and Gender

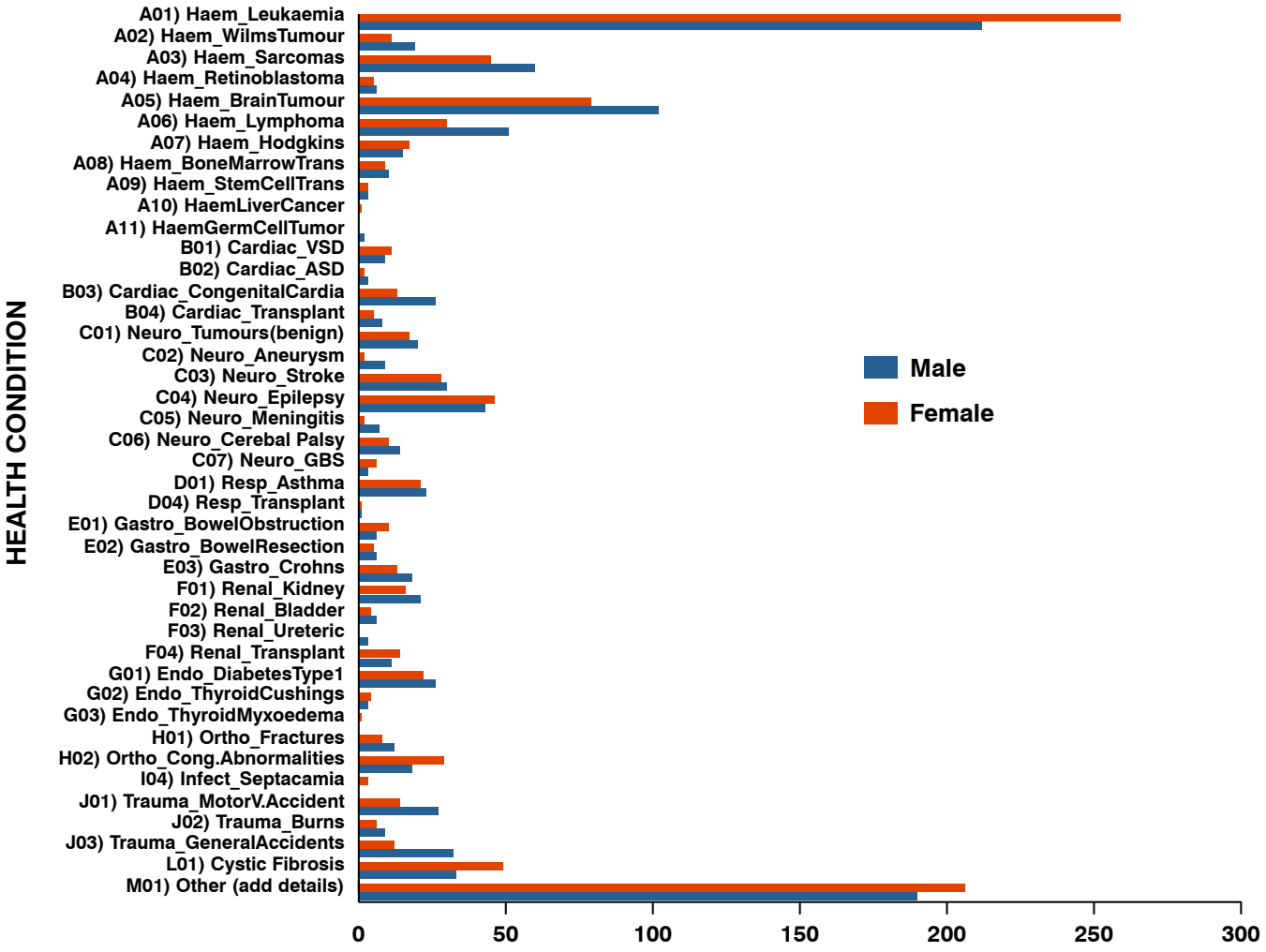


Figure 4.5.3 Students with Cancer and Gender

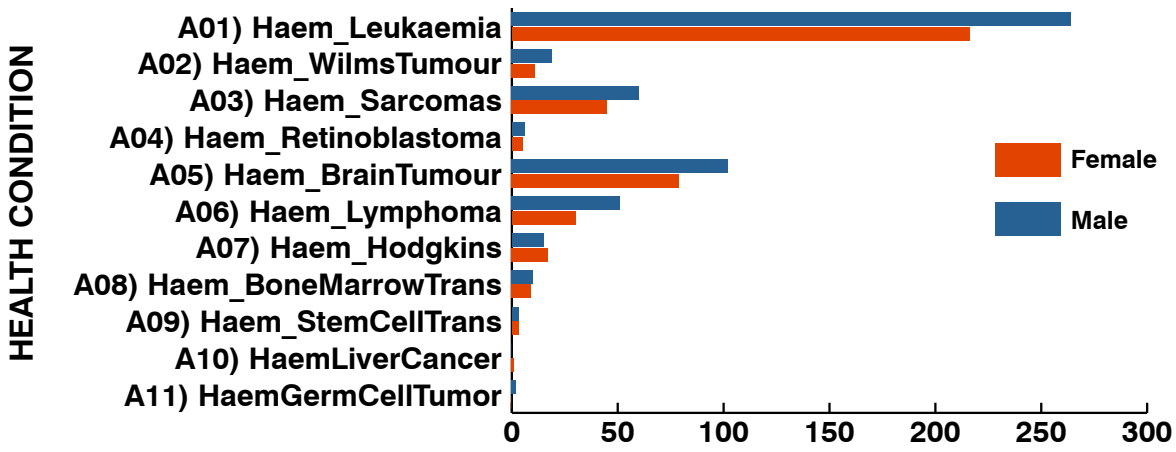
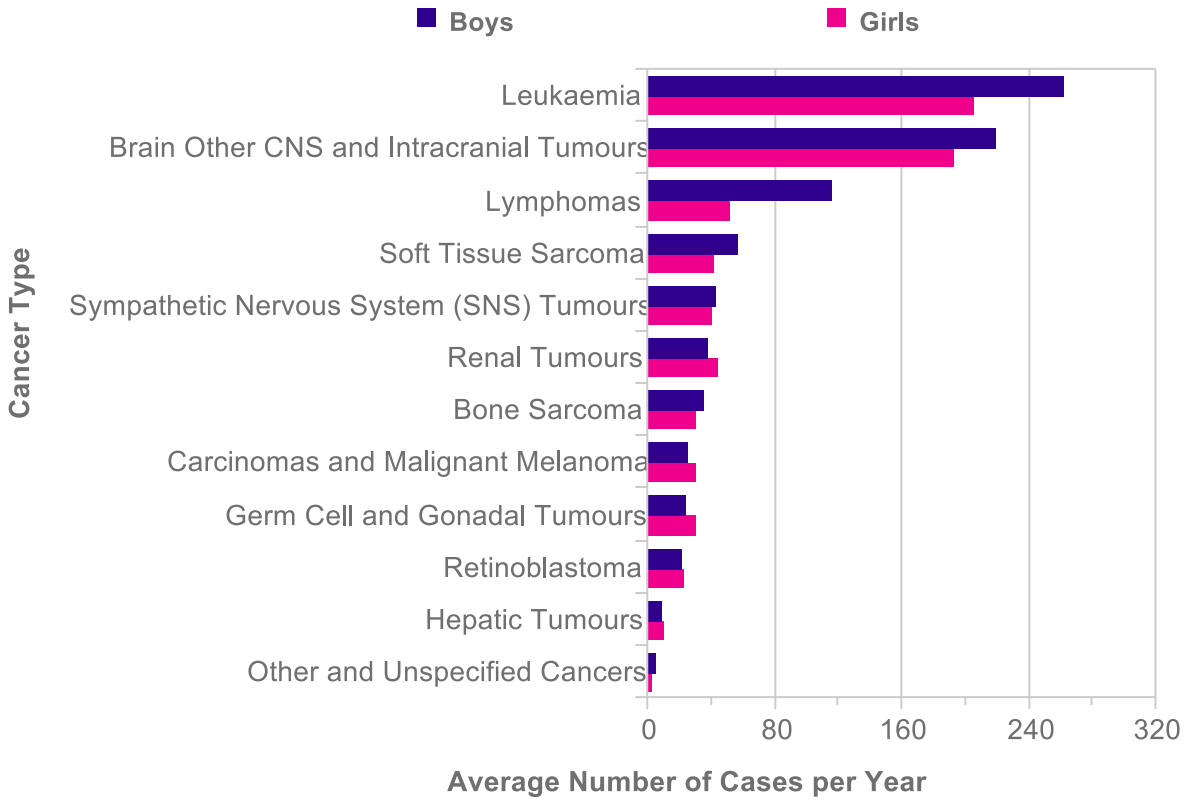


Figure 4.5.4 Average Number of New Cases Diagnosed per Year, Children (0-14), Great Britain (Cancer Research UK, 2014)



4.6 School Absence

Of the 2360 student records in the RMLP database used for this analysis, 1885 have listed the amount of school they missed due to their health condition. The remaining 475 students do have not the amount of missed school listed for a combination of reasons[4].

Three quarters of the 1885 database student records that include amount of missed school, indicate absences of more than a term[5] (Figure 4.6.1). The majority (63%) of students in the database missed school over a period of up to one year, with a significant minority seeking help after missing school over much longer periods (Figure 4.6.2)[6].

4. Some education coordinators did not enter these details into the database from the intake form, some parents did not provide these details on the intake form, and some students have been entered into the database, but RMLP has not yet received the intake forms (which includes information about missed school), from the parent/s or guardian/s.
5. An Australian school term is generally 8 - 10 weeks in length.
6. A smaller number of students are included in Figure 4.6.2, compared with Figure 4.6.1, because not all parents included information about the period

Figure 4.6.1 Amount of School RMLP Students have Missed (at time of entry to RMLP)

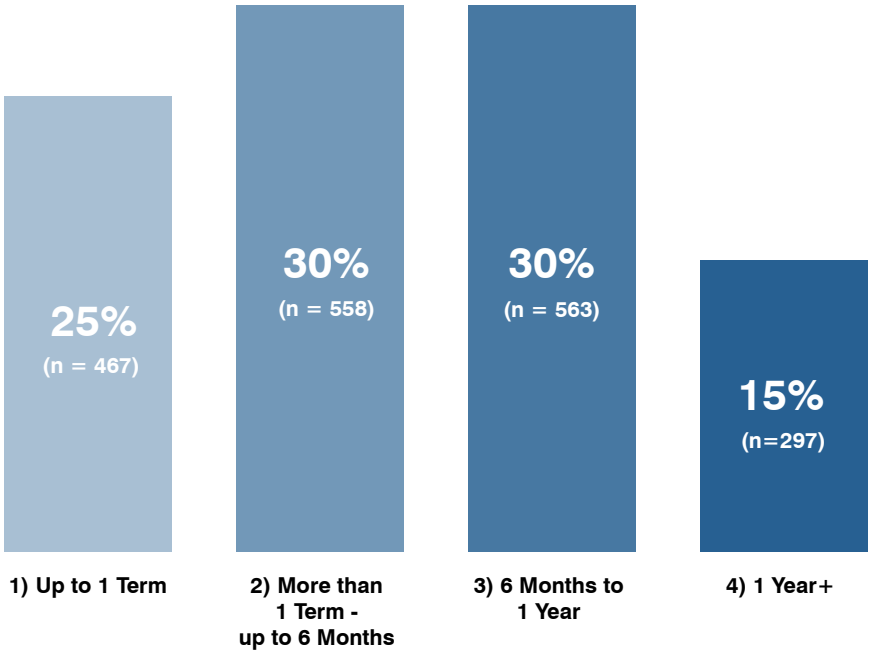
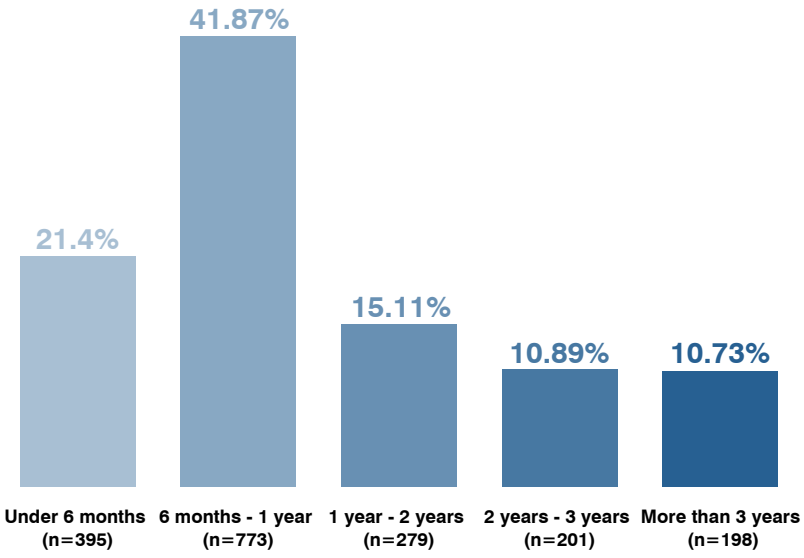


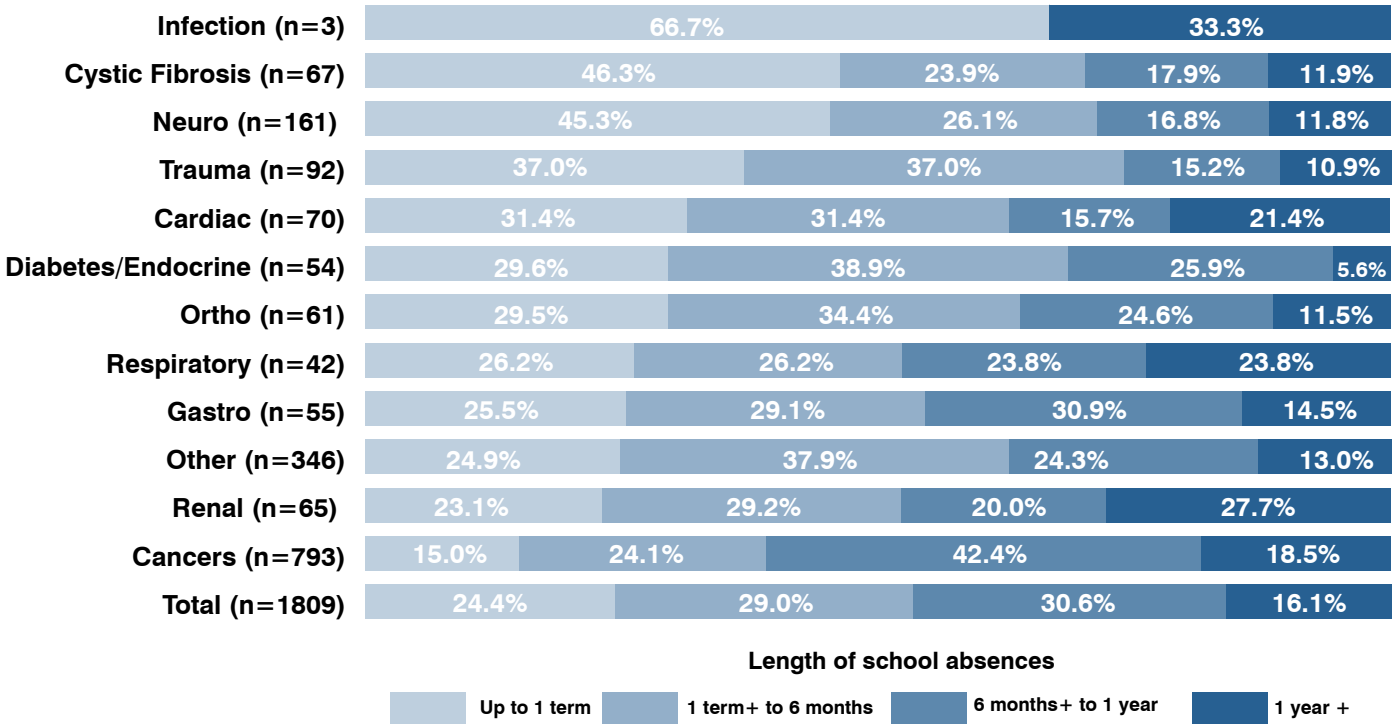
Figure 4.6.2 Over What Period of Time was School Missed



4.7 School Absence and Health Condition

While the amounts of school missed, are significant for all students in the RMLP program, students with some health conditions are likely to miss more school than others (Figure 4.7.1). For instance 26% of students with trauma missed over 6 months of school, while 61% of students with cancer missed over 6 months of school. Students with renal conditions are most likely to miss over one year of school (28%), while students with cystic fibrosis, are most likely to miss up to one term of school (46%).

Figure 4.7.1 Amount of Missed School and Health Condition



Looking at the length of time over which school was missed for different health conditions (Figure 4.7.1), together with the amounts of school missed for different health conditions (Figure 4.7.1) reveals differences in the patterns of missing school.

For example, 81.5% of students with cancer missed up to one year of school and 63.3% of them missed that school, over a period of a year or less. This means most students with cancer who missed one year or less of school, did it within that year, while 18.2% of students with cancer who missed up to 1 year of school, did it over a period of longer than a year.

