IMMUNISING THE INVISIBLE: THE SCHOOL-BASED IMMUNISATION PROGRAM FOR YOUNG PEOPLE WITH DISABILITY IN SPECIALIST SCHOOLS IN VICTORIA, AUSTRALIA

A thesis submitted in fulfilment of the requirements of the degree of
Doctor of Philosophy

Jenny O'Neill
BA BN RN PGDip MN
ORCHID Identifier: 0000-0002-2137-3776

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The Department of Paediatrics
Melbourne School of Health Sciences
Faculty of Medicine, Dentistry and Health Sciences
The University of Melbourne

ABSTRACT

Immunisation reduces morbidity and mortality, and affects equity in health. This is evident between countries and regions, and within them, where there may be pockets of the population vulnerable to under-immunisation that experience more barriers to preventive health care. People with disability are one such group that are largely invisible in research and immunisation policy decisions. In particular, there is a paucity of data on adolescent immunisation in young people with disability in Australia.

In Australia, students receive adolescent immunisations through the School-based Immunisation Program at 12 to 13 years of age. Vaccine uptake data for the majority of young people with disability attending specialist schools are not included in aggregate immunisation reports. Therefore, there is a clear need for coverage data, as well as qualitative research to clearly identify the barriers and enablers to immunisation for young people with disability in specialist schools. The aim of this thesis was to explore and describe acceptance and delivery of immunisation in specialist schools for young people with disability in Victoria, Australia.

The research was designed as a mixed methods qualitative dominant and sequential explanatory study, with a quantitative phase followed by a qualitative phase. **Phase One** consisted of a prospective cohort study that aimed to measure the uptake of immunisations in specialist schools for young people with disability in Victoria, Australia. Data were collected on immunisation days in the 2017 school year from specialist schools in Victoria in order to determine uptake of diphtheria-tetanus-pertussis (dTPa) and human papillomavirus (HPV) immunisations in eligible students. Demographic data, motor and intellectual function of students, and reasons for non-receipt of dTPa and HPV vaccine were recorded using REDcap^{TM} software and were analysed using descriptive statistics.

Results from this study found that of the 28 specialist schools that participated, dTPa was received by 63% (237/374) of participating students, and HPV dose 1 (HPV1) was received by 66% (76/114) of female students and 67% (174/260) of male students. Three doses of HPV were received by only 41% (100/241) of students. The main reasons for missed immunisation were absence from school, lack of consent and inability to immunise due to the student's behaviour and/or anxiety. Comparative data during the same time period for students in mainstream schools demonstrated significantly higher uptake, at 89% for dTPa and 75% for three doses of HPV, confirming under-immunisation of students in specialist schools.

Phase Two consisted of an in-depth qualitative inquiry that utilised the Socio-Ecological Model (SEM) as a framework, which aimed to determine barriers and facilitators of immunisation for young people with disability in specialist schools in Australia. Data collection included 10 observations of specialist school immunisation sessions, 40 in-depth semi-structured interviews and two focus groups with key stakeholders, including representatives from state government, local government immunisation teams, specialist schools and parents of students. Data were coded and themed using Reflexive Thematic Analysis, as described by Braun and Clarke (2006; 2019). Five main themes were identified: *an invisible population*, *searching for support*, *going the extra mile*, *competing priorities* and *trust takes time*. The intersection of the themes across layers of the SEM varied, demonstrating the complex nature of the issue and the need for this multilayered approach.

The integrated inferences from these two phases resulted in key recommendations. These recommendations include: ongoing rigorous coverage data recorded for ungraded schools; stronger central support for immunisation teams; a review of the immunisation funding model to reflect the extra work and resources required in some schools and to provide for increased follow-up and catch-up; clear guidelines for the use of restraint during immunisation in specialist schools; and a referral pathway for students with disability who cannot be immunised in the school setting.

This thesis has generated new knowledge by establishing that young people with disability in specialist schools in Australia are missing their adolescent vaccinations, and that there are unique barriers to immunisation in this school setting. Phase One provided the first Victorian figures on coverage of adolescent immunisations of young people with disability and Phase Two constitutes the first qualitative research that has been conducted internationally on immunisation in children or young people with disability. Recommendations arising from the integration of findings from both phases have the potential to be translated into policy and practice, and thereby have a significant impact on the health and health equity of young people with disability.

DECLARATION

I declare that:

(i) *This thesis comprises only my original work towards the degree of Doctor of Philosophy, except where indicated in the Preface;*

(ii) *Due acknowledgement has been made in the text to all other material used; and*

(iii) *This thesis is fewer than 100,000 words, exclusive of tables, maps, bibliographies and appendices.*

Jenny O’Neill
March 2020

PREFACE

This is submitted as a thesis with publication. The *Declaration for a Thesis with Publication* is included in Appendix A. The PhD Candidate, Jenny O'Neill, is the first author of all three papers included, and she had primary responsibility for collecting and analysing the data and drafting the manuscripts. Details of the nature and proportion of the contribution of co-authors are included in Appendix B.

ARTICLE 1: ORIGINAL RESEARCH

O'Neill J, Newall F, Antolovich G, Lima S, Danchin M. The uptake of adolescent vaccinations through the School Immunisation Program in specialist schools in Victoria, Australia. Vaccine. 2019;37(2):272-279. DOI: 10.1016/j.vaccine.2018.11.034

Final published version included in Chapter 4 with publisher permission.

ARTICLE 2: COMMENTARY ARTICLE

O'Neill, J, Danchin, M., Antolovich, G, Lima, S, Newall, F. Adolescent immunisation in young people with disabilities in Australia. Med J Aust. 2019 Sep 2;211(5):199-200. DOI: 10.5694/mja2.50293

Final published version included in Chapter 5 with publisher permission.