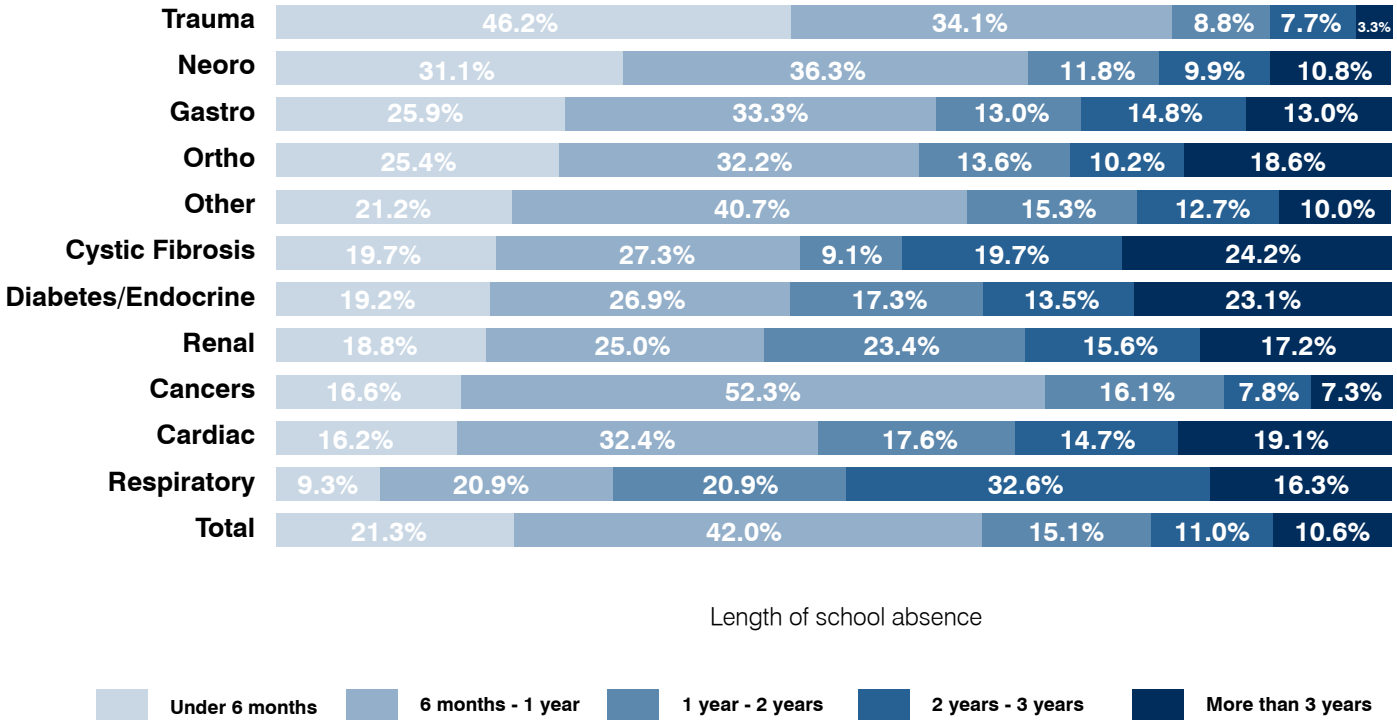
However, database records for students with cystic fibrosis show a very different pattern. 70.2% of students with cystic fibrosis missed up to 6 months of school, but only 19.7% of these students missed that school in less than 6 months, and 43.9% these students missed school over a period of 2 or more years. So, it appears that students with cystic fibrosis are more likely to miss school in smaller spread out periods of time[7].

Respiratory conditions (mainly asthma) show a similar pattern. 52.4% of students with respiratory conditions miss up to 6 months of school, while only 30.2% of students with respiratory conditions miss that school over a period of up to 6 months, and 48.9% of students with respiratory conditions miss school over a period of 2 or more years, before seeking assistance from the RMLP.

7. Cystic fibrosis is a lifelong condition. Regular periods in hospital for 'tune-ups' occur for many students. If this is required several times a year, this would mean shorter blocks of time when students are absent from school for their entire school career.

As discussed in section 1.4, students with illnesses that tend to lead to a series of shorter periods of absence spread over a long period, might be more likely to remain relatively invisible. That is, teachers, schools and health professionals are less likely to notice that these students have a debilitating illness that interferes with their learning (and are less likely to refer them to a program such as RMLP), compared to students with a condition such as cancer or a trauma (motor accident, burn or other accident), who tend to miss a long period of school during one year or less.

Figure 4.7.2 Over What Period of Time was the School Missed and Health Condition



4.8 Age and School Year Level

The age and school year level charts (Figures 4.8.1 and 4.8.2), show a relatively even spread of students in RMLP across year levels, with fewer students in pre-school and prep/kindergarten[8] and in Year 12.

8. In some Australian states (ACT, NSW & WA), the first year of school (age 5) is known as kindergarten and the years from age 3-4 as pre-school. While in other states (NT, QLD, TAS, VIC, SA) the first year of school is known as Prep or Foundation, and the earlier years as kindergarten.

Figure 4.8.1 Age at Entry to RMLP

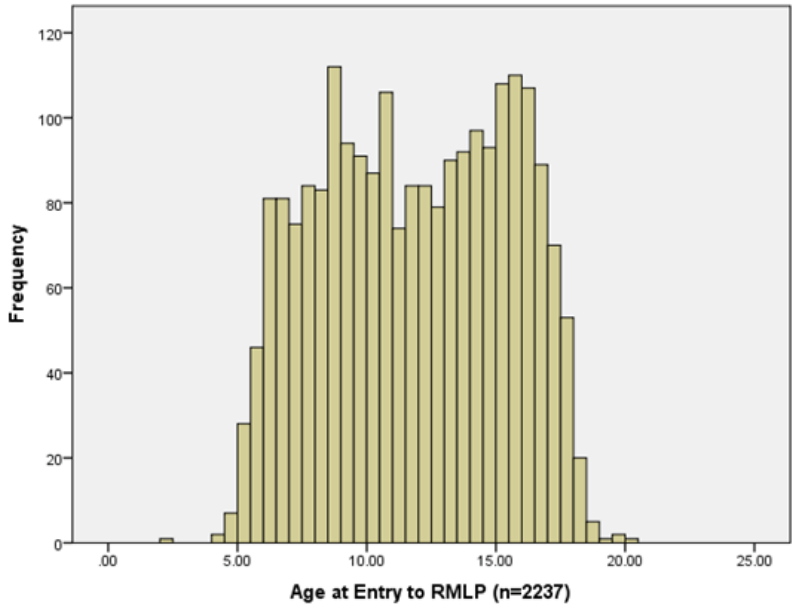
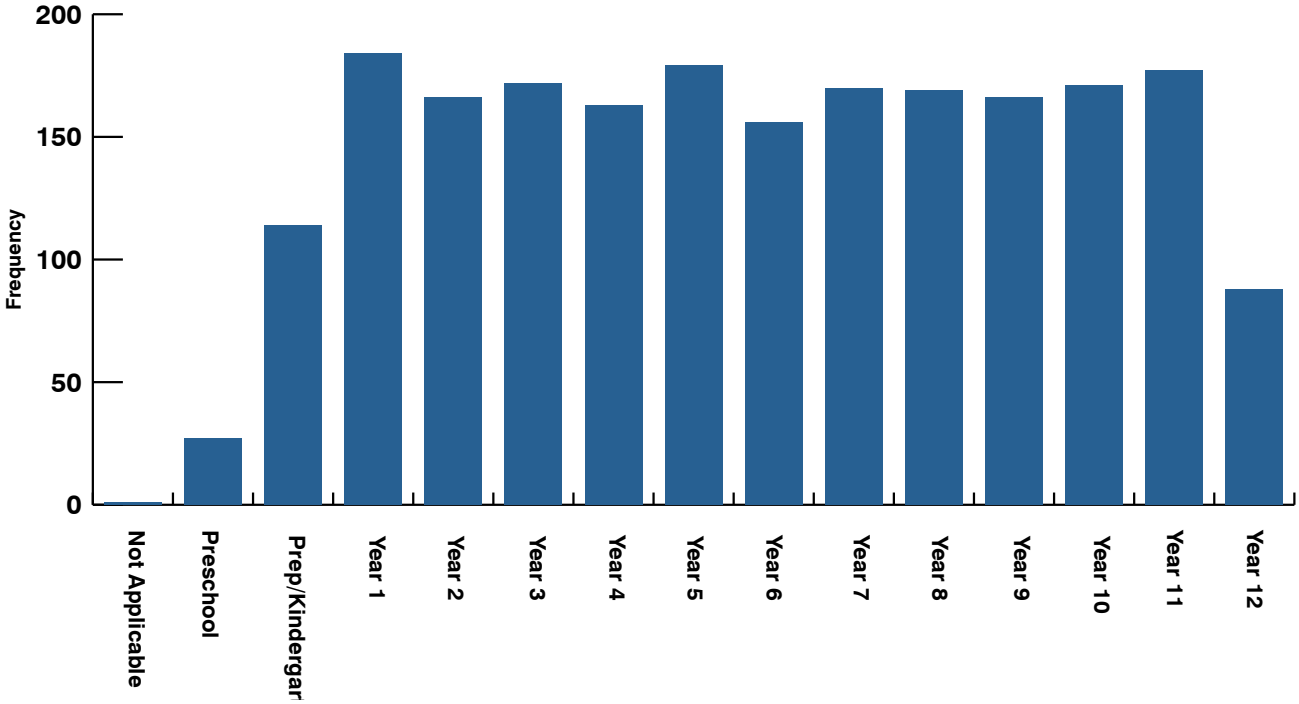


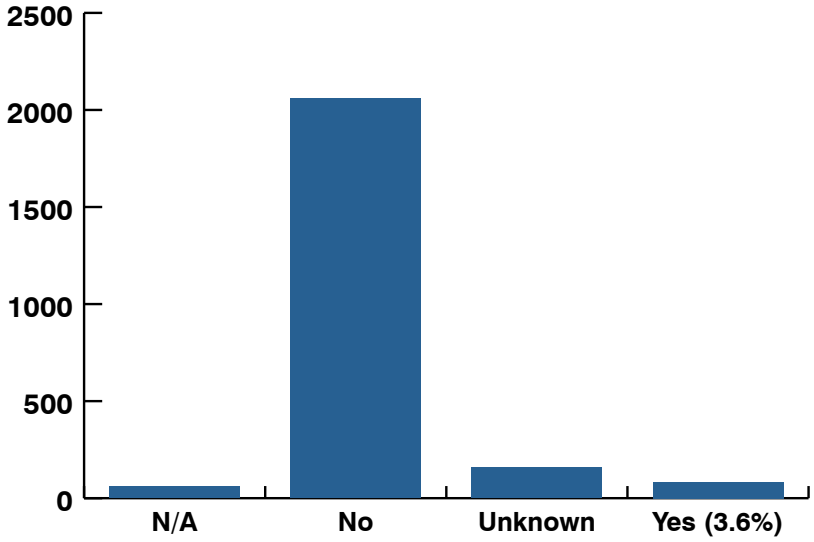
Figure 4.8.2 School Year Level at Entry to RMLP



4.9 Aboriginal and Torres Strait Islander

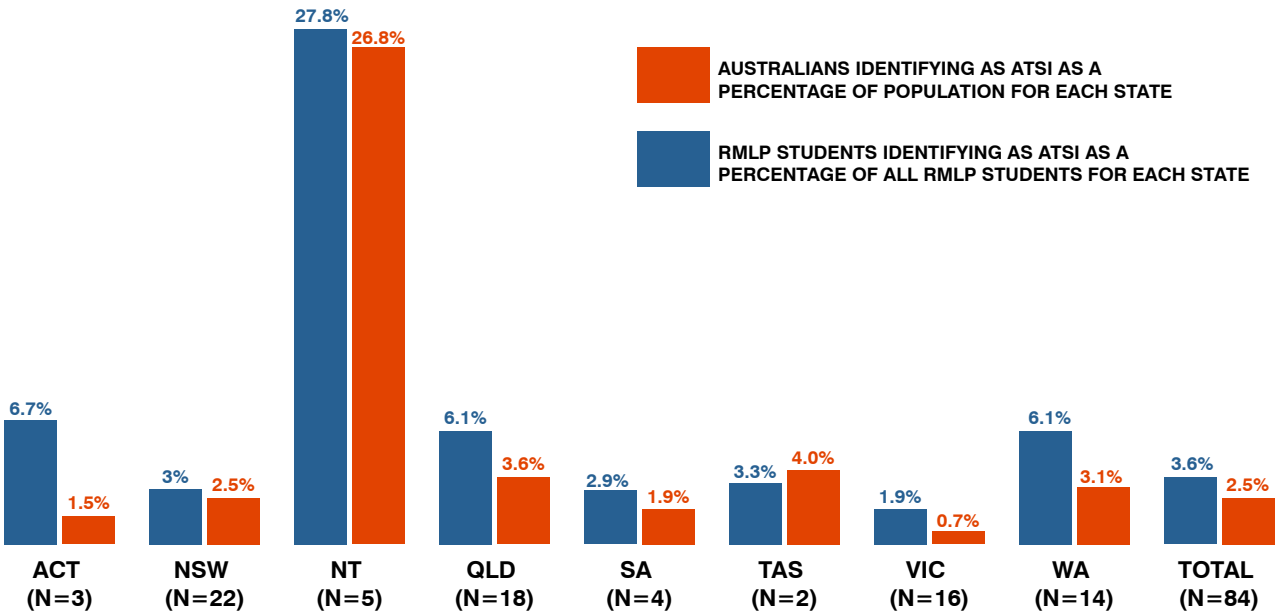
Of the 2360 students in the RMLP database, 84, or 3.6% identified as Aboriginal or Torres Strait Islander (ATSI) (Figure 4.9.1). This is a slightly higher than the 2.5% of people identifying as ATSI in Australian census figures from 2011 (Australian Bureau of Statistics, 2012a).

Figure 4.9.1 Students Who Identify as Aboriginal or Torres Strait Islander



In most Australian states, the percentage of ATSI students in the RMLP program is slightly higher than in the general population (Australian Bureau of Statistics, 2012a), (see Figure 4.9.2). While the numbers of students are small, so one would not want to draw conclusions based on this, nonetheless, it is possible that these higher numbers are linked to the higher rates of ill health and accidents among Aboriginal and Torres Strait Islander people, including young people, compared to the general population in Australia (Australian Institute of Health and Welfare, 2011, pp. 80-88).

Figure 4.9.2 RMLP Students and Australian Population Identifying as ATSI in Each Australian State



(n=the number of RMLP students in each state)

4.10 Language Other than English at Home

Just over 10% (240) of the students have listed on their intake forms, that they speak a language other than, or in addition to English at home. Of those students, the majority (221) speak another language in addition to English. Only 19 students (0.8%) have stated that they speak only another language (Figure 4.10.1). In the Australian 2011 census, 19% of people reported speaking a language other than English at home, and 2% didn't speak English at all (Australian Bureau of Statistics, 2012c).

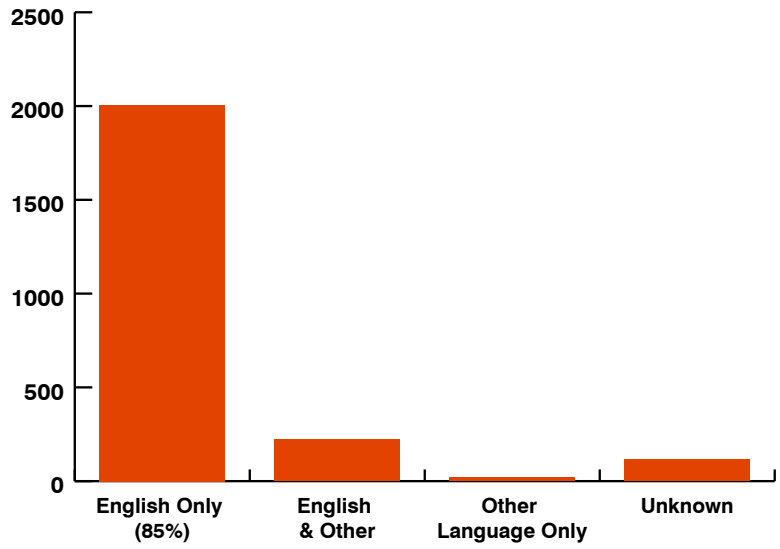
There are various possible explanations for the lower percentage of people speaking a language other than English at home in the RMLP database, than in the general Australian population. Firstly it is possible that some people who speak a language in addition to English at home, have not answered this question on the RMLP intake form, perhaps because they speak English well. Secondly, much research suggests systematic differences in seeking professional help among different cultural groups. "For example, people from Asian and Asian American cultural contexts are less willing to seek out professional help than those from European American contexts" (Mojaverian, Kim, & Hashimoto, 2013, p. 1).

It is notable, that among Australians who speak another language at home, Mandarin is the most commonly spoken language (Australian Bureau of Statistics, 2012c), but among RMLP students, Mandarin is the 11th most commonly spoken language[9]. This does suggest that cultural factors, as outlined by Mojaverian et al. (2013), may well be at work here.

Thirdly, people who are more recent migrants or refugees (from non-English speaking backgrounds) may be less likely to access resources like the RMLP programs because of a range of barriers to accessing services associated with being a newcomer, see for example Asanin and Wilson (2008).

This issue of access to the RMLP programs by people who speak languages other than English at home, is worthy of further exploration.

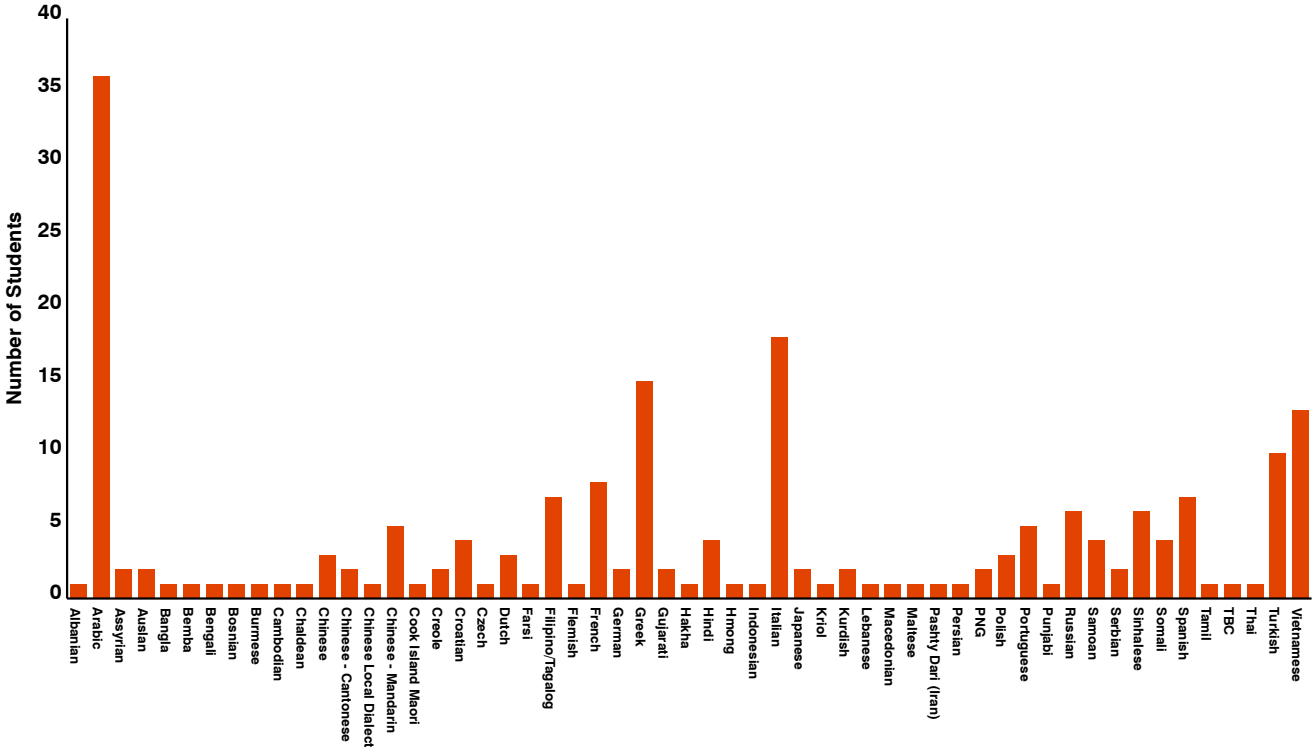
Figure 4.10.1 Language Spoken at Home



9. Alternatively, if the 3 students who simply listed 'Chinese', rather than Mandarin or Cantonese, speak Mandarin, Mandarin would be the 6th most common language.

Of the 240 students who list speaking a language other than English, 207 identify the language. Those 207 students list a total of 55 different languages spoken (Figure 4.10.2), with a few families also listing a second additional language (for example, French & Swahili). For the purposes of this report, just the first language listed has been shown. Interestingly, by far the most common language in the RMLP program was Arabic (spoken by 36 students). In Australia as a whole, Arabic is the third most commonly spoken language at home, after Mandarin and Italian (Australian Bureau of Statistics, 2012c).

Figure 4.10.2 Languages Spoken at Home Other than English



4.11 School Sector

Data for the type of school students attend was readily accessible for 550 of the students in the RMLP database. These figures showed that 64% of RMLP students attend a Government school (Figure 4.11.1), which is very similar to the figure of 65% of students attending a government school in Australia overall (Australian Bureau of Statistics, 2013b) (Figure 4.11.2).

That RMLP has drawn slightly more students from Catholic schools (27%) than attend Catholic schools in Australia (21%) (Australian Bureau of Statistics, 2013b), might be explained by a number of factors. For example, perhaps there are differences in the way Catholic schools operate in relation to students with serious health conditions, or perhaps connections with the Catholic education sector, of personnel from the RMLP program, have lead to more education and information sessions with people in Catholic schools.

There are fewer students in the RMLP program from Independent schools (10%), compared with 14% of Australian students attending an Independent school (Figures 4.11.1 & 4.11.2). This might also be explained in a number of ways. Because independent schools are better resourced, it may be that these students are more likely to receive adequate support through their school. Or perhaps parents of students

at independent schools being more likely to have the resources, including cultural capital, may seek private tutoring support for their children.

Figure 4.11.1 School Sector for RMLP Students

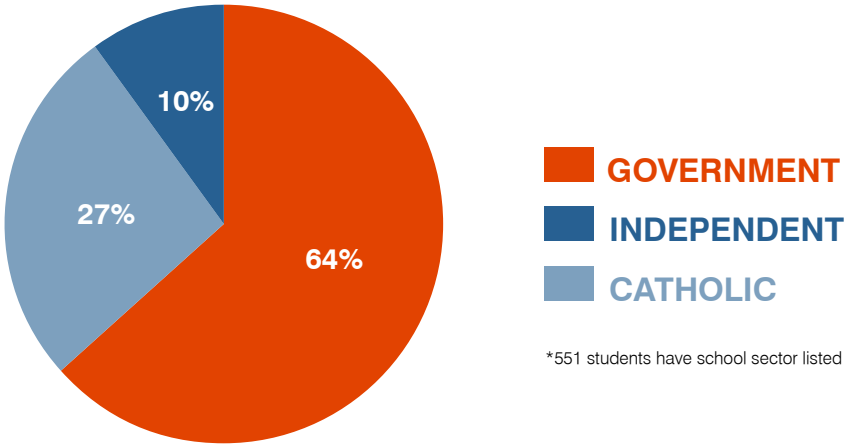
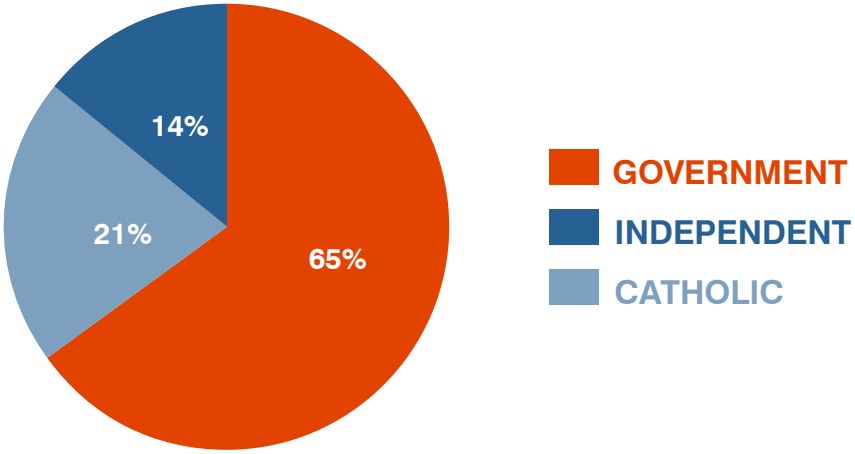


Figure 4.11.2 School Sector for All Australian Children in School[10]



4.12 Location of Students

The maps and charts in this section, showing the location of students, are based on the data about student postcodes[11].

Students in the RMLP database are located, as one would expect, around major cities and along the eastern seaboard, where the majority of Australia's population lives. The following map and chart provides an overview of where students in the database are located around Australia. (See Figure 4.12.1 & 4.12.2).

10. Figures from ABS (Australian Bureau of Statistics, 2013b)
11. See section 3.2 for more details about student addresses.

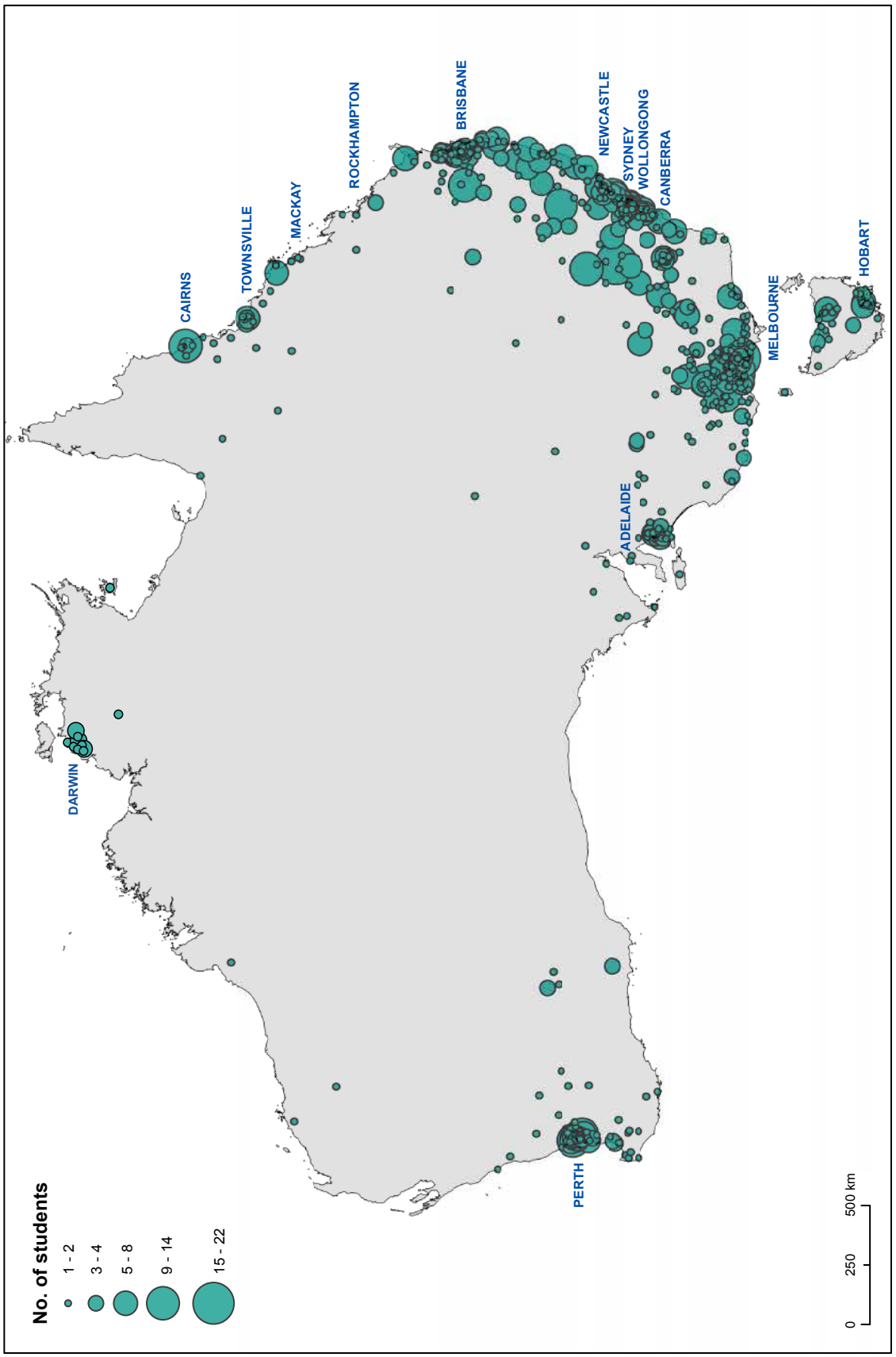


Figure 4.12.1 Map of All RMLP Students in Australia

Figure 4.12.2 shows how many students are located in each state. The number of students in each state roughly follows the relative populations of each state, as can be seen in Figure 4.12.3, which shows the percentage of RMLP students in each state compared with the percentage of the Australian population in each state. It is noticeable that the state of Victoria has a much higher percentage of RMLP students, and the state of Queensland a much lower percentage, compared to their relative populations. These figures are influenced by a number of factors, which are outlined in the following paragraphs and figures.

Figure 4.12.2 Number of RMLP Students in Each State

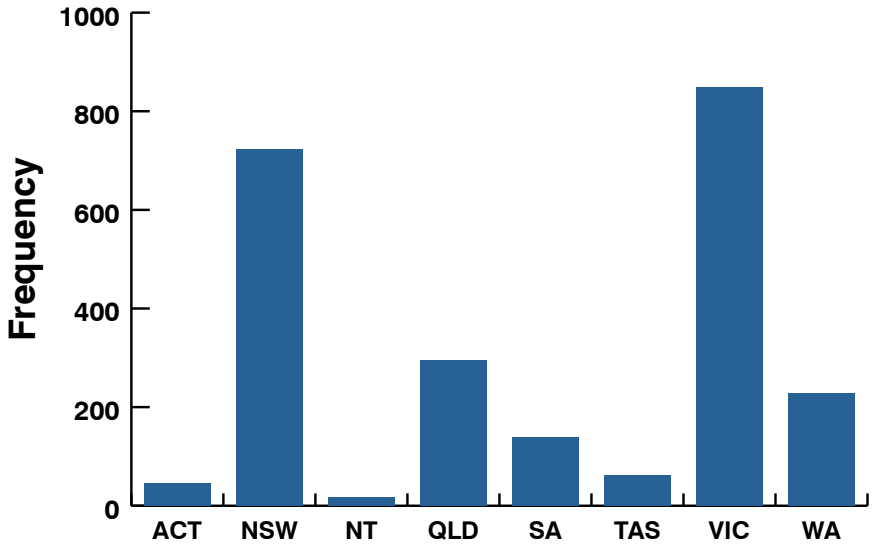
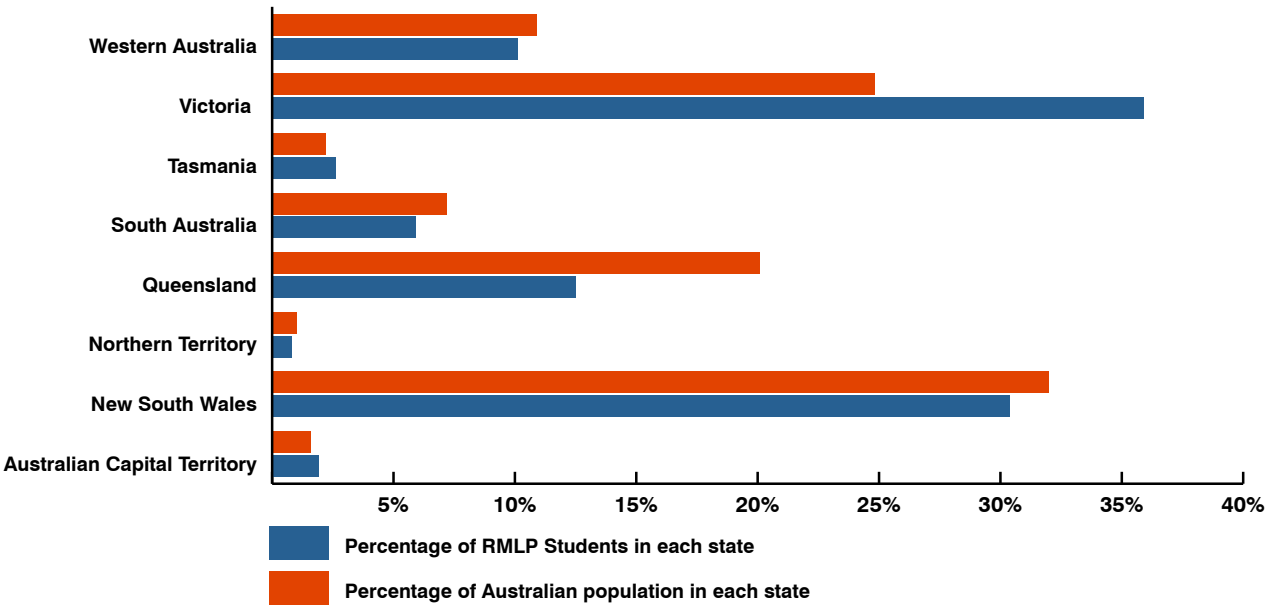


Figure 4.12.3 Percentage of RMLP Students in Each State, Compared with Percentage of Australian Population in Each State



One of the factors that can influence the location of RMLP students is the location of education coordinators (Figure 4.12.4).

Figure 4.12.4 Location of RMLP Education Coordinators

City / Suburb	State
Adelaide	SA
Perth	WA
Darwin	NT
Townsville	North QLD
Herston (Brisbane)	QLD
Coffs Harbour (Korora)	NSW
Newcastle	NSW
Westmead (Sydney – outer)	NSW
Randwick (Sydney)	NSW
Wollongong (Austinmer)	NSW
Albury/Wodonga	NSW
Canberra	ACT
Hobart	TAS
Epping	VIC
Monash (Melbourne - outer)	VIC
Parkville (Melbourne)	VIC

Discussion with Program Managers and education coordinators revealed a number of factors that could have influenced the location of RMLP students. These factors include:

- More referrals from schools where there is someone, such as a teacher, welfare coordinator or psychologist who is familiar with the RMLP program:
    - ◊ For example, in Victoria the EDMed professional development program for teachers, started in the suburbs of Narre Warren, Pakenham, Cranbourne and Berwick, and these areas have a particularly large number of students. While this is a growth area of outer Melbourne, the numbers are still significantly large. Similarly there have been a number of EDMed presentations at a large P-12 school in South Morang, which boosted the number of students referred to RMLP (see Figures 4.12.5 & 4.12.6).
- Referrals result from relationships that education coordinators and managers build within children's hospitals, including with nursing staff, medical or allied health staff. For example in Melbourne, education coordinators have built strong relationships with staff at Monash Medical Centre, Northern Hospital, Royal Children's Educational Institute and Royal Children's Hospital.
- The focus of the program in different areas. For example in NSW the program has had more of a regional focus, with education coordinators in regional centres such as Orange, Coffs Harbour and Newcastle, while in Victoria the program has had a metropolitan focus, with nearly all education coordinators located in Melbourne (see Figures 4.12.4, 4.12.6 & 4.12.7). The state of Victoria now has

an Education Coordinator located in the country town of Wodonga, and the state of NSW now has a coordinator located in Randwick (inner Sydney).