ARTICLE 3: LITERATURE REVIEW

O'Neill, J, Newall, F, Antolovich, G, Lima, S, Danchin, M. Vaccination in people with disability: a review. Hum Vaccin Immunother. 2020;16(1):7-15. DOI: 10.1080/21645515.2019.1640556

Author submitted version, arising in part from Chapter 3, included in Appendix C with publisher permission. Final published version available online at the Taylor & Francis Ltd web site: https://tandfonline.com/doi/full/10.1080/21645515.2019.1640556

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Fiona, throughout the last seven or so years you have been a true wise advisor on academic, clinical and personal matters. You remain the calm and rational voice in any storm and are able to quietly inspire those around you to find the thrill in hard thinking. Thank you for your academic rigor which I hope has washed onto me, but even more thank you for your positivity and joy in what you do, your ability to see the big picture, and for giving me a desk next to Meg at RCH while I completed this PhD.

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Giuliana, over more than 12 years I have been lucky enough to work with you clinically and I have learnt from you so much about what it is to work in true partnership with families. I feel so fortunate that you were part of my supervision team, as the truest advocate of children and young people with disability that I know. Thank you for helping me realise the core of this research explores – that is the invisibility of those with disability, and how this impact on health care.

Sally, thank you for persevering with the somewhat unreliable technology to provide support to me from a distance. In particular, your wealth of qualitative research experience and knowledge was invaluable.

I would also like to thank my advisory committee, A/Prof Jan Hodgson (chair) and Dr Margaret Heffernan OAM for their support, particularly when I needed to take a period of leave.

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From a personal perspective:

To Nursing Research at RCH - I don't know if you all realise how important it is to have a home during the PhD journey, and you as a team provided the stability, friendship, laughter, spirited discussions and acceptance of everyone's uniqueness that combined to form a rare working atmosphere. You are the best cheer-squad for all achievements and a safe place for all disappointments. Beyond my PhD, being part of the NRD team taught me so much about the power of celebrating the small stuff.

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And to my family – I come from fairly academic stock, and married into a family of academics. The fact that undertaking a PhD was nothing unusual, allowed me to believe that I could do it. The fact that undertaking a PhD was respected by those people closest to me, enabled me to have the support at home to do it.

My love and thanks to Mum and Dad, who, in particular, provided the best writing retreat at Kaye's Paddock, with peace and quiet, beautiful surrounds, amazing food, cups of coffee appearing at a moment's notice and a gentle nudge to return to writing when needed. And to Rob and our girls, for your patience, support, love and encouragement, thank you. Rob you are my rock, always. We have found our way together now through many surprises and challenges, and always your calmness and good humour balances and grounds me. I love you.

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these three years and who found my enormous piles of notes and ceremoniously and gleefully tore them up.

It seems fitting that this thesis should be dedicated to my grandfather Stanislaw (Stanley) Weiner. As a refugee doctor working odd jobs while the Australian government did not recognise his medical degree, Stan ensured that my father was in the first group of children to receive the polio vaccine in 1956. He went on to make an enormous contribution to Australia, politically and professionally, despite a background of significant hardship, displacement and loss. In researching and writing on health and equity I pay respect to the hard yards of those before me, like Stan.

PUBLICATIONS AND PRESENTATIONS DURING PHD CANDIDATURE

PUBLICATIONS

O'Neill J, Newall F, Antolovich G, Lima S, Danchin M. The uptake of adolescent vaccinations through the School Immunisation Program in specialist schools in Victoria, Australia. Vaccine. 2019;37(2):272-279. doi: 10.1016/j.vaccine.2018.11.034.

O'Neill, J, Danchin, M., Antolovich, G, Lima, S, Newall, F. Adolescent immunisation in young people with disabilities in Australia. Med J Aust. 2019 Sep 2;211(5):199-200. doi: 10.5694/mja2.50293.

O'Neill, J, Newall, F, Antolovich, G, Lima, S, Danchin, M. Vaccination in people with disability: a review. Hum Vaccin Immunother. 2020;16(1):7-15. doi: 10.1080/21645515.2019.1640556.

PRESENTATIONS

Immunising the invisible: Immunisation in specialist schools for young people with disabilities. Completion Seminar, The Royal Children's Hospital, Melbourne, 9 December 2019.

Immunising the invisible. The Department of Paediatrics, The University of Melbourne 3MT, The Royal Children's Hospital, Melbourne, 16 October 2019.

Immunisation in specialist schools for young people with disabilities: Qualitative findings. The Melbourne Children's Campus Student Symposium, The Murdoch Research Institute, Melbourne, 11 October 2019.

"Little tiny teams doing big programs": Immunisation in specialist schools in Victoria, Australia. Melbourne Children's Nursing Research & Clinical Innovations Symposium, The Royal Children's Hospital, Melbourne, 10 September 2019.

"Doing what we have to do": Giving school immunisations to young people with disabilities. The 11th National Paediatrics Bioethics Conference, The Royal Children's Hospital, Melbourne, 5 September 2019.

"Little tiny teams doing big programs": Immunisation in specialist schools in Victoria, Australia. The 11th NZ Immunisation Conference, The University of Auckland, Auckland, 6 September 2019.

The uptake of adolescent vaccinations through the School Immunisation Program in specialist schools in Victoria, Australia. The 16th National Immunisation Conference, Adelaide, 5-7 June 2018.

Immunisation in specialist schools: Early findings. Melbourne Children's Nursing Research & Clinical Innovations Symposium, The Royal Children's Hospital, Melbourne, September 2017.