- Some postcode areas, particularly outer suburban areas, are larger and have higher population numbers. For example around Melbourne it is noticeable that a number of newer outer suburban areas have more students on RMLP programs (See Figure 4.12.6). This could be due in part to the larger size of the postcode areas and having higher populations than inner suburban postcode areas. For example the outer suburb of Narre Warren had a population of 27,172 in June 2013, while the inner suburb of Fitzroy had a little over a third of that population with 10,826 people (Australian Bureau of Statistics, 2013g). It may also reflect these areas having larger numbers of young families. For example children under 15 years of age, make up 19% of Australia's population overall (Australian Bureau of Statistics, 2014a), but 21.2% of the population in Narre Warren (Australian Bureau of Statistics, 2013g).

- Conversely it is noticeable that in inner-Melbourne and inner-Sydney suburbs, there are many postcode areas with no students, or only one student (see Figures 4.12.6 & 4.12.8). There are various possible explanations:

    - ◊ The ABS reports that two of the areas with the lowest percentage of children under 15 years of age in Australia in 2013 were Sydney City & Inner South (10%) and Melbourne Inner (12%) (Australian Bureau of Statistics, 2014a). Some individual suburbs have even lower numbers of children, for example, in the inner Melbourne suburb of Fitzroy 5.1% of its population is under 15, and in the inner Sydney suburb of Surry Hills 5.4% of the population is under 15 years old, while the outer Melbourne area of Narre Warren has 21.2% and the region of Orange 21.8% of its population under 15 years old (Australian Bureau of Statistics, 2013f, 2013g).

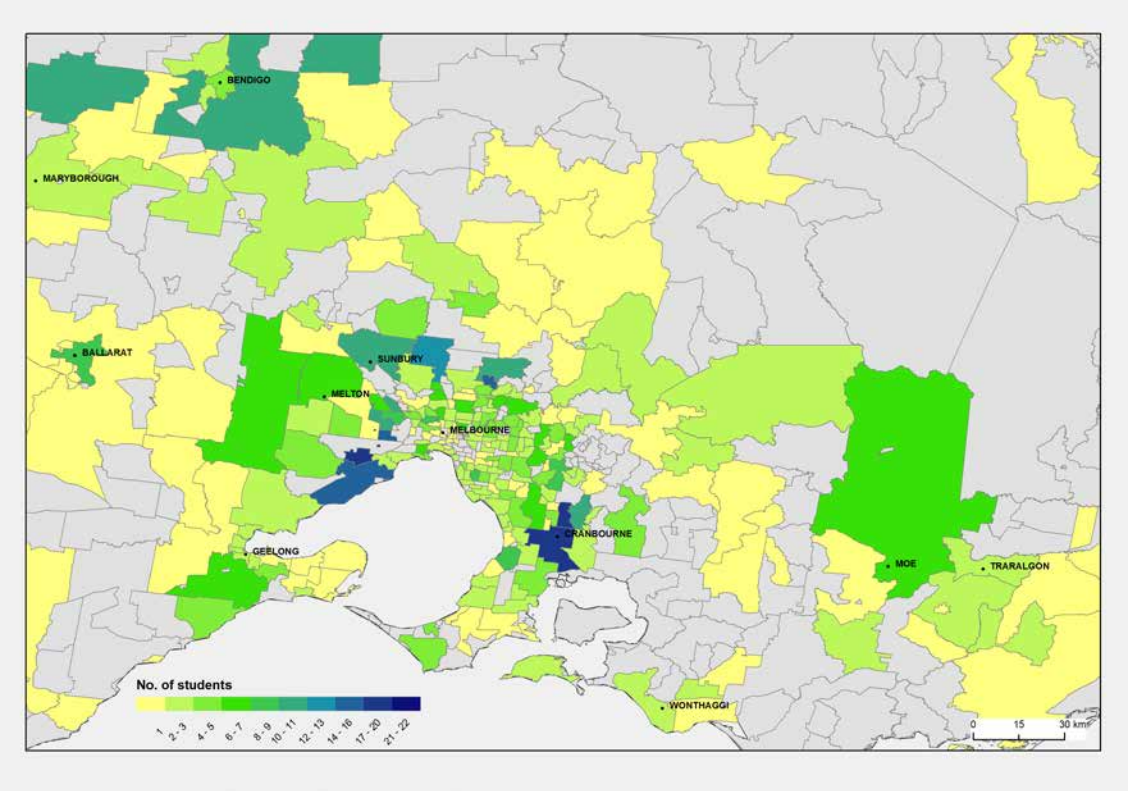
    - ◊ It is also possible that many families living in these areas have more resources, including financial, educational and other forms of cultural capital, so they employ private tutors and other forms of support, rather than draw on a program such as those offered by RMLP. This fits with the discussion in the previous section, that proportionally fewer students who attend independent schools use the RMLP program. However, RMLP staff also noted that significant numbers of well-resourced families do access the program. This fits with the observations of social researchers, such as Lareau (2011), that middleclass parents are typically much more equipped to access resources for their children.

    - ◊ It is also worth mentioning that within this database Victoria has a higher incidence of students at least in part, because of trialling entry into the database first. For a period of time the only records entered in the database came from Victoria, leading to overall greater numbers compared to other states.

Figure 4.12.5 Postcode areas with 10 or more students

Postcode	Suburb Name	Number of Students	IRSAD[12]
2800	Orange, NSW	22	5
3805	Narre Warren, VIC	20	7
3029	Hoppers Crossing, VIC	19	6
3977	Cranbourne	18	5
3030	Werribee & Point Cook, VIC	16	7
3752	South Morang, VIC	14	8
2340	Tamworth, NSW	13	4
3064	Craigieburn & Roxburgh Park, VIC	12	4
4870	Cairns, QLD	12	5
6110	Gosnells, WA	12	6
2830	Dubbo, NSW	11	4
3023	Caroline Springs & Deer Park, VIC	11	6
3429	Sunbury, VIC	11	7
3806	Berwick, VIC	11	9
6027	Joondalup & others, WA	11	9
2259	Wyong & others, Central Coast, NSW	10	4
2560	Campbelltown, NSW	10	4
3038	Taylors Lakes, VIC	10	7
3551	Bendigo, VIC	10	8
3754	Mernda & Doreen, VIC	10	9

Figure 4.12.6 Location of Students in the Melbourne Region – by Postcode Area



12. The IRSAD is the Index of Relative Socio-economic Advantage and Disadvantage. This score is a measure of relative socio-economic status developed by the ABS, it is more fully explained in chapter 5 of this report. Scores can range from 1 (an area of very low SES) to 10 (an area of very high SES).

Figure 4.12.7 Location of Students in the Wider Sydney Region – by Postcode Area.

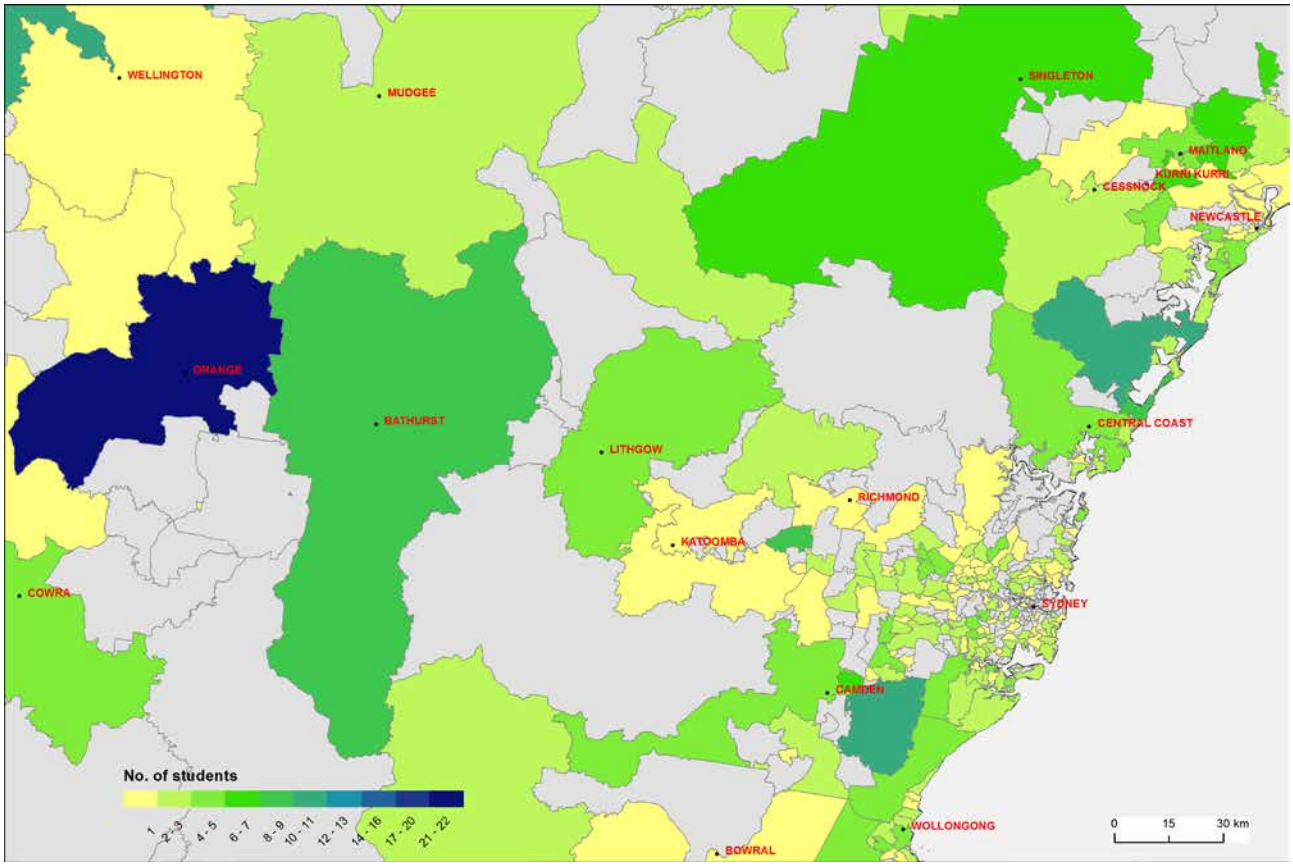
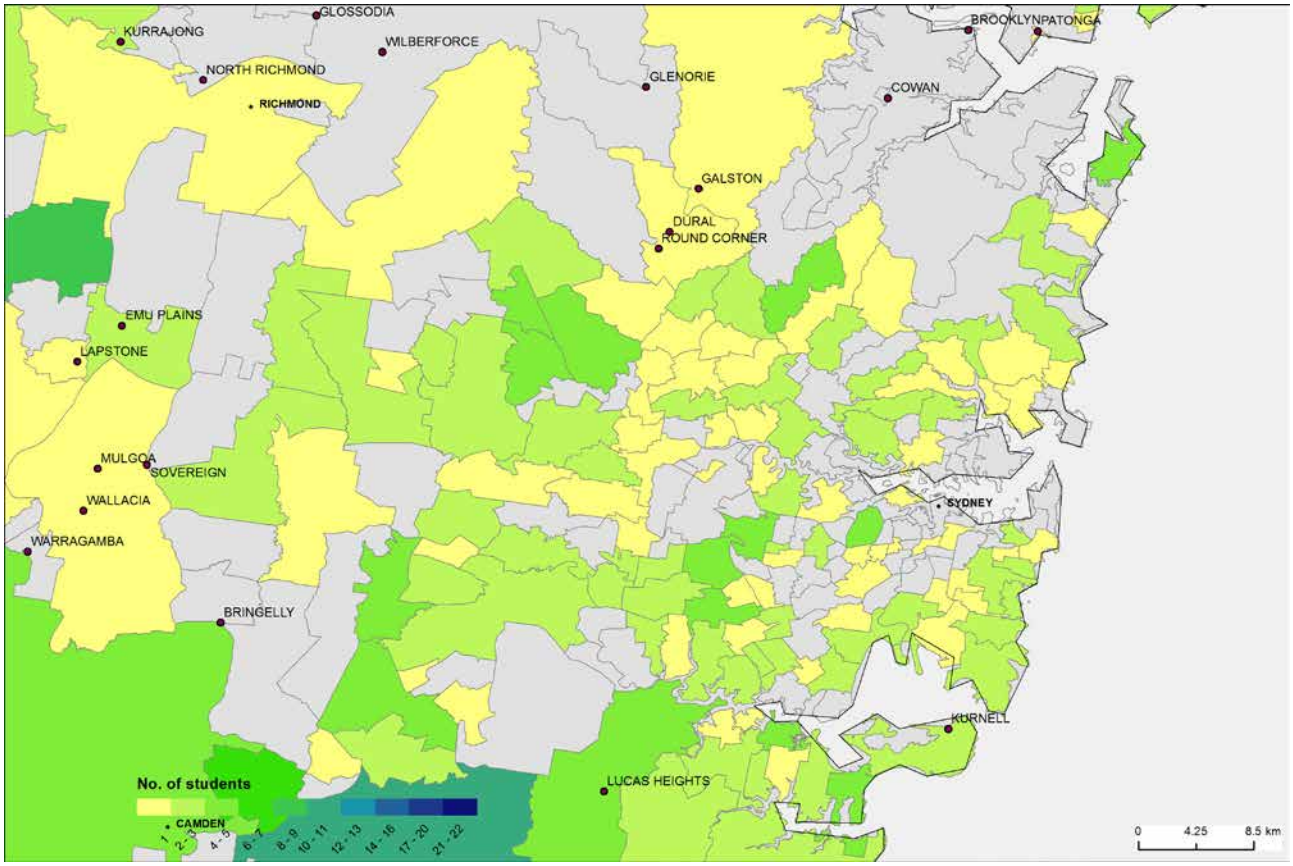


Figure 4.12.8 Location of Students in the Sydney Region – by Postcode Area



4.12.1 Questions Raised by Mapping

The creation of maps showing student numbers was useful in helping the Program Managers identify their working knowledge of the program, to tell stories and provide explanations of high numbers in different places, and to ask questions and consider the meaning of these areas of concentration. Many of these questions were generative, in that they suggest different approaches to thinking about and addressing the research questions.

Concerns about who accesses the programs and why, provide useful lines of enquiry about the different factors that impact on students accessing the program and thinking about the project's third research question:

> *What factors and processes shape these students' trajectories and what recommendations can be proposed for improved practices?*

Questions that were asked in relation to maps of student locations include:

- Why do so few students who access the program live in inner suburban areas? (Possible answers to this questions have been offered in the preceding pages (section 1.12)
- Why are significant numbers of students located in some areas where there is no Education Coordinator, and EDMed has not been particularly emphasised, such as the country town of Bendigo in Victoria?

RMLP STUDENTS AND SOCIO ECONOMIC STATUS (SES) 5

As discussed in the overview of research about young people with serious health conditions and their education, lower SES[13] is associated with poorer educational outcomes in a range of ways. It is also associated with disability and illness, with single parenting and access to services. In considering what could be learned from the database about young people with serious illness and their education, priority was given to examination of SES factors. It was not known whether students from lower or higher SES areas accessed the RMLP services. The investigation also sought to reveal new or confirm existing knowledge in relation to SES and other factors such as type of illness, amount of missed school[14], or single parenting.

This chapter begins with:

1. An explanation of the Australian Bureau of Statistics (ABS) socio-economic indexes that were used to examine SES in this study.

The chapter then proceeds to outline investigations about these issues:

2. The spread of RMLP students across higher and lower SES areas;
3. Connections between different health conditions and SES;
4. Connections between other factors and SES.

5.1 Using the ABS Socio-Economic Indexes

Socio-economic indexes for areas (SEIFA) developed by the ABS (Australian Bureau of Statistics, 2013i), were used to examine the socio-economic status (SES) of students in the RMLP database.
The ABS socio-economic indexes rank areas around Australia, based on the level of advantage and disadvantage of people in each area. The indexes are based on various data from the 2011 Census, including income, employment, occupation, housing, education and disability (Australian Bureau of Statistics, 2013h). Based on these variables, scores were allocated to geographic areas. A low score means people living in that area have relatively few resources or advantage, and a higher score, means they have more resources and advantage. These areas are ranked in order from lowest to highest score around Australia. It is these rankings, rather than the raw scores that are used to compare the SES of different areas.

The SEIFA rankings that were used in this project are based on postcode areas. While the ABS can also provide data based on much smaller geographic areas, which allows a more accurate approximation of SES

13. SES = Socio-economic status
14. In the case of amount of missed school, the graphs did not appear to reveal any new information, so these graphs are not presented here. Amount of missed school appeared to be connected with type of illness (as one would expect), but not in any noticeable way with SES.

for a given household, this requires coding of all addresses, which was beyond the scope of this project. Using postcode based SES rankings necessarily masks a lot, as within one postcode, might be a wide range of different socio-economic areas. However when looking for trends with larger numbers of people, it can nevertheless prove a useful measure.

The ABS ranks all the postcode areas according to their SEIFA scores, and then divides the scores into deciles. '10' means the postcode area is in the top 10%, and is among the most advantaged of all areas in Australia. '1' means that the suburb is in the bottom 10%, and is most disadvantaged. This report also uses quintiles, to make the charts more accessible. In this case, a '5' means the suburb is in the top 20%, and a '1', the bottom 20%.