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LIST OF ABBREVIATIONS

ABS	Australian Bureau of Statistics
ACIR	Australian Childhood Immunisation Register
AIR	Australian Immunisation Register
ASD	Autism Spectrum Disorder
ATAGI	Australian Technical Advisory Group on Immunisation
CFIR	Consolidated Framework for Implementation Research
COM-B	Capability-Opportunity-Motivation-Behaviour Model
CP	Cerebral Palsy
CSHCN	Children with Special Health Care Needs
DET	Department of Education and Training
DHHS	Department of Health and Human Services
DM	Dual Mode School
DTP	Diphtheria-Tetanus-Pertussis Vaccine
dTPa	Diphtheria-Tetanus-Pertussis Booster
GP	General Practitioner
GVAP	Gavi Vaccine Alliance Partnership
HBM	Health Belief Model
Hep A	Hepatitis A
Hep B	Hepatitis B
Hib	Haemophilus Influenza Type B
HIV	Human Immunodeficiency Virus
HPV	Human Papillomavirus
HREC	Human Research and Ethics Committee
ICF	International Classification of Functioning, Disability and Health
ID	Intellectual Disability
IPD	Invasive Pneumococcal Disease
IQ	Intelligence Quotient
LGA	Local Government Area
LMIC	Low-Middle Income Countries
Men B	Meningococcal B
Men ACWY	Meningococcal ACWY
MMR	Measles-Mumps-Rubella Vaccine

NCIRS	National Centre of Immunisation Research and Surveillance
NDIS	National Disability Immunisation Strategy
NDS	National Disability Strategy
NHMRC	National Health and Medical Research Committee
NIP	National Immunisation Program
NiTAG	National Immunisation Technical Advisory Group
NSW	New South Wales
PBAC	Pharmaceutical Benefits Advisory Committee
PD	Physical Disability School
Polio	Poliomyelitis
PPCT	Process-Person-Context-Time Model
PSD	Program for Students with Disabilities
SAGE	Strategic Advisory Group of Experts on Immunisation
SBIP	School-based Immunisation Program
SDH	Social Determinants of Health
SDM	Shared Decision-Making Model
SDS	Special Development School
SEM	Socio-Ecological Model
SES	Socioeconomic Status
SHCN	Special Health Care Needs
SMD	Social Model of Disability
SS	Specialist School
STI	Sexually Transmitted Infection
TDF	Theoretical Domains Framework
TIP	Tailoring Immunization Program
TTI	Theory of Triadic Influence
UK	United Kingdom
UN	United Nations
UN CRPD	United Nations Convention on the Rights of Persons with Disabilities
UNICEF	United Nations Children’s Fund
USA	United States of America
VPD	Vaccine-Preventable Disease
WHO	World Health Organization

1 INTRODUCTION

1.1 Origins of the Thesis Topic

This PhD thesis arose out of observations in the clinical setting. The PhD candidate (referred to in the thesis as 'the Researcher') is a paediatric nurse with 20 years' experience, most of this at The Royal Children's Hospital, a large tertiary paediatric hospital in Melbourne, Australia. For the last eight years, the Researcher has worked as a Clinical Nurse Consultant in the Department of Neurodevelopment and Disability, assisting families with children with a range of neurodevelopmental disabilities. Incorporating the Researcher's additional interest in adolescent health, this work involved meeting with many families with children with disability in early adolescence to assess their health education and assist with puberty questions and needs. Part of this assessment concerned adolescent immunisations that are offered to all young people aged 12 to 13 years old in Victoria through the School-based Immunisation Program (SBIP). When questioned, families were consistently unsure if their child had received these vaccines, or whether they needed them given their other health needs and underlying disability. Based on this experience, the Researcher was led to question the adequacy of information available to families with children with disability about the adolescent immunisations, and whether these families perceived the immunisations as relevant. At this stage, the Researcher's main questions were:

1 *What specific concerns do families of adolescent children with disability have about immunisations?*

2 *What resources are there to support these families' immunisation information needs?*

With no specialised immunisation background beyond general paediatric nurse knowledge, there was some assumption by the Researcher that barriers to immunisation for these families would be largely issues of vaccine hesitancy, leading to reluctance to consent. However, very early in the research process, it became apparent that barriers to adolescent immunisation for young people with disability were determined by much broader issues than consent. These issues included coverage data, systems, policies and logistics. Furthermore, it became clear that this important preventive health measure within the context of this population has received little to no attention in policy or research. Therefore, at its core, this research became a thesis centred around the concept of health equity.

This thesis fills a gap in knowledge about adolescent immunisation in young people with disability and the SBIP in specialist schools. In addition, this thesis exposes the reality that in a wealthy country such as Australia, which has comprehensive immunisation programs and high childhood immunisation rates, there can be groups who remain significantly under-immunised and therefore vulnerable to vaccine-preventable disease (VPD) in a way that would be deemed unacceptable for the population as a whole. The fact that this particular group are young people in specialist schools should be alarming, not only due to their potential extra health vulnerabilities, but also in relation to the political and cultural climate in Australia, which is only just now recognising the extent of historical inequities, prejudice and abuse, which has resulted in significant harm for individuals with disability.

1.2 Structure of the Thesis

This research evolved over the three years of candidature, as connections with stakeholders developed and knowledge, or previously unrecognised absence of information, was discovered. The structure of this thesis represents the evolution of the research while adhering to the academic requirements of a dissertation. The reader will find a variation in the usual discussion of the overall research design early in the thesis. Due to the absence of any applicable data regarding uptake in this group, (described in Chapters 4 and 5), the second phase of the study, and therefore the mixed methods study design was not conceptualised until the Phase 1 study was complete. Therefore the mixed methods overview is described in Chapter 7 to reflect the true chronological process and the iterative nature of the thesis. In this way the reader is asked to appreciate the challenges of researching an invisible population.

Chapter 1 provides extensive background on immunisation as a public health measure, including explanation of key terms, the impact on public health, and an overview of immunisation in Australia with particular concentration on the adolescent immunisations and the SBIP used to deliver these. This chapter also provides a background on disability history and disability rights, before presenting information on disability in Australia, and education for young people with disability in Australia, in order to provide context for the specialist schooling system. Finally, this chapter introduces the key concept of health equity, which is necessary to appreciate the significance of this topic.

Chapter 2 reviews the literature on immunisation in young people with disability and identifies the gap in research, particularly with regard to adolescent immunisation in young people with disability in Australia, immunisation in specialist schools, and qualitative research. This highlights the importance and significance of this thesis. This literature review resulted in a publication in the peer-reviewed journal, *Human Vaccines & Immunotherapeutics*, which was published in 2019 and is included in Appendix C.

Chapter 4 comprehensively outlines the first of the two studies presented in this thesis (Phase One Study), which is a prospective cohort study measuring immunisation coverage of the diphtheria-tetanus-pertussis booster (dTPa) and the human papillomavirus (HPV) vaccine given through the SBIP in specialist schools in Victoria. This chapter is presented as a published article with some additional information on methods.

Chapter 5 is a bridging chapter that brings together the prior knowledge on the topic and the results of the Phase One Study to justify the significance and research design of the Phase Two Study. This chapter is presented as a published commentary article.

Chapter 6 discusses the choice of conceptual framework used in the Phase Two Study. This includes discussion of the criteria deemed important for a framework to assist in answering the research questions, a brief appraisal of some common conceptual frameworks used in preventive health research, and the justification of the adoption of the Socio-Ecological Model (SEM). Further information is then provided about the development and iterations of the SEM, and how it is applied to the Phase

Two Study.

Chapter 7 outlines the methods used for the Phase Two Study, which is an in-depth qualitative study using interviews, focus groups and observations of a range of stakeholders with roles in the SBIP in specialist schools. This includes discussion of the mixed methods utilised in the thesis, the design, participant recruitment, data collection, data analysis and ethical issues.

Chapter 8 discusses the findings of the Phase Two Study, presented as five themes with thirteen subthemes. Each theme and subtheme is supported with participant quotes. This develops an illustrated representation of the interaction of these themes and subthemes, which highlights barriers and facilitators to immunisation of young people with disability in specialist schools.

Chapter 9 is the final chapter, which brings together the findings from both studies in three integrated inferences. These overall inferences are discussed in reference to the literature and the new knowledge contributed by this thesis is highlighted. The policy and practice considerations are summarised in seven key recommendations. This chapter also discusses limitations and future research.

2 BACKGROUND AND CONTEXT

2.1 Introduction

This chapter will provide background information relevant to immunisation, disability and health equity. An overview of immunisation across the lifespan, immunisation internationally and in Australia, and specifically the SBIP in the State of Victoria will be presented. The definitions and types of disability, disability in Australia and disability education in Australia will be discussed. The concept of health equity with respect to disability and issues of equity in public health and immunisation will be addressed. Thus, key background information will provide the context for the following literature review, and the topic under research.

2.2 Immunisation and Public Health

The public health impact of immunisation[*] is unparalleled. The World Health Organization (WHO) estimates that two to three million lives a year are saved through immunisation by preventing or reducing the severity of disease, and eliminating or reducing the risk of associated complications.[1] Reducing morbidity and mortality is far more cost effective than treating disease and supporting associated lost productivity, so immunisation also has significant economic benefits. In addition, immunisation has the potential to reduce the inequity of poor health, as vulnerable groups in society have a higher burden of infectious disease.[1,2]