It is important to note that it is postcode areas that are being ranked. The score is based on the SES (level of advantage or disadvantage) of the people living in that area, but it is the area as a whole that gets a score. Different postcode areas can have different sizes (the map in Figure 5.1.1 illustrates) and different populations. The importance of this factor will be further discussed in the following section of the report, looking at SES and RMLP students.

There are four different indexes that the ABS has designed:

1. Index of Relative Socio-economic Advantage and Disadvantage (IRSAD);
2. Index of Relative Socio-economic Disadvantage (IRSD);
3. Index of Economic Resources (IER); and
4. Index of Education and Occupation (IEO) (Australian Bureau of Statistics, 2013c).

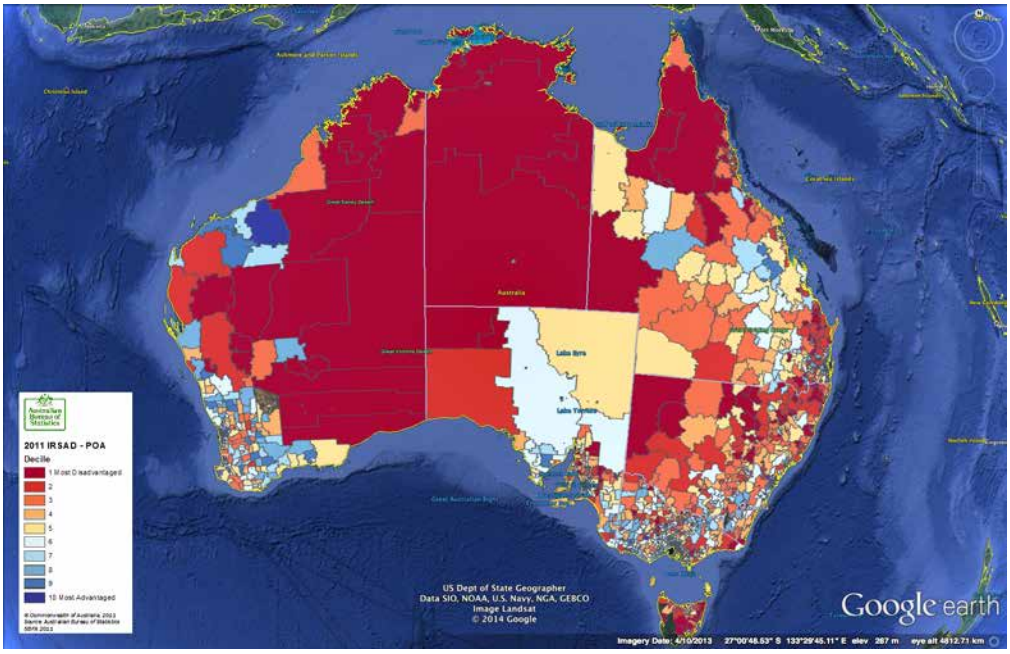
The most comprehensive index is the Index of Relative Socio-economic Advantage and Disadvantage (IRSAD), which is the index used for this project. It takes into account variables that indicate advantage and variables that indicate disadvantage. The ABS advises that this index is the most appropriate index for users who want to compare the entire range of areas, as in this project, rather than focussing only on disadvantaged areas (Australian Bureau of Statistics, 2013d).

Below is a map of Australia that identifies the IRSAD for each postcode area (Figure 5.1.1). This map was produced using Google Earth, which allows for integration with files from the ABS (Australian Bureau of Statistics, 2013e). This map shows a number of very large postcode areas, most of which are very disadvantaged (coloured red or orange). These postcode areas are very large, because very few people live in them. This map does not show RMLP data, but is included here to provide understanding of postcode areas and the indexes, and the process of analysis.

Similar maps were produced during the process of analysing the data, which zoomed into specific areas. These maps were compared with maps showing the location of students (see section 4.12)[15].

15. These maps were displayed during the data-analysis workshop, and can be readily reproduced, using the directions on the ABS website (Australian Bureau of Statistics, 2013e).

Figure 5.1.1 Index of Relative Advantage and Disadvantage for Australian Postcode Areas



For the analyses that follow, Excel's capabilities were used to match each student's postcode with the IRSAD ranking for that postcode, which was added to the student's record. As explained above, using IRSAD ranking based on postcode areas is not useful in terms of knowing the actual socio-economic situation for a particular person, but can be useful in looking for patterns among groups of people.

5.2 SES and RMLP Students

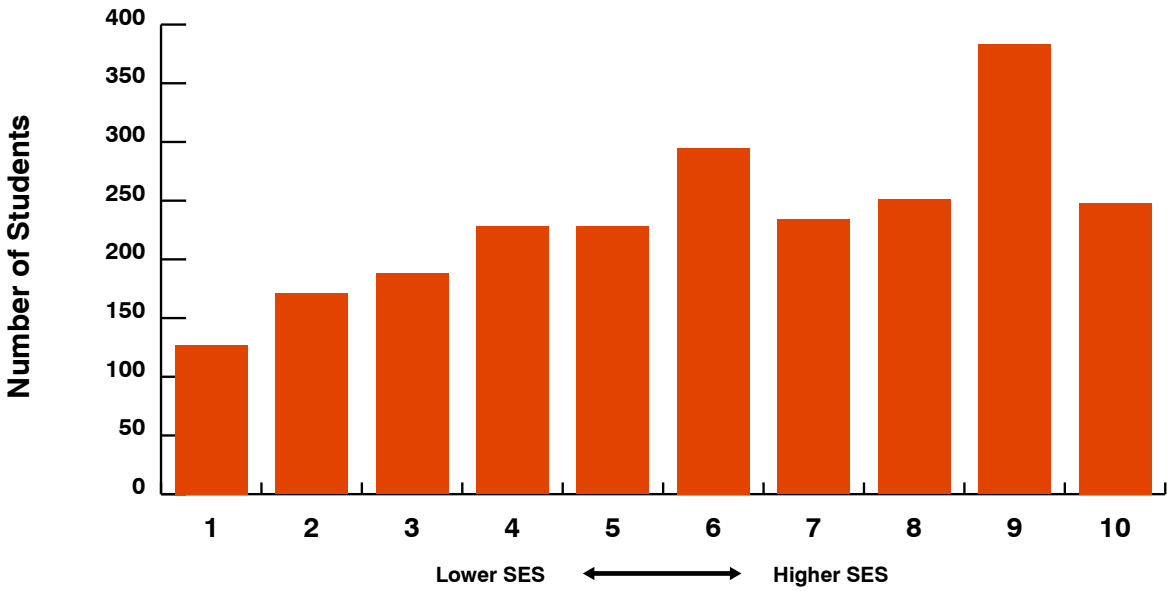
Investigations into SES for the RMLP students began with graphing the number of students living in higher or lower SES areas, using the index of relative socio-economic advantage and disadvantage (IRSAD[16]) (Figure 5.2.1).

In Figure 5.2.1 and subsequent graphs, column 10, the 10th decile, represents the number of people (students in this case) living in postcode areas that are in the most advantaged 10% in Australia. And column 1, the 1st decile, represents the number of people living in postcode areas that are in the most disadvantaged 10% in Australia.

This graph shows that there are more students living in areas with a higher SES than living in areas with a lower SES. 1412 or 60% of students live in postcode areas ranked in the top 50% for level of advantage (deciles 6 - 10), while 942 or 40% of students live in postcode areas ranked in the bottom 50% for level of advantage (deciles 1 - 5).

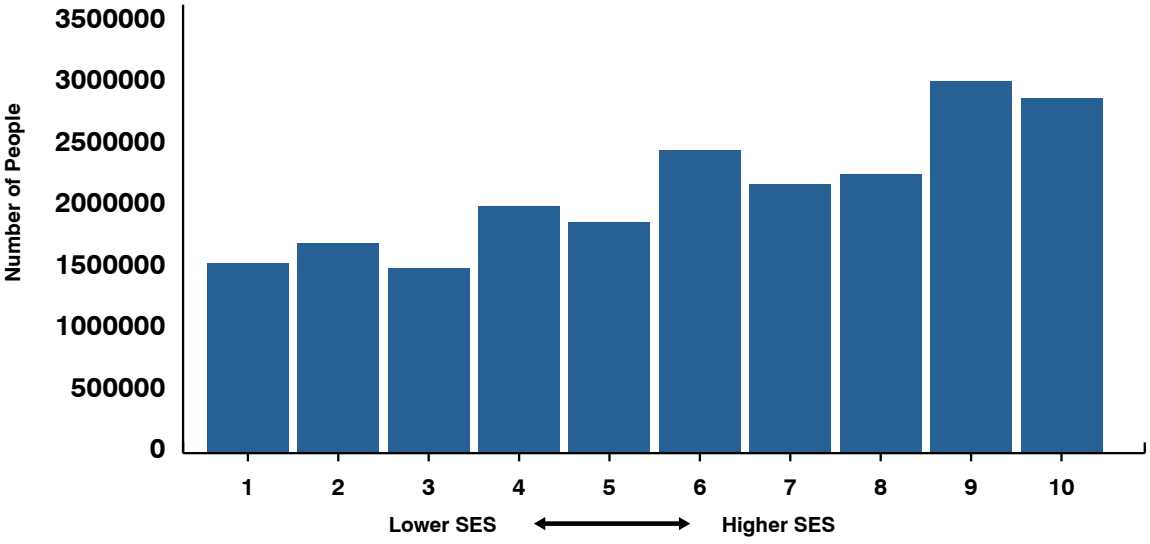
16. In the charts and graphs throughout the rest of this report, the index of relative socio-economic advantage and disadvantage (ISRAD), was used as the indicator of SES.

Figure 5.2.1 RMLP Students and SES



While the preceding graph (Figure 5.2.1), shows that more RMLP students live in higher SES areas, looking at a similar graph for the whole Australian population (Figure 5.2.2), one can see that in fact *more Australians* live in higher SES areas. Mirroring the figures for RMLP students, 60% of Australians live in postcode areas in the top 5 deciles for level of advantage and 40% of Australians live in postcode areas ranked in the lower 5 deciles. Taking the population figures into account, it seems very reasonable that there are more RMLP students from higher SES areas, because more people live in these areas.

Figure 5.1.2 Australian Population and SES

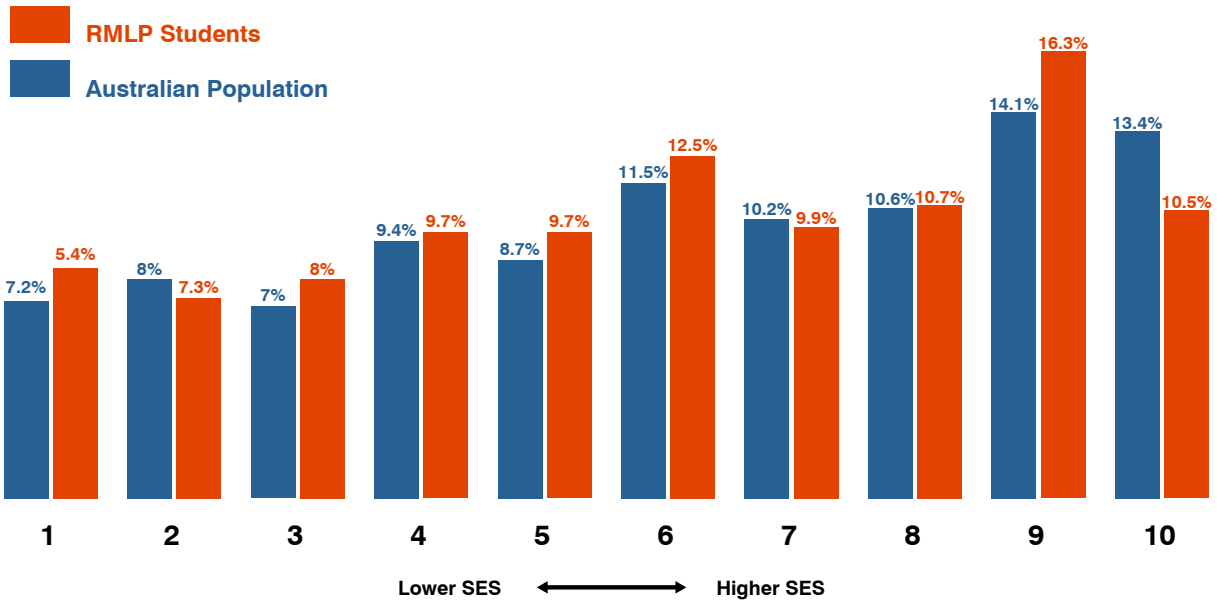


Another way to examine the spread of students across areas of higher or lower SES areas in Australia, is to look at the percentage of all the RMLP students who live in postcodes in each decile, and then compare

this with the percentage of the Australian population, who live in postcodes in each decile (see Figure 5.1.3). Here we can see that the RMLP database has a relatively similar spread of students across the moderately lower and higher SES areas.

The biggest differences are in the very highest SES areas, where RMLP has a noticeably smaller percentage of students from the 10th decile and a noticeably higher percentage of students from the 9th decide. Also in the lowest SES area (decile 1), RMLP has a noticeably smaller percentage of students.
The smaller numbers of RMLP students from the lowest SES areas, might at least in part, be explained by the fact that a number of these areas are also very isolated geographically. The smaller numbers in the highest SES areas, might be explained (at least in part), due to the smaller number of children living in many of the highest SES areas, as discussed in in section 4.12 Location of students.

Figure 5.1.3 RMLP students, Australian Population and SES



These initial inspections of the spread of students across SES give the impression that the RMLP program is catering for a representative spread of young people.

The following section of this report will explore the spread of RMLP students further, through looking at how illness is distributed across higher and lower SES areas.

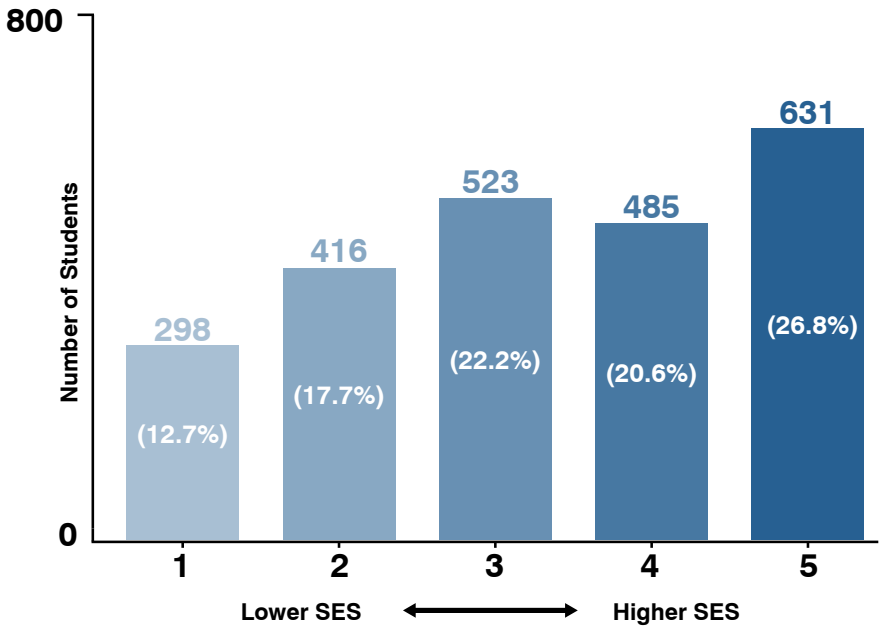
5.3 SES and Health Condition

The project explored patterns in the data for different illnesses and SES. In the previous section it was explained that because there are fewer people living in the areas of lowest SES and more people living in areas of higher SES, it could be misleading to examine only the raw numbers of students living in higher or lower SES areas. Nevertheless, it is possible to use these raw numbers to compare *patterns* of distribution across high and low SES areas, for different illness.

The advantage of these graphs is that the actual student numbers under discussion can be seen. To make the graphs easier to interpret, the students are grouped into quintiles.

Figure 5.3.1 shows a simple spread of the students in the RMLP database. This is the same data as used for graphs in the previous section of the report (1.2 SES and RMLP students), but using quintiles instead of deciles to allow for comparison with the following graphs.

Figure 5.3.1 Student Spread Between Postcode Areas that have More or Less Advantage



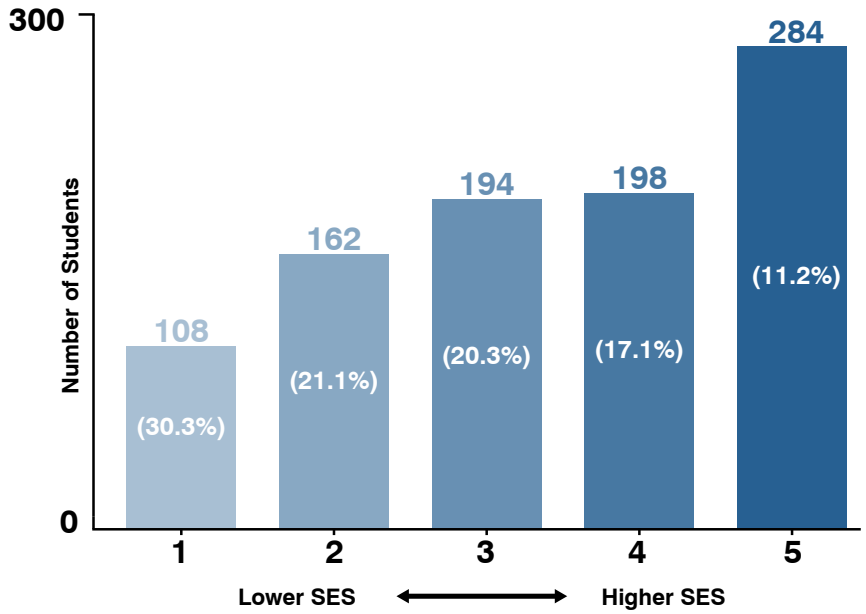
The following sections explore the spread of students across different SES areas for students with:

- Cancer;
- Asthma;
- Cystic fibrosis;
- Trauma;
- Diabetes;
- Cardiac conditions;
- Renal conditions; and
- Neurological conditions.