Since 1990, child deaths from VPDs have decreased from over five million to 1.8

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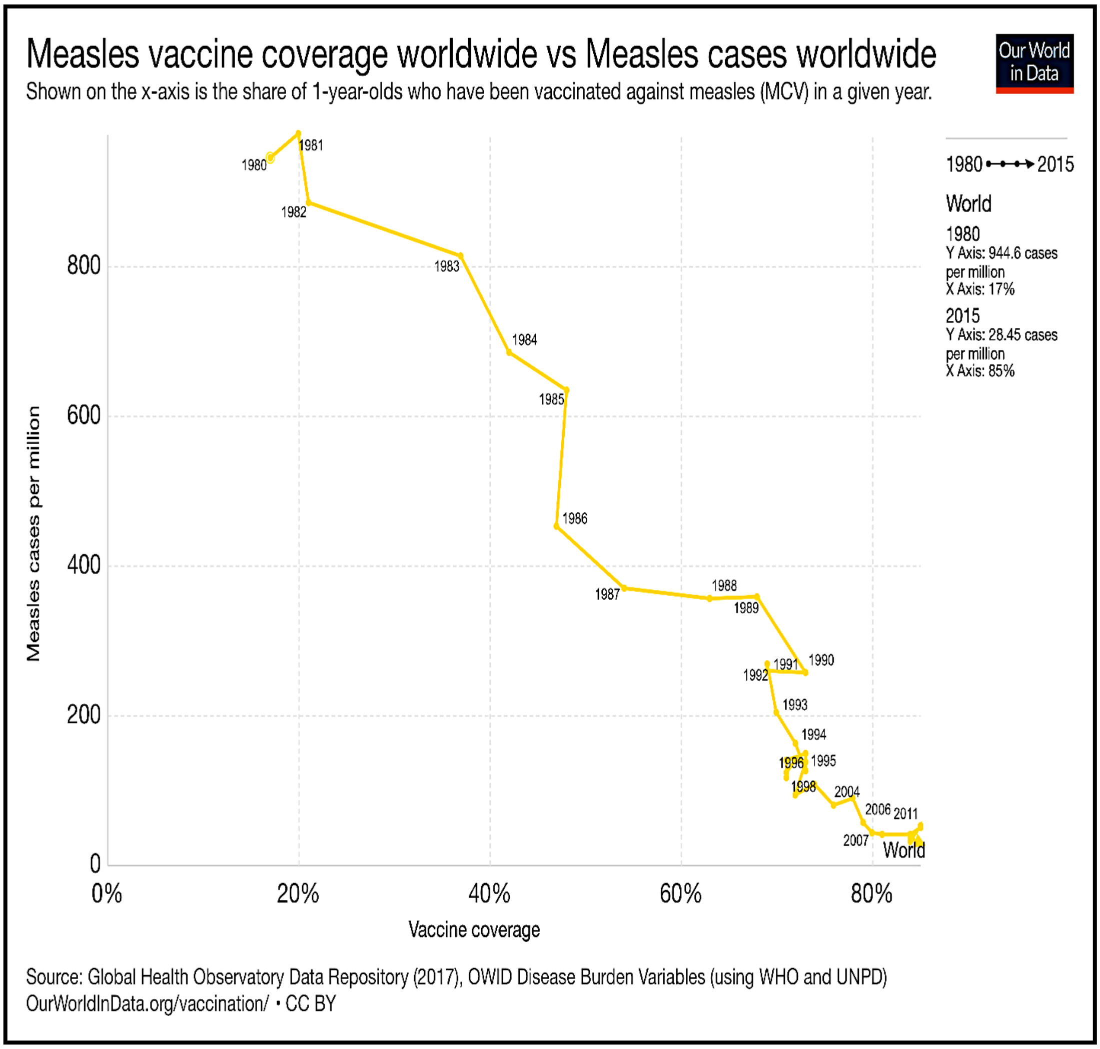
[*] The definition of 'vaccination' refers to the physical act of having the vaccine, whereas the term 'immunisation' encompasses the act of receiving the vaccine and the process of inducing immunity to an infectious agent as the result of administering that vaccine. In both academic and lay writing, these two terms are used somewhat interchangeably and are accepted as such. For consistency, this thesis will refer to the agent as a vaccine and the process as immunisation.

million a year.[3] This directly correlates with immunisation development and delivery and is illustrated in Figure 2-1, with reference to measles cases in relation to measles immunisation coverage globally.



Measles vaccine coverage worldwide vs Measles cases worldwide

Shown on the x-axis is the share of 1-year-olds who have been vaccinated against measles (MCV) in a given year.

Source: Global Health Observatory Data Repository (2017), OWID Disease Burden Variables (using WHO and UNPD)
OurWorldInData.org/vaccination/ • CC BY

Figure 2-1 Measles Cases in Relation to Measles Immunisation Coverage Globally

Source: OurWorldInData.org/vaccination/

2.3 Vaccine-Preventable Diseases: A Global Perspective

The WHO currently lists 26 VPDs for which there are effective vaccines available (see Table 2-1).[†]

[†] For detailed information about the recommended populations, administration and scheduling of all vaccines available see https://www.who.int/immunization/diseases/en/

Table 2-1 World Health Organization List of Vaccine-Preventable Diseases

Cholera	Malaria	Rubella
Dengue	Measles	Tetanus
Hepatitis A	Meningococcal meningitis	Tick-borne encephalitis
Hepatitis B	Mumps	Tuberculosis
Hepatitis E	Pertussis	Typhoid
Haemophilus influenzae type B (Hib)	Pneumococcal disease	Varicella
Human papillomavirus (HPV)	Poliomyelitis	Yellow Fever
Influenza	Rabies	
Japanese encephalitis	Rotavirus	

Source: https://www.who.int/immunization/diseases/en/

The ultimate goal of an immunisation program is high vaccine coverage and ultimately eradication of the related VPD. This is achieved when the global incidence of the disease is zero. Vaccine-preventable diseases are susceptible to eradication if:

- *they are only transmitted by humans*
- *the illness is easily diagnosed when transmitted*
- *infection from the disease provides lifelong immunity*
- *there is an effective and widely administered vaccine*

Vaccine-preventable diseases have varying virulence and consequently require varying levels of population uptake to afford true herd immunity. Herd immunity occurs at the point where there are enough individuals vaccinated against a disease within a population to confer protection to both the vaccinated individuals and to those who are unimmunised. Once achieved there is the potential to eradicate the disease.[4]

Smallpox remains the only VPD to have been eradicated. Although a number of other VPDs are on the verge of eradication, this achievement still remains elusive despite elimination from significant portions of the globe. Elimination, where the incidence of the disease is zero in a specific geographical region, occurs inequitably, usually due to the socioeconomic situation in the region. Lower and middle income countries (LMICs) often lack the economic resources to build the robust primary care infrastructure necessary to support widespread and organised public health programmes such as immunisation, and are often disrupted by conflict, famine, displacement and natural disasters.[5–8] This results in stark differences in the incidence and deaths from VPDs between regions, as seen in the comparison of VPDs in Sub-Saharan Africa and Central Europe over time in Figures 2-2 and 2-3.

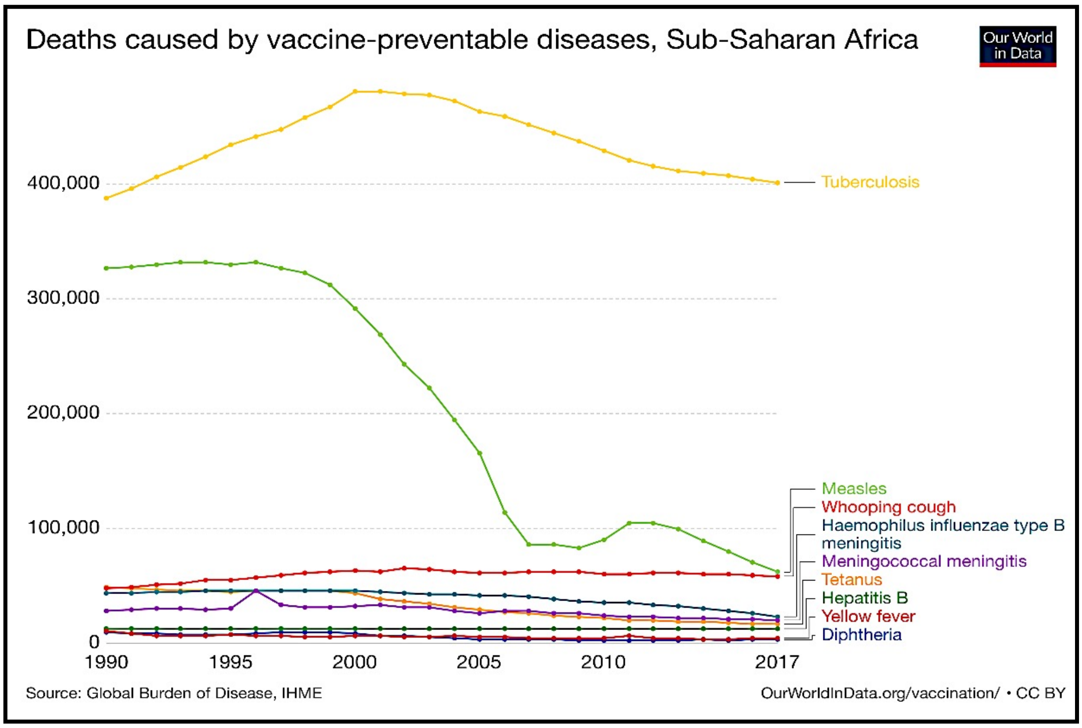


Figure 2-2 Deaths Caused by VPD in Sub-Saharan Africa

Source: OurWorldINData.org/vaccination/

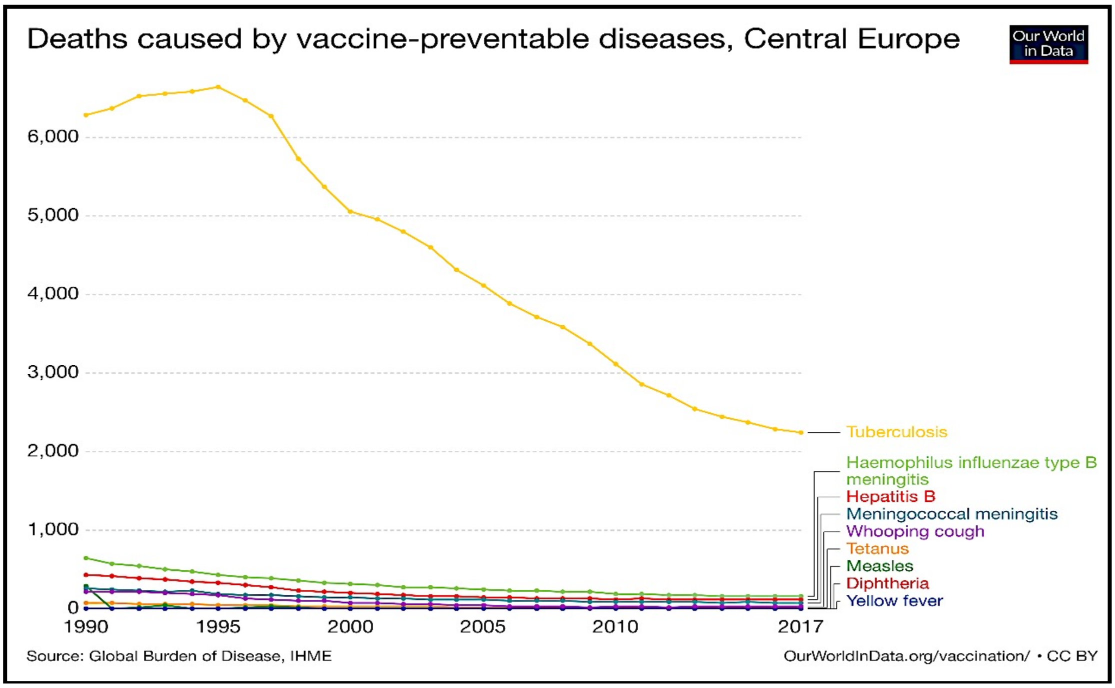


Figure 2-3 Deaths Caused by VPD in Central Europe

Source: OurWorldINData.org/vaccination/

In recognition of this global inequity in immunisation supply and delivery, the current Global Vaccine Action Plan (GVAP) was developed in 2011 as a joint endeavour between several international partners, including WHO, Gavi (the Vaccine Alliance), the Bill and Melinda Gates Foundation, the United Nations Children's Fund (UNICEF) and the United States National Institute of Allergy and Infectious Disease.[8] The GVAP sets out goals and objectives to reach targets in immunisation, specifically focused on LMICs. While a full examination of issues of supporting and optimising immunisation in LMICs is beyond the scope of this thesis, some notable gains have been made. This includes an increase in fully immunised infants across LMICs, an increase in countries with a National Immunisation Technical Advisory Group (NiTAG), and the elimination of neonatal tetanus from three countries since the plan was put in place.[9]

However, there is certainly still much work to be done globally to ensure that people living in LMICs have access to universal health care, including immunisation, especially those living some distance from health centres in countries with poor infrastructure.[1] These ongoing barriers to immunisation in LMICs are closely related to the Social Determinants of Health (SDH).[10] An appreciation of the role of the SDH in immunisation uptake can also aid in understanding pockets of low coverage in high-income countries.