5.3.1 Students with Cancer and SES

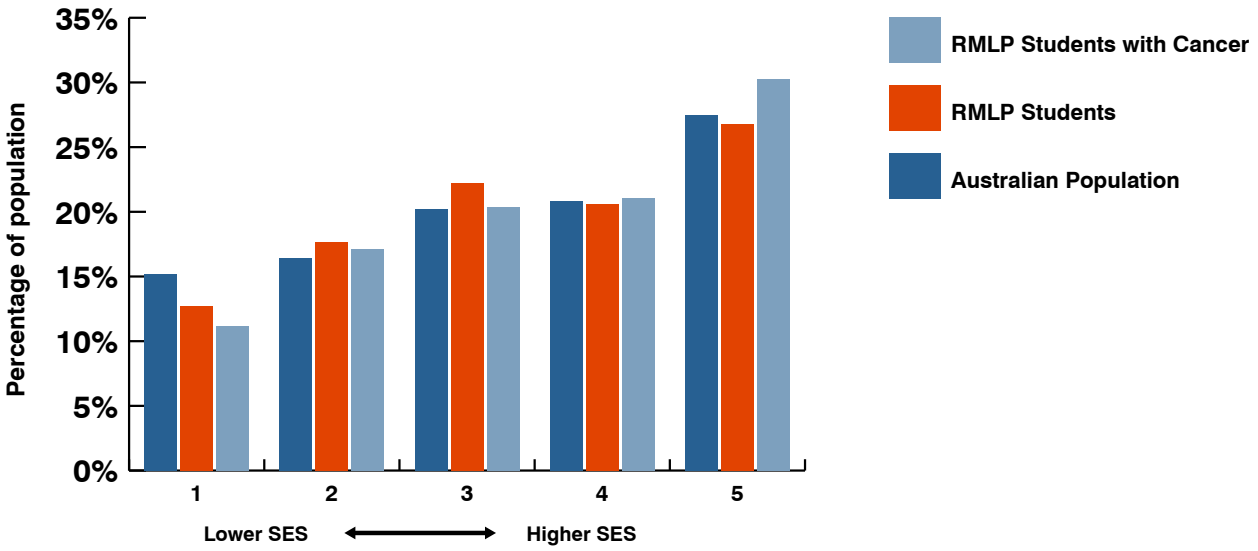
While the shapes of the graphs for students with cancer (Figure 5.3.1.1) and for all RMLP students (Figure 5.3.1) are similar, closer inspection reveals an interesting difference. The graph for students with cancer has a noticeably higher percentage of students from the highest SES areas (30% compared with 27%).

Figure 5.3.1.1 Students with Cancer and SES



Given the large number of students with cancer in the RMLP database (946 students) and the unexpectedly high number of students from the highest SES groups, the spread of students was explored further. Figure 5.3.1.2 compares the percentage of students with cancer living in higher and lower SES areas, with the percentage of all RMLP students and all Australians living in these areas. Not only is there a higher percentage of RMLP students with cancer from the highest SES areas, there are also noticeably fewer students with cancer from the lowest SES areas.

Figure 5.3.1.2 RMLP Students with Cancer, all RMLP Students and All Australians and SES



In a recent report on the health of Australia's children, the AIHW (Australian Institute of Health and Welfare, 2012) noted that a slightly lower 5-year survival rate for children with cancer from the lowest SES areas exists compared to the highest SES areas (81% and 84% respectively) (p. 23). Conversely, the rates of

hospital visits are 15% lower for children with cancer from the lowest SES areas (Australian Institute of Health and Welfare, 2012, p. 23).

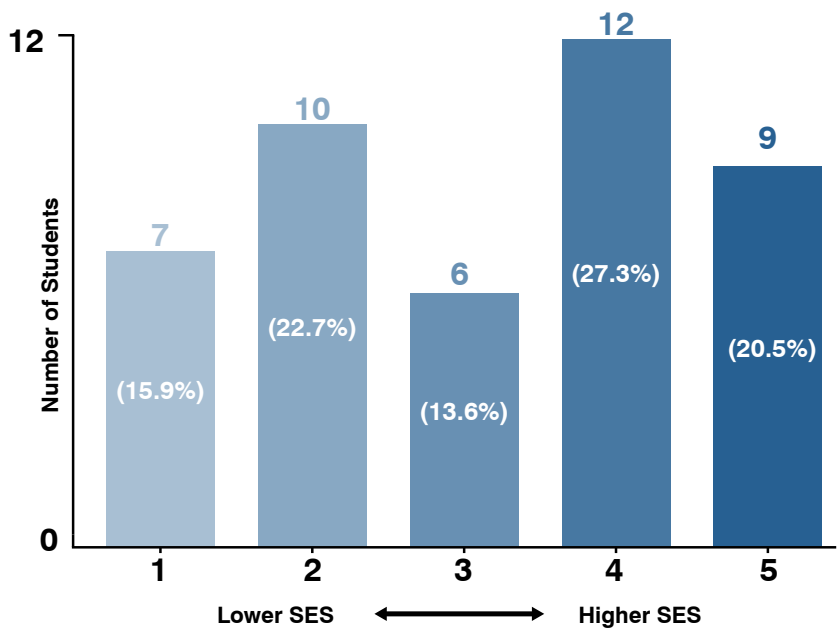
Taking into account information from this AIHW report along with the above graphs of RMLP students with cancer and SES, questions are raised for further investigation. For instance, might it be the case that children from higher SES areas (while not any more unwell from cancer than children from lower SES areas) are for reasons related to SES, more likely to use hospital services and more able to access services such as the RMLP programs?

5.3.2 Students with Asthma and SES

Examination of the graph of RMLP students with asthma and SES (Figure 5.3.2.1) reveals a higher percentage of students from lower SES areas than for RMLP students with cancer, and a noticeably higher percentage of students in the second highest quintile. However, with only 44 students with asthma in the RMLP database, conclusions could not be drawn.

It is interesting to note that the AIHW (Australian Institute of Health and Welfare, 2012) found prevalence of asthma was higher among children living in the lowest SES areas and lower for children living in the highest SES areas. The RMLP data shows some evidence of this.

Figure 5.3.2.1 Students with Asthma and SES



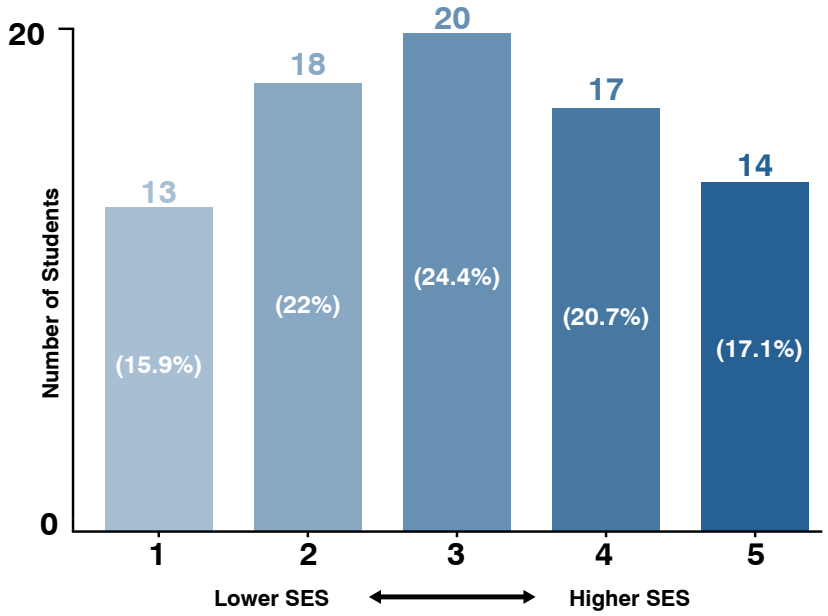
5.3.3 Students with Cystic Fibrosis and SES

There were 82 students with cystic fibrosis in the RMLP database. In the graph of these students and SES (Figure 5.3.3.1) it is noticeable that students from middle and lower SES areas are more highly represented and there is a lower percentage of students from higher SES areas than might be expected. For instance, only 20.5% of the RMLP students with cystic fibrosis (versus 26.8% of all RMLP students) come from the top quintile for SES.

Research from the USA and the UK has shown that low SES is linked to significantly poorer outcomes and earlier death from cystic fibrosis (Barr et al., 2011; Schechter et al., 2001). If Australia follows similar trends,

then it could be assumed that children with cystic fibrosis from low SES groups are more frequently unwell and miss more school, and thus the RMLP programs would expect to have more children from lower SES areas.

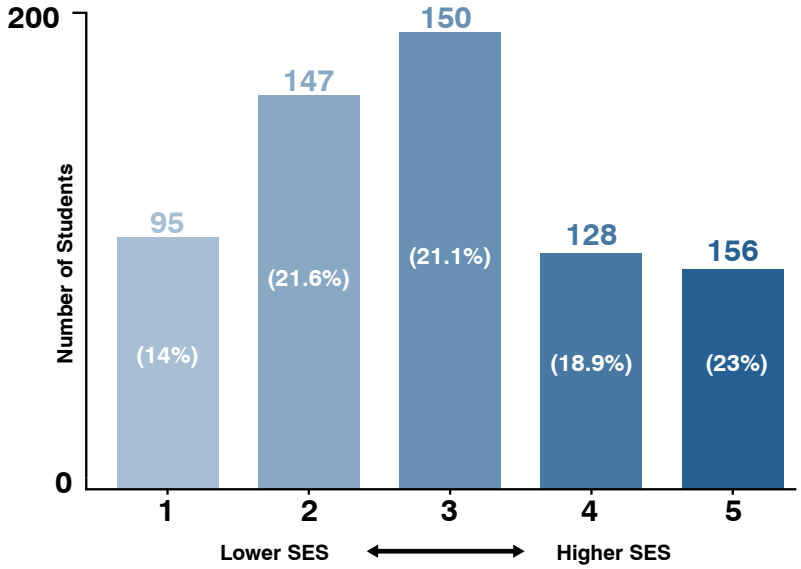
Figure 5.3.3.1 Students with Cystic Fibrosis and SES



5.3.4 Students with Trauma and SES

The data for students with trauma, which includes burns, general accidents and motor accidents, includes 99 students. The graph is strongly oriented towards children from lower SES areas (Figure 5.3.4.1). 41.5% of students with trauma are in the lower two SES quintiles (versus 30.4% of all RMLP students) and 29.3% of students with trauma come from the upper two SES quintiles, (versus 47.4% of all RMLP students). Research from Monash University's accident research centre in Melbourne, shows that at all ages, people from a lower SES, are significantly more likely to suffer injuries (Stokes et al., 2001). Similarly a recent study in the UK, found that "strong socio-economic inequalities persisted" between 1990 - 2009 in levels of injury among children under five years of age (Orton et al., 2014, p. 1).

Figure 5.3.4.1 Students with Trauma and SES

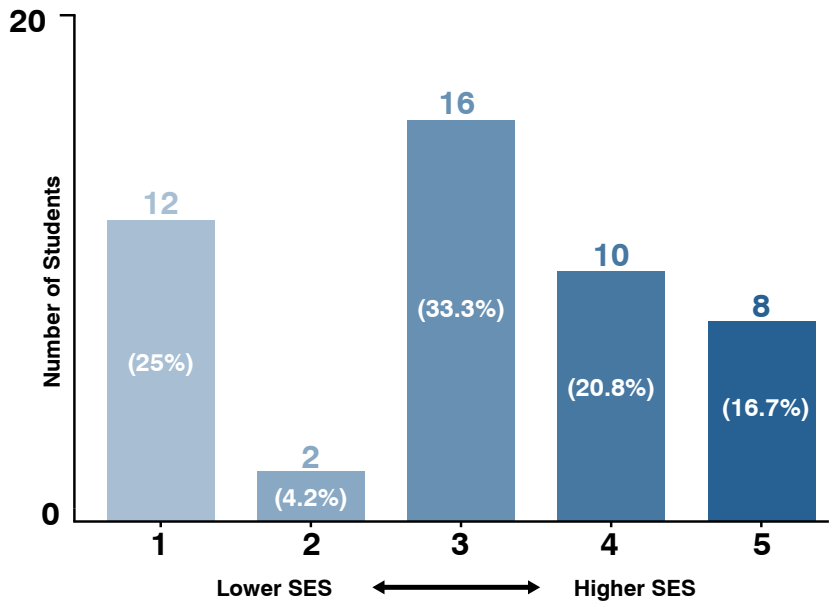


5.3.5 Students with Diabetes and SES

Looking at the graph of students with diabetes and SES (Figure 5.3.5.1), the pattern is not as clear as for trauma, with a notable lack of students in the second lowest quintile for SES. Nonetheless there are clearly proportionally fewer students with diabetes from higher SES areas, and more from middle to lower SES areas. Only 37% of students with diabetes come from the top two quintiles for SES, while 51.4% of students with cancer and 47% of all RMLP students come from the top two quintiles for SES. However with only 48 students with diabetes in the RMLP database, caution is required when interpreting these figures.

The Australian Institute of Health and Welfare investigated the relationship between SES and three chronic health conditions - asthma, cancer and diabetes. For diabetes, the AIHW reported that while no data was available for the prevalence of Type 1 diabetes among children by SES, visits to hospitals for children with diabetes were 34% higher in the lowest SES areas compared with those in the highest SES areas (Australian Institute of Health and Welfare, 2012, p. 23). While the RMLP data for diabetes (Figure 5.2.6) does not mirror this precisely, and the numbers are small, there is a clear trend towards the lower SES areas and away from the higher SES areas.

Figure 5.3.5.1 Students with Diabetes and SES



5.3.6 Students with Cardiac Conditions and SES

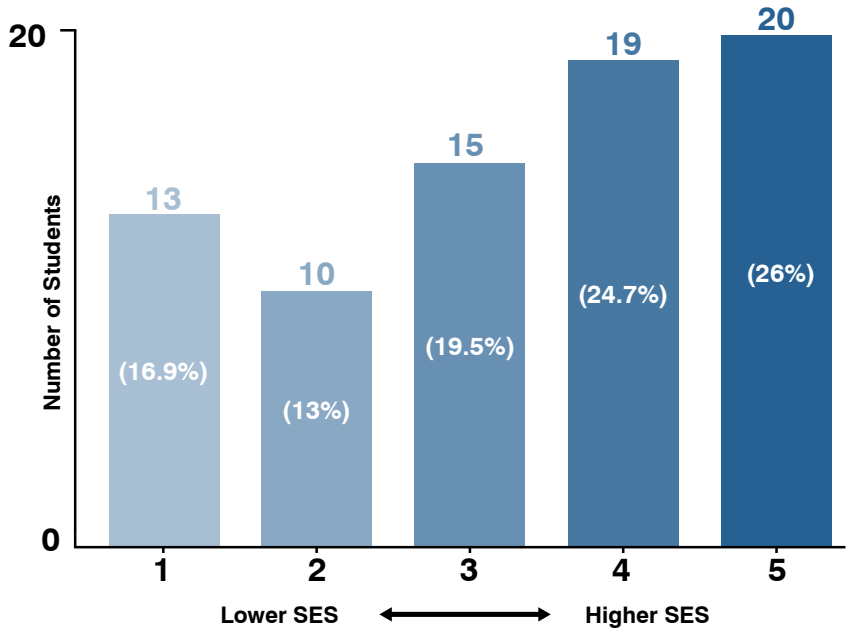
The trend in the graph for students with cardiac conditions and SES (Figure 5.3.6.1) shows 50.7% of students located in the two highest quintiles for SES (compared with 47.4% for all RMLP students). At the same time a relatively high proportion of students (16.9%) are from the lowest SES area, compared with 12.7% of all RMLP students living in the lowest SES areas.

Interestingly, a recent large study from the USA, which investigated children aged 8 - 18 with congenital or acquired heart disease and SES (Cassedy et al., 2013), reported that there was an association with lower SES and more severe effects of heart disease. Similarly, a meta-analysis of 33 North American and European studies into the possible association between maternal socio-economic status and congenital heart disease, found a moderate connection between lower SES and congenital heart disease (Yu et al.,

2014). While the results from the RMLP database do raise questions, the numbers are fairly small (77 students) and the studies about SES and cardiac conditions do not use Australian figures, so further investigation would be required before any conclusions could be drawn.

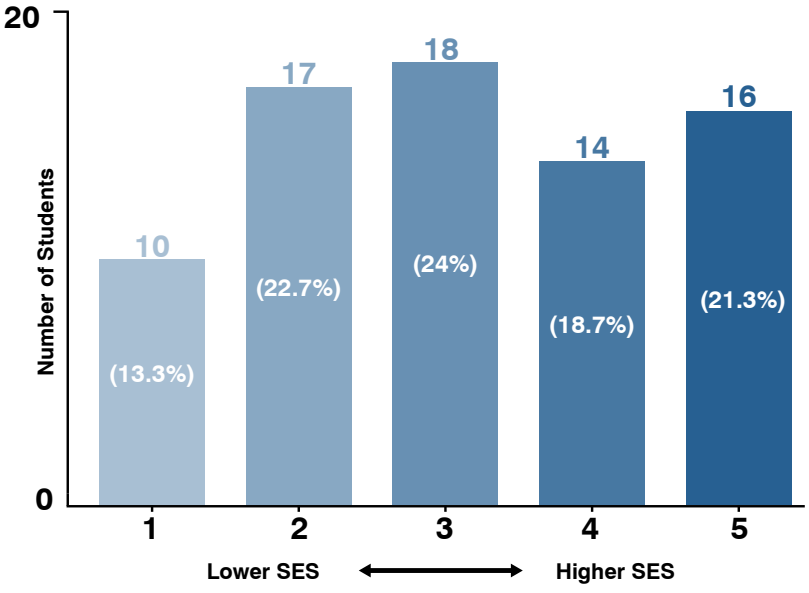
Figure 5.3.6.1 Students with Cardiac Conditions and SES

5.3.7 Students with Renal Conditions and SES



There were 75 RMLP students with renal conditions, the large majority of these being kidney disease or a kidney transplant. Proportionally more of these students come from middle to lower SES areas (quintiles 1-3), than for RMLP students as a whole (60% vs. 53%). Conversely, a smaller percentage of students come from the higher SES areas (40% vs. 47%), see Figure 5.3.7.1.