2.4 The Social Determinants of Health

The SDH describe the social and environmental factors, often shaped by economic, political and cultural conditions, that affect the health of individuals and groups.[11] This can include factors such as access to education, which may impact health literacy, earning potential and mental health; geographical area and housing environment, which may affect access to health care; resources such as clean water and sanitation; and susceptibility to natural disasters, food security and conflict.[5] Other key factors within the SDH include socioeconomic position, early life circumstances, social exclusion, social capital, employment and work.[12]

The Dahlgren-Whitehead model in Figure 2-4 illustrates the SDH. This model demonstrates the relationship between individual, social and environmental factors. Factors most closely related to the individual are in the proximate layers, expanding out to encompass more indirect social and environmental influences. This model allows for a complex understanding of health and disease influences and the multi-component interventions that are usually required in addressing health disparities. A core tenant of this model is the pivotal role of policy, in particular its capacity to provide and promote equity of access to health care.[13]

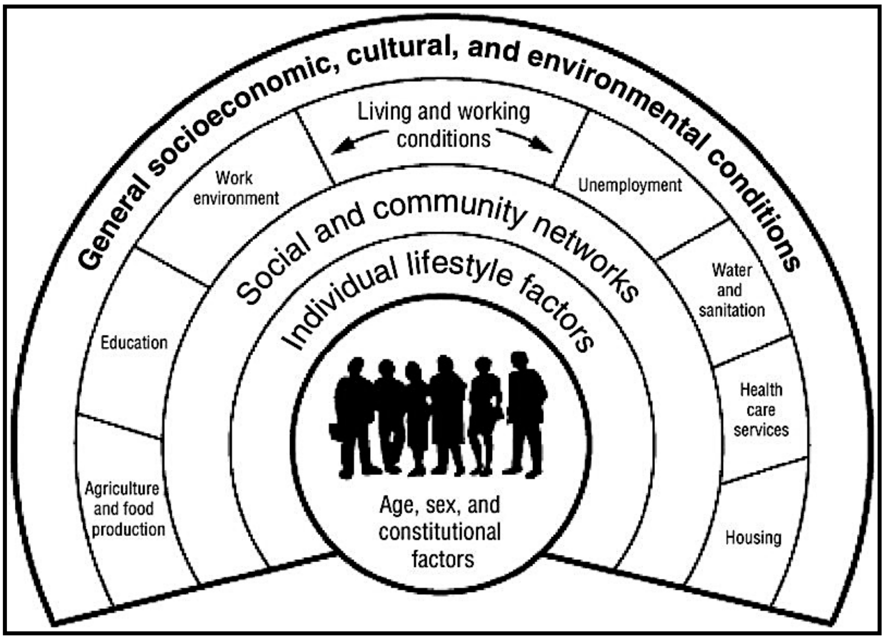


Figure 2-4 The Dahlgren and Whitehead Social Determinants of Health Model

Source: Dahlgren G, Whitehead M. Policies and strategies to promote social equity in health. Stockholm, Sweden: Institute for Futures Studies; 1991.

In recognition of this pivotal role of policy, Boyce et al. (2019) describe inequity in immunisation related to the SDH succinctly:

> *Avoidable differences in immunisation coverage between population groups that arise because barriers to immunisation among disadvantaged groups are not addressed through policies, structures, governance or programme implementation.*[6]

The reality is that existing programs often do not target those who are already vulnerable to missing immunisations.[10] Under-immunised populations within high-income countries may be particularly invisible as overall immunisation rates are usually high.[6] The consequences of sometimes unrecognised pockets of under-immunisation can be significant. An example is the United Kingdom (UK), which previously attained endemic measles elimination status, only to recently have this revoked due to re-emergence of this disease.[14] Thus, an understanding of the many factors that impact immunisation in specific populations is vital in reducing and maintaining a reduction in VPDs. This is true also for immunisation in Australia.

2.5 Immunisation in Australia

Australia, like many high-income countries, has a well-coordinated and established immunisation program. Indeed, Australia is a world leader in vaccine research and immunisation delivery, with routine immunisations offered across the lifespan to the Australian population since the 1940s.[9] The immunisation schedule in Australia throughout the last decade in particular, has changed frequently, in response to new vaccine development, research findings and social and political influences.

The National Immunisation Program (NIP) in Australia is responsible for overseeing the administration of vaccines through state and local government authorities. This body was established in 1997 as a consequence of the first immunisation strategy in Australia, which was initiated in 1993 aiming to restructure immunisation delivery and records to enable governments to better improve uptake rates and target immunisation efforts.[15] Any changes to the immunisation schedule are effected through the Australian Technical Advisory Committee (ATAGI) and the Pharmaceutical Benefits Advisory Committee (PBAC).

The Australian Childhood Immunisation Register (ACIR) commenced in 1996 to record immunisations given up to seven years of age. From September 2016, this became the Australian Immunisation Register (AIR), which now provides a whole-of-life register for all immunisations, predominantly given at general practice and community clinics.[4] Since 2018, the AIR also records adolescent immunisations, given through the SBIP, which is the focus of the thesis. Historical milestones relevant to adolescent immunisations and the SBIP in Australia are shown in Table 2-2, with developments that have occurred during this thesis research, which commenced in 2016, highlighted in bold.