Figure 5.3.7.1 Students with Renal Conditions and SES



The data from the RMLP database suggests that children from lower SES areas may have more renal disease, or that they get sicker with it. This would fit with research mentioned throughout this report, linking various chronic diseases with low SES[17].

Research specifically about children with kidney disease and SES is in its earlier stages. A recent US study found a clear connection between race and kidney disease in children, but at this stage they were unable to say to what extent this was connected to socioeconomic factors (Minnick et al., 2010)[18]. An Australian study is underway examining the connection between SES and kidney disease in children (Wong et al., 2014).

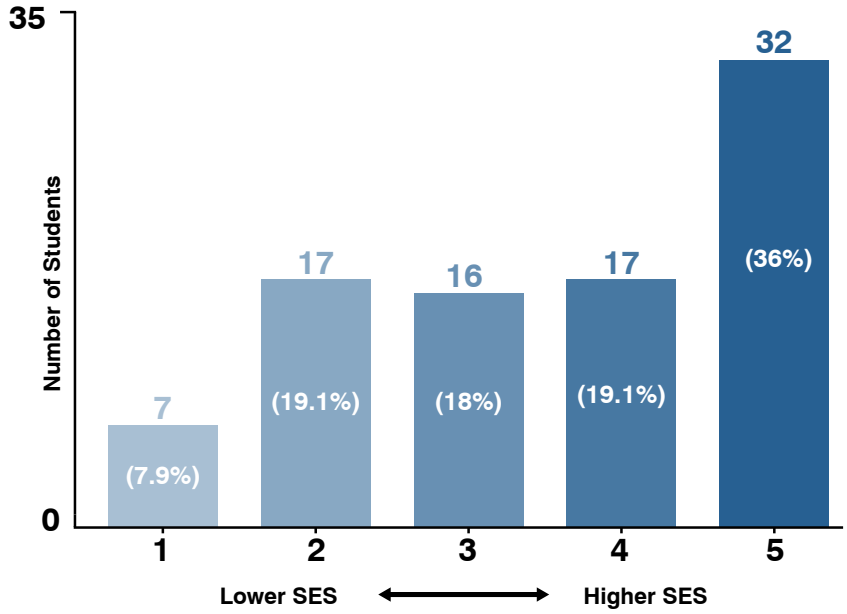
5.3.8 Students with Neurological Conditions and SES

Initial investigations revealed that there are proportionately even more students with neurological conditions[19] living in the higher SES areas (quintiles 4 & 5), than students with cancer (56% vs. 51.4%), and substantially more than the student group as a whole (47.4%). This surprising result, led to the exploration of SES for epilepsy, the neurological condition most represented in the RMLP database.

Figure 5.3.8.1 shows the spread of SES for students with epilepsy. The results are stark, with 36% of students living in the highest SES areas (quintile 5), compared with 27.5% of the Australian population and 26.8% of all RMLP students living in these areas. Conversely only 7.9% of students with epilepsy live in the lowest SES areas (quintile 1), compared with 12.7% of all RMLP students.

In direct contradiction to these results, studies have shown a connection between low SES (or increased rates of deprivation) and increased rates of epilepsy in children (Heaney et al., 2002). The reasons for this disparity are worthy of further investigation.

Figure 5.3.8.1 Students with Epilepsy and SES



17. See for example Australian Institute of Health and Welfare (2012)
18. In the USA race and SES have know associations, see American Psychological Assocation (2014).
19. The conditions categorised as neurological conditions in the RMLP database are: epilepsy (89 students), stroke (59 students), benign tumours (37 students), cerebral palsy (24 students),

5.4 Exploring SES and other variables

The following sections examine the spread of RMLP students across higher and lower SES areas, for the following variables:

- Students in lone parent households;
- Aboriginal and Torres Strait Islander students;
- Students who speak a language in addition to English at home.

5.4.1 Students in Lone Mother or Lone Father Households[20] and SES

Lone Mother

The RMLP data includes 679 students (28.8%) who have only a mother listed out of a total of 2360 students in the database[21]. RMLP Program Managers explained that sometimes mothers fill in the form and do not list the father, even though the parents are not separated and the father is involved, so it is unclear exactly how many of these apparently lone mother households, are genuinely so. Nonetheless, it is much higher than ABS figures, which indicates that single mother families make up 17.8% of Australian families with a child under 15 years old (Australian Bureau of Statistics, 2012b). Given the Program Manager's caution we cannot draw any conclusions from these figures, but even if the number of students with lone mothers is only 25% or 20%, this is still a large number of lone mothers parenting seriously ill children.

This fits with the research, which would lead us to expect that a higher percentage of parents in the RMLP database compared to the general population, would be lone mothers, because (as discussed in chapter 2.1 Prior research), mothers with a child with a serious health condition are more likely to either be single or to become single.

Lone Father

There are 61 RMLP students (2.6%) out of the 2360 students, who have only a father listed. ABS statistics (Australian Bureau of Statistics, 2012b), show that lone father families make up 3.1% of Australian families with a child under 15 years old and that 15% of lone parents with a child under 15 years old were fathers, and 85% were mothers (Australian Bureau of Statistics, 2012b). In the RMLP database, 92% of the apparently single[22] parents are mothers, and 8% are fathers.

Further Investigation

These findings are worthy of further investigation. Not only do they appear to confirm the existing research that children who are seriously ill, are more likely to have a lone mother, but also that children who are seriously ill or injured, are even less likely to have a lone father than children in general.

Lone Mother and SES

Turning now to SES for the students with only a mother listed (see Figure 5.4.1.1). These students came from somewhat lower SES areas than the students overall. 35.5% of these students live in the lower SES areas (quintiles 1 & 2) as opposed to 30.4% for all students. 41.9% of students with only a mother listed, were living in the higher SES areas (quintiles 4 & 5), compared with 47.4% for all RMLP students.

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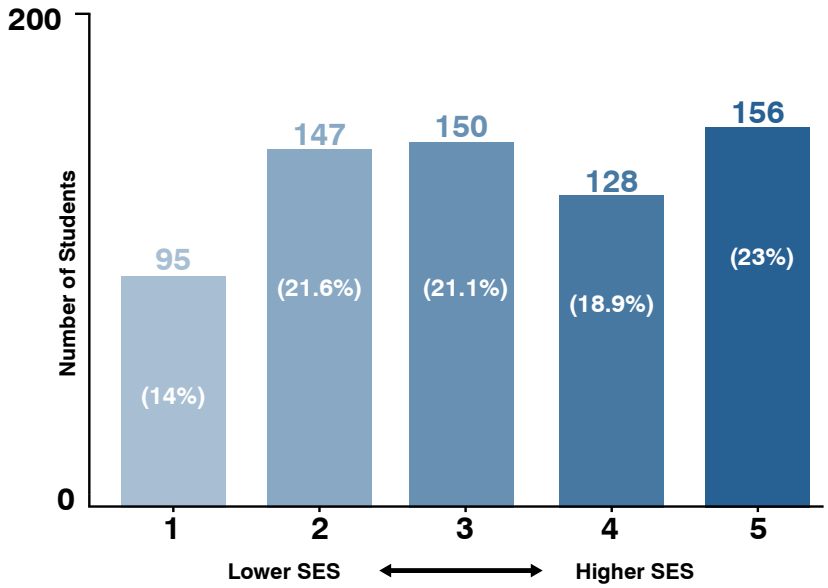
20. 'Lone mother households' (and lone father households) is the term used by the ABS (as opposed to single mother households), and is adopted here.
21. It is worth noting that a further 57 or 2% of RMLP students had different addresses listed for the mother and the father. Because it is not known which parent these students live with, or to what extent there is a genuine co-parenting occurs, these students were not included with students living with a lone mother or lone father.
22. See comment in the preceding paragraph about there being some mothers who fill out the RMLP application form without listing the father, although they cohabit and share parenting.

This fits with research that indicates that lone mothers are more likely to either come from a lower SES, or to be downwardly mobile as a result of their circumstances (see chapter 2.1 Prior research). The RMLP database indicates that a significant number of these students are from lone mother households, which was raised as a concern in White (2014) and Drew and White (2010) and (White, Drew, & Dumenden, 2012) and following Drew and White's research on the Keeping Connected project Yates et al. (2010).

Further Investigation

Parenting a child with a serious health condition warrants further investigation, including implications for lone mothers and their child's education. To assist in this research, it would be useful to investigate what percentage of RMLP students live with a lone mother, and to do further explorations with data from those students.

Figure 5.4.1.1 Students Who Only have a Mother Listed and SES



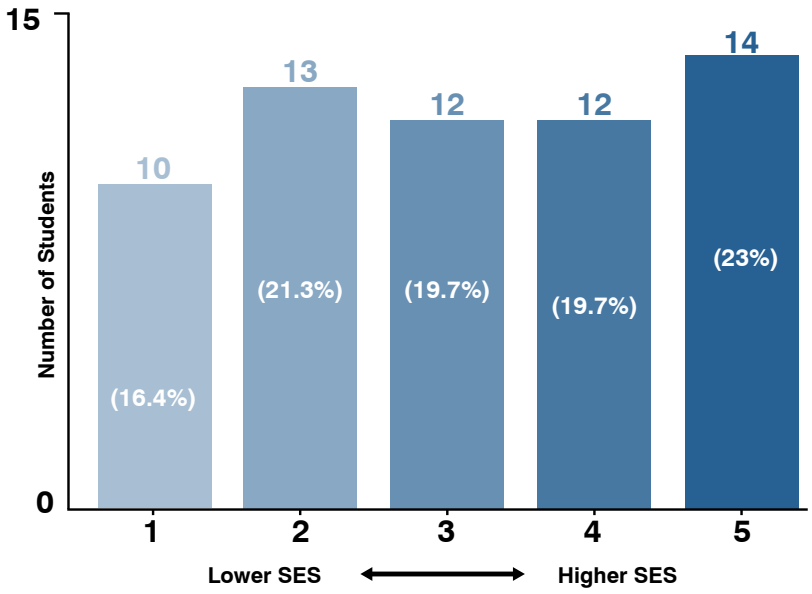
Lone Father and SES

Similarly to the students from apparently lone mother households, RMLP students from lone father households are more likely to come from lower SES areas. 37.7% of students from lone father households live in lower SES areas (quintiles 1 & 2), compared with 30.4% of all students. 42.7% of students from lone father households live in the higher SES areas (quintiles 4 & 5) compared with 47.4% of all students.

Further Investigation

While the numbers of lone fathers are low in the RMLP database (and are low in general), the RMLP database findings indicate that lone fathers with a child who is seriously ill or injured, may just like lone mothers, be more likely to have a lower SES. It would be worthwhile to investigate the situation for lone fathers of children who have a serious health condition, along with lone mothers.

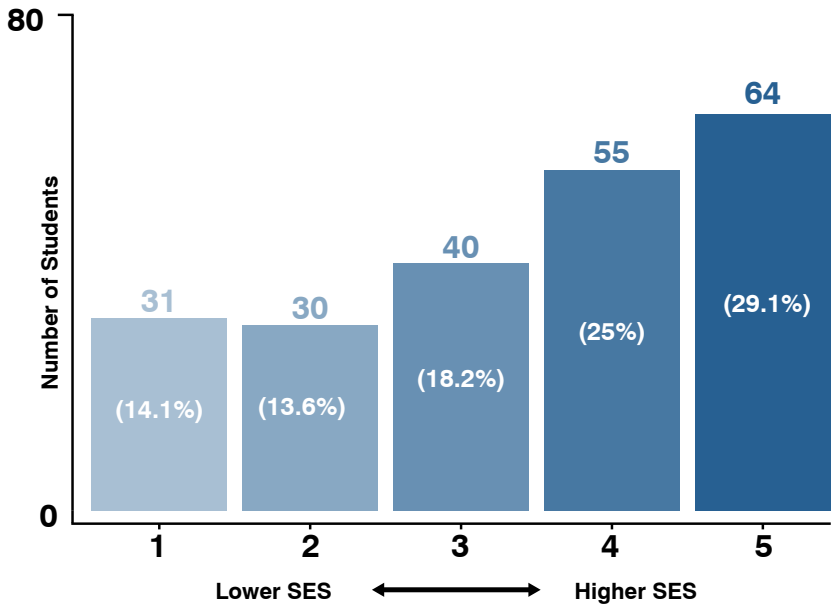
Figure 5.4.1.2 Students Who Only have a Father Listed and SES



5.4.2 Aboriginal and Torres Strait Islander Students & SES

Of the 84 students listed as Aboriginal or Torres Strait Islander (ATSI), a much higher percentage (22.6%) live in the lowest SES areas than for the students overall (12.66%) (See Figure 5.4.2.1). Unfortunately, this is not surprising, given the current situation for Aboriginal and Torres Strait Islander people in Australia. While the 18 students in the highest SES areas, does look surprising at first, reversing the trend of fewer students in the higher SES areas, it is still a lower percentage than for all the students (21.4% vs. 26.8%).

Figure 5.4.2.1 Students Identified as Aboriginal or Torres Strait Islander and SES



5.4.3 Students with Another Language at Home and SES

Of the 2,246 students for whom the language(s) spoken at home is known, 220 (9.8%) list speaking English plus another language at home. The spread of the 220 students with English plus another language at home (Figure 5.4.3.1), is interesting. Slightly more of those students live in the lowest SES areas compared with all the students (14.1% compared with 12.7%), however there is also a higher percentage living in the highest and second highest SES areas.

The following graph (Figure 5.4.3.2) allows comparison of the spread of students with English plus another language at home, with all RMLP students and with all Australians, across lower and higher SES areas. Here for example it can be seen that 25% of RMLP students with English plus another language at home live in the second highest SES areas (quintile 4), while a noticeably smaller percentage (20.6%) of all RMLP students live in these areas and a very similar percentage (20.8%) of the Australian population live in these areas.

Figure 5.4.3.1 Students with a Language at Home in Addition to English and SES

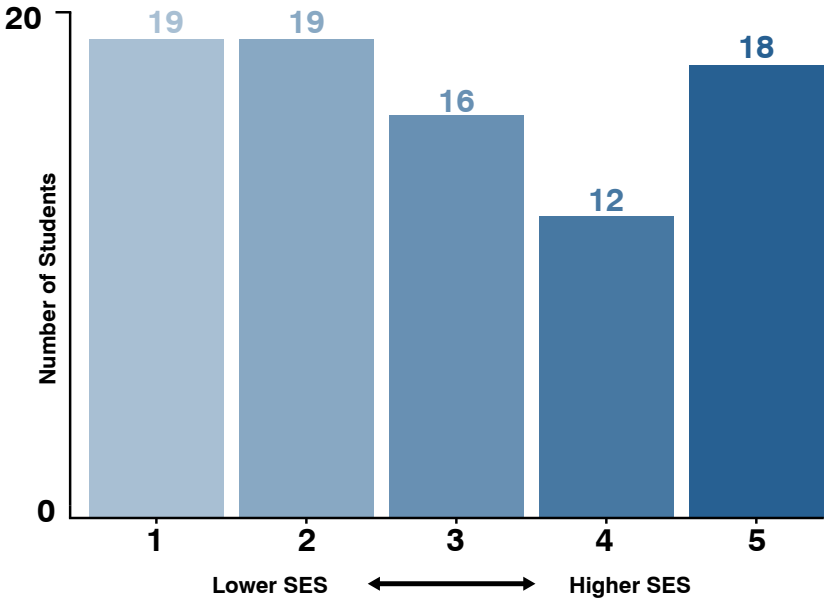
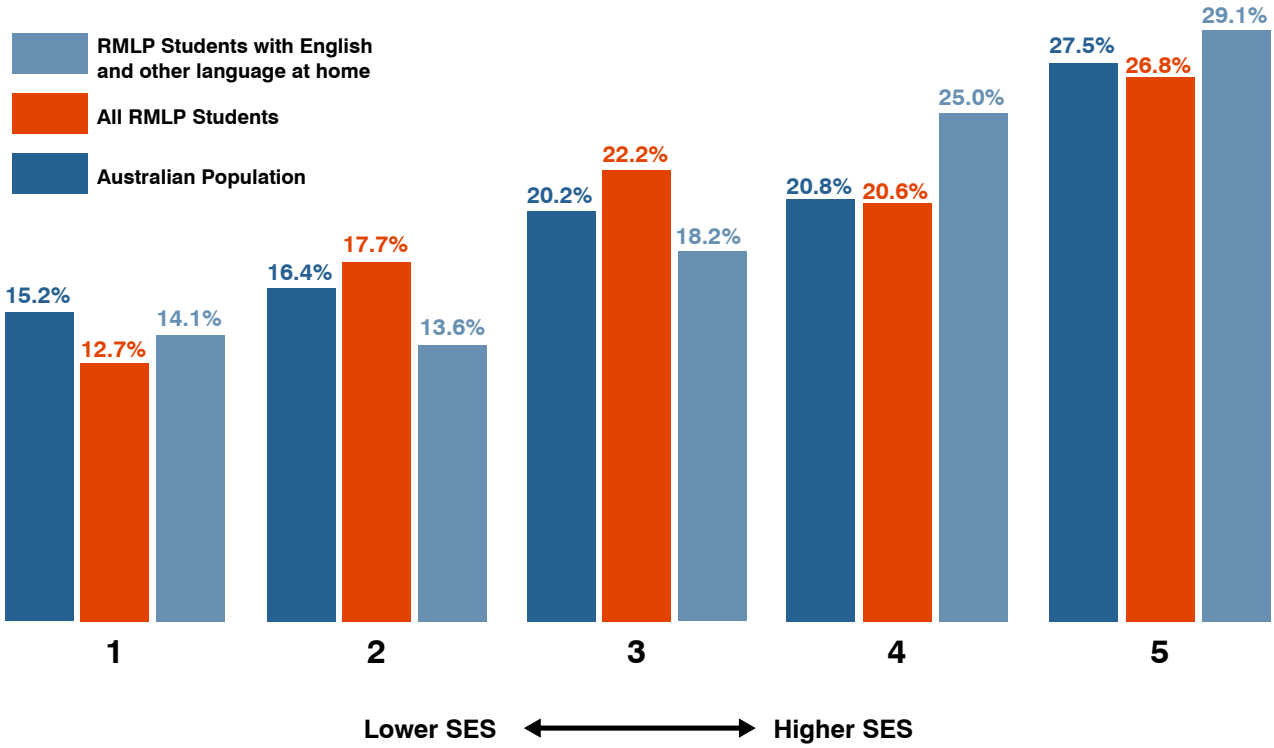


Figure 5.4.3.2 RMLP Students with English and Another Language Spoken at Home, All RMLP Students, All Australians and SES



So how might the surprising spread of students with English plus another language be explained? This seemed a worthwhile question to pursue, given that this group included 220 students, a sufficient number for patterns in the data to have meaning.

Several possibilities are considered and outlined below and it is suggested that this is another issue worthy of further investigation.

One possibility is that people who have arrived in Australia more recently are more likely to list the languages spoken at home, and are more likely to live in higher SES areas, perhaps in government housing or through other housing programs, or live in very low SES areas.

Another possibility is that there are two distinct groups of students from Culturally and Linguistically Diverse (CALD) backgrounds who are accessing the RMLP programs, those who are from families with a high SES and those from families with a low SES. And for some combination of reasons, both of these groups of students are more likely to access RMLP than CALD students living in middle SES areas.

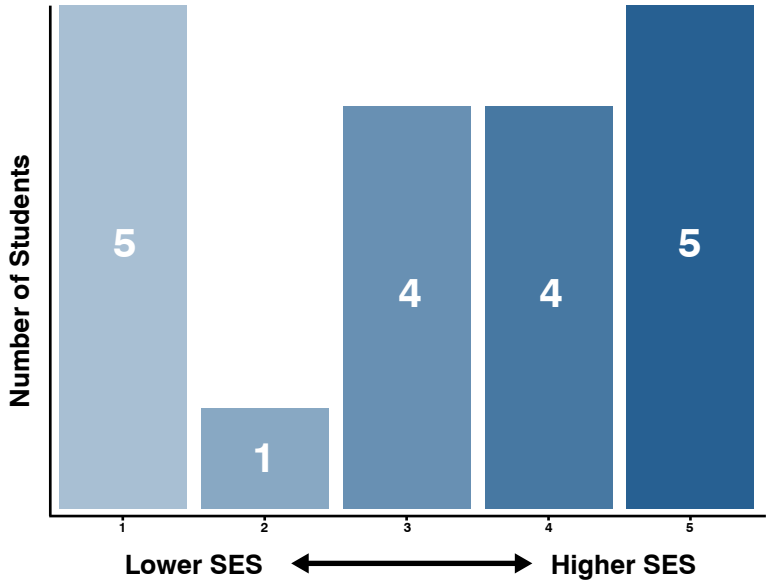
Further Investigation

What is of interest for further research, is to explore whether there are children from CALD families who are getting excluded and why. This will assist in thinking about barriers to supporting children with serious health conditions with their education.

Students with Only a Language Other than English

Finally, the graph of students with **only** a language other than English at home and SES, is included for the sake of completeness. There are equal numbers of students in the lowest and highest SES areas. However, as there are only 19 students in this group in total, no attempt is made to discuss these results.

Figure 5.4.3.3 Students with Only a Language Other than English at Home and SES



DISCUSSION AND RECOMMENDATIONS 6

6.1 Overview

In this chapter the findings from this study are summarised and discussed and then recommendations are provided for government and further research. The broad nature of the research questions ensured that the researchers undertook this investigation in light of the Australian education context and the international literature.

The analysis of the RMLP database was undertaken using the records of 2360 students. Analyses were undertaken about health conditions, referral source, school absence, school sector, gender, age, languages spoken at home and Indigenous identification. Demographic analyses were also undertaken using Australian Bureau of Statistics (ABS) demographic indexes.

This chapter begins by noting the 12 major themes for education that emerged from the literature regarding these students from the fields of medicine, public health, nursing, psychology, psychiatry, social policy as well as education. This is followed by discussion and recommendations, organised around 5 key topics:

1. Counting these students
2. School absence
3. Individual illness studies
4. Support provision
5. Parents

6.2 Key Themes from the Literature

All fields report concerns about the education of this cohort of young people. As biomedicine improves, many children and young people who would have formerly died are now surviving at extraordinary rates with most living into adulthood. The numbers of students with health conditions is growing exponentially. This means that education for this group has a new importance, as they will need to be as independent and socially connected as everyone else, as adults.

It also means that Australian school systems and schools need to adapt so they are more in step with dramatic recent progress in medicine. These students need to be better accommodated in education. This has frequently been raised in the literature from many fields, but rarely in education. As most young people with health conditions do not spend long periods of time in hospital[23], schools and school systems need to become much more aware of their obligations to actively monitor and support students who are (a) recuperating at home, for lengthy, frequent or intermittent periods of time, or (b) attending school while managing challenging health conditions.

23. The exception to this is children and young people with cancer who are a very small proportion of the cohort under discussion here.

Disruption of education progress as the result of ill health is complex and highly individualised, but these 12 themes emerged from the literature:

1. Effective communication between the health and education sectors is currently lacking.
2. The ways in which health conditions affect students is highly individualised. Within education, this means that consultation with individual students has particular importance.
3. Communication between staff within a school (teachers, welfare teachers, year level coordinators, psychologists, nurses) and communication with the student and parents is a significant area of concern.
4. The lack of educational policy for this cohort of students results in inequities and exclusion.
5. There is a dearth of Australian educational research about these students.
6. Connection and communication with school has particular importance for children and young people during periods of absence from school. While ICT may be used within programs for these students, it cannot replace a teacher's attention. School level education is not about content alone; it is highly reliant on relationships, communication and connection.
7. School absences are detrimental to learning, but can easily go unnoticed. While some students have major periods of absence (e.g. a year for some with cancer), others have frequent or intermittent absences that are less visible, but are just as damaging to their learning.
8. Social goals have particular importance for adolescent students with health conditions. Not wanting to be seen as different from other students can work against educational achievement.
9. Many students attend school when not fully well which affects attention and learning (e.g. pain, depression, tiredness, lethargy).
10. Pain, fatigue and other health condition effects are invisible and teachers are often not aware of challenges faced by these students.
11. Teachers can have low expectations of students with health conditions.
12. Bullying of these students frequently occurs.

6.3 Counting These Students

The literature reports a range of different figures for estimating the number of children with chronic health conditions, which are mostly derived from US studies. These figures depend on definitions used and the type of study conducted, and range from 5% to over 30%. Recent Australian researchers from the field of adolescent health estimate a figure of 12%.

Within the field of epidemiology, determining numbers of those with chronic illness has been identified as a challenge. Ireys (2001) noted in his important work that conceptual boundaries are required before the prevalence of children with chronic health conditions can be estimated, for any given population. He argues that the 'list-based' or 'conditions-specific' approach in which categories and diagnoses are determined will inevitably exclude many. The main difficulty with this condition-specific list approach, as he pointed out, is that "well over 200" (p. 124) conditions need to be considered for such a list. Who makes decisions about such a list becomes important and any set of criteria will be contested. He also observes,

> *Furthermore, some children have serious ongoing health problems long before an accurate diagnosis is made. Should these children be excluded from services simply because they have an obscure or unknown condition?* (p. 124).

He argues that an alternative 'non-categorical' or 'functional' approach where the consequences of the health condition, including limitations and challenges, is of greater use than the diagnosis, or label, that provides little information about how the individual is affected. And this has particular importance for Australian education.

Within the Australian education context, the list approach is of little use. Most Departments of Education do not have policy for this specific cohort of students, beyond the addition of the words 'health conditions' within general disability policy.

The Victorian Department of Education and Training (DET) does recognise and offer support for those students with "comorbid fragile health"[24] and for those who "are unable to attend their enrolled school" due to the nature and impact of their health conditions (Department of Education and Early Childhood Development, 2014)[25]. This condition-focused list is so limited, however, that few would meet the eligibility criteria. As (White, 2015) points out, most Australian children and young people who live with chronic health conditions do not reside at this extreme end of the continuum.

From this study we know that the RMLP database contains records of at least 61% of Australian school children with cancer, which is very comprehensive. Those with cancer comprise 44% of the RMLP database (949 of 2147 student records). However, childhood cancer is very rare, with rates of 0.014% of the population (Australian Institute of Health and Welfare, 2012).

Given that learning for children and young people with health conditions is likely to be affected by frequent, sporadic or extended periods of school absence, by not being fully well at school (fatigue, pain, impaired concentration) or by bullying, the children and young people represented in the RMLP database indicates only the tip of the iceberg, in terms of the number of children who are entitled to attention and support.

More sensibly, clear policy is required that takes account of the legislative framework surrounding this issue (See White, 2015 forthcoming) should be developed, focused on supporting this growing cohort of Australian students. The United Kingdom, for example, provides a process including advocacy and liaison between health, education and family (Department for Education, 2013) and the American system appears to implement legal requirements more effectively.

In Australian legislation the requirement for schools and education systems to provide 'reasonable adjustment', for students with disability clearly includes those students with health conditions. However, the enactment of this legislation into policy and practice is highly problematic for this cohort of students (See White, 2015).

24. It should be noted that this term 'comorbid' refers to multiple medical conditions that occur simultaneously but may or not be related to each other.
25. The nature of this support is unspecified but the policy states that 'schools will be supported' to provide for assistance for these students.

The discourse in Australian education seems dominated by fear about additional resources, leaving government departments without policy—almost as if this would commit them to significantly larger budgets for this sort of inclusion.

However, students with health conditions and their parents have usually reported that they do not require money or support staff allocated to them. Rather, they want their teachers to know that they have been in hospital or at home because of their condition, or that they are having a bad day and have been struggling with their schoolwork. Communication, flexibility and negotiation about due dates for assignments, work requirements, homework and general consideration is what is usually wished for.

This points to the need for schools and teachers to be supported in their work and to be made aware of their responsibility for these students. Formal processes need to be established to improve communication within schools, so that individual students do not need to explain themselves repeatedly to each of their teachers[26], and so parents are not required to continually seek assistance for their child within their school (See White, 2014; Yates et al., 2010).

This raises legal obligations and logistical challenges, particularly for government education systems. As White (2015) points out, governments are presently left vulnerable to litigation without this clarity.

6.4 School Absence

Records about school absence due to health conditions in Australia are not available. However, the investigation of the RMLP database has provided valuable and important information about school absence. 1,418 of the RMLP students are recorded to have missed more than one school term, which is significant[27].

It is also estimated that approximately 709 students who enter the RMLP programs each year are absent from school for more than one term.

However, not all children and young people who meet eligibility criteria for the RMLP programs gain access to these programs. And many other students have survived illness and now live with health conditions, but numbers are not available from government. Many more children are known to be absent from school for shorter periods each year (e.g. several weeks, several times a year for those with cystic fibrosis) due to their health conditions. While the figures from the RMLP database indicate a significant amount of students are absent from school for substantial periods of time, it only represents a very small number of the entire Australian cohort of students with health conditions. These numbers suggest that most Australian students with one of the 200 health conditions remain invisible and unaccounted for.

6.5 Individual Illness

Students in the Ronald McDonald Learning program have a wide range of chronic health conditions, with many of them having more than one health condition. Despite there being 42 different health conditions specified, there are still 396 students (18.4%) who fall into the ‘other’ category. This is a practical example of the difficulty with trying to list chronic health conditions. As noted earlier, Ireys (2001) observes that there are at least 200 conditions that count. However, this categorization by diagnosis or condition is of little use in education.

26. This applies mostly to secondary schools.
27. Students with cancer and trauma tend to be absent from school for substantial blocks of time.

This project looked specifically at various health conditions, or categories of health condition, for the purpose of trying to understand if there are any different patterns, or things that could be learned, by looking at separate illnesses.

For example, when investigating how many students are in the program from higher or lower socio-economic areas, looking at separate health conditions allowed results to be compared with Australian or international data about connections between socio-economic status and various different childhood health conditions.

With at least 61% of the children with cancer in Australia, in the RMLP database, this has the potential to be developed into a very valuable resource for research about children with cancer.

6.6 Support Provision

Gortmaker et al. (1993) found that the success of young people with childhood chronic health conditions as they transitioned to adulthood, was strongly linked to their socio-economic status in childhood. Goldfeld et al's (2014) recent study also notes the importance of SES in relation to serious childhood illness and advocates education and health professionals working together to improve educational attainment of this cohort.

As a program funded by philanthropy, the RMLP was developed because of the substantial gap in service provision for children and young people with serious health conditions. However, responsibility for educational support rightly belongs to government, particularly Departments of Education. That is not currently acknowledged in policy, programs or monitoring of students.

The Ronald McDonald Learning Program includes many students from the lowest socio-economic areas, and a proportion of students in its programs identify as Aboriginal and Torres Strait Islander. Nevertheless, a bias towards students from higher SES areas exists in the program. Including more students in more remote and disadvantaged areas would no doubt demand additional resource allocation.

Through exploration of the connection between SES and various childhood chronic health conditions in the literature and in the RMLP database, it became apparent that for many conditions, the RMLP database has fewer students from lower SES areas, than one would expect. For many reasons that have been investigated by various researchers in the past, it is often harder for people from lower socio-economic areas to access services.

6.7 Parent Associates

Data from the RMLP database tentatively indicates that more mothers of children with a serious chronic health condition are lone parents, than in the general population. While this fits with research about parenting children with disabilities, it warrants further investigation. Both lone mother and lone father families in the RMLP database, come from lower socio-economic areas, indicating the additional hardships they face.

Recent Australian research (Donnan, 2011; White et al., 2014; Yates et al., 2010) has repeatedly indicated that parents experience significant difficulties when they attempt to communicate with their children's

schools. Legally, parents are acknowledged as 'associates' and have the right to formally advocate on behalf of their children. In the absence of other systems of support, the literature reports that parents are required to continually negotiate educational programs for their children in schools, often meeting with indifferent responses. The need to improve communication with (and within) schools has been identified as the major concern for parents.

6.8 Conclusion

Together with the 12 key themes from the international literature from many scholarly fields, this project focused on the education of young people with health conditions. In the absence of any official government data for education, the Ronald McDonald Learning Program was closely analysed to discern patterns, particularly in relation to Australian Bureau of Statistics (ABS) SES Indexes. The project found that the RMLP, a generous philanthropic organisation, is providing a substantial level of services for a significant number of students with health conditions, and does so particularly comprehensively for those Australian students with cancer.

However, in light of Australian disability legislation, that clearly points to the entitlements of these students, together with what is known from the international literature, Australian educational policy and service provision is lagging seriously behind the substantial improvements made in recent years in medicine.
In summary, Australian state, territory and national Departments of Education, can do much more to meet their obligations towards these students, the majority of whom do not spend extended periods of time in hospital. On the contrary, most of the children and young people who are living long lives due to medical improvements, are not acknowledged, counted or supported through any systematic education-focused process.

Parents are living in strained circumstances and are required to continually advocate for their children in schools, where the invisible nature of the health challenges limit perceptions about entitlement to support. Responsibility for the education of these children and young people, when they are neither in hospital nor in school—but recuperating at home—is not accepted in any systematic way by Departments of Education through either their small-scale hospital special schools or the schools in which the students are enrolled.

6.9 Recommendations

1. To systematically identify students enrolled in Australian schools who have health conditions.
2. To identify students with health conditions as a collective educational cohort, rather than individual young people who are medical aberrations.
3. To retrieve and analyse data related to school absence from education system databases for (a) student stays in hospital, (b) students who spend periods of time at home recuperating, and (c) students with patterns of frequent or sporadic absences due to health conditions.
4. To develop and publish government policy and guidelines to explain the legal entitlement to reasonable adjustment for students with health conditions.
5. To provide practical assistance to schools that explain the legal obligations to support students with health conditions.
6. To establish guidelines and procedures for schools regarding assistance for students with health conditions.
7. To establish a comprehensive checklist for use by families, teachers and health professionals that supports clear communication and monitoring of (a) the effects of the student's health condition on their learning, and (b) reasonable adjustment measures.
8. To develop a system to monitor Australian students with health conditions.
9. To use the RMLP database as a quality resource for further research, particularly about students with cancer and their education.
10. To undertake research into the connections between: (a) social determinants of health, (b) Australian SES data, and (c) the education of students with health conditions.

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