Table 2-2 Significant Developments in the Immunisation Program in Australia, Relevant to Adolescent Immunisations

Date	Development
1804	First vaccine (smallpox) used in Australia
1924	First mass vaccination program in Australia (diphtheria toxoid)
1923	First school-based vaccination program commenced (diphtheria)
1956	Inactivated polio introduced in May, oral polio introduced in September
1980	Smallpox eradicated globally
1983	Measles-Mumps vaccine and Hep B vaccine introduced
1988	The responsibility for immunisation programs transferred to the states and territories
1989	Measles-Mumps-Rubella (MMR) vaccine introduced
1990	Legislation in Victoria to require documentation of immunisation status when a child is enrolled in primary school enacted through the Health Amendment Act 1990
1993	The First National Immunisation Strategy (1993-2001) established, produced by a panel of experts on behalf of the National Health and Medical Research Council (NHMRC) and including a common vaccination schedule and pricing in all states and territories
1994	MMR vaccine introduced in Year 6
1996	The ACIR launched as the first national childhood immunisation register in the world
1997	The NIP launched. Public Health Outcome Funding Agreements established between the Australian federal and state and territory governments to fund the NIP
	The ATAGI established to provide technical advice related to government vaccine funding decisions directly to the federal health minister
	The National Centre for Immunisation Research and Surveillance (NCIRS) established to provide technical support to ATAGI
	The first Victorian Immunisation Strategy (1997) developed

Date	Development
1998	MMR primary school program ceases. Hep B introduced in Year 7 secondary school
	Introduction of a national scheme of financial incentives linked to immunisation delivery and uptake for General Practitioners (GPs) and parents
2001	Hep B vaccine introduced in the Year 7 school program
2003	Mass Meningococcal C program introduced (until 2006)
2004	Diphtheria-tetanus-pertussis booster (dTPa) introduced in Year 10 of the School Immunisation Program
2005	Varicella vaccine introduced in Year 7 for those who have not had it or evidence of varicella infection
	The National Vaccine Storage Guidelines (Strive for 5) published to assist immunisation service providers to maintain the safety and viability of vaccines
	The *National Health Act 1953* amended to provide for the evaluation of the cost-effectiveness of vaccines by the Pharmaceutical Benefits Advisory Committee
2007	The National HPV Vaccination Program commenced for females, with school-based immunisations offered in Year 7 with catch-up available for females 14-18 years
2008	National HPV Vaccination Program Register established
2009	Second Victorian Immunisation Strategy (2009-2012) developed
2010	Report on the management of adverse events associated with Panvax and Fluvax (the Horvath Review) published, examining the vaccine safety system in Australia following adverse events associated with the influenza vaccine in children
2013	National HPV Vaccination Program rolled out through the SBIP to males in year 7 with catch-up until Year 9
2014	AusVaxSafety implemented, led by the NCIRS and funded by the Australian Government Department of Health
	The Essential Vaccines Procurement Strategy developed. Under the new arrangement, the Commonwealth is responsible for procurement of NIP vaccines while the implementation will remain the responsibility of the states and the territories
2015	The dTPa booster transitions from Year 10 to Year 7

Date	Development
2016	**Family assistance linked to immunisation requirements *'No Jab, No Pay'* legislation. Under this legislation, children with medical contraindications can continue to be exempt but conscientious objection on non-medical grounds is no longer a valid exemption**
	Victorian legislation *'No Job, No Play'* introduced, with immunisation requirements linked to enrolment in early childcare education and childcare centres. ACIR expanded to become the AIR, a whole-of-life register
2017	**NIP expanded to provide free catch-up vaccination for all people aged 10-19 years and refugees aged 20 years and older**
	Meningococcal ACWY (Men ACWY) introduced for young people aged 15-19 as a time-limited campaign in Victoria. Offered in the SBIP for Years 10-12
	Catch-up varicella program at Year 7 ceased
2018	**HPV vaccination records transferred to the AIR**
	HPV Vaccination Program changed from 3-dose 4 valent vaccine to 2-dose 9 valent vaccine
	Legislation in Victoria to allow an approved pharmacist to administer MMR vaccine from the age of 16 years
2019	**The Third National Immunisation Strategy for Australia (2019-2024) developed**

Source: Adapted from the National Centre for Immunisation Research and Surveillance (2019) and Royle J, Lambert SB. Fifty years of immunisation in Australia (1964-2014): the increasing opportunity to prevent disease. J Paediatr Child Health. 2015 Apr;51(1):16-20.

Currently, Australia has a comprehensive government-funded immunisation schedule across the life span protecting against 17 diseases,[‡] including childhood and adolescent immunisations, immunisations for older people and immunisations for special risk groups.[4] As a consequence of this program, polio has been eradicated in Australia since 2000 and endemic measles since 2005 (ratified by WHO in 2014).[16,17] The impact of many other VPDs, such as diphtheria, tetanus, pertussis, Haemophilus influenza type B (Hib), rotavirus and HPV have been greatly reduced.[16]

Although national immunisation rates for childhood vaccinations in Australia are already high, with 93.5% of children aged five years fully immunised in the 2016-2017 year, a key aim of the NIP is to increase uptake to 95%.[4,15] While immunisation in Australia is not mandated, there are some financial incentives to encourage compliance. Medical practitioners have financial incentives to immunise children overdue for immunisations. The '*No Jab, No Pay'* policy introduced by the Federal Government in January 2016 prevents an unimmunised child from accessing certain social welfare payments.[18] State governments in Victoria and Queensland have also introduced the *'No Jab, No Play'* policy mandating that to attend childcare or kindergarten a child must be up-to-date with their immunisations.[19,20] Under both these policies, conscientious objection is no longer an approved exemption.[18,20,21]

Despite the overall high immunisation coverage in Australia, there are recognised pockets of low coverage in every state in Australia, especially on the north coast of New South Wales (NSW) and in the inner-city areas of both Melbourne and Sydney. This is due, in part, to a small but persistent anti-vaccination group. An estimated 3.3% of Australian children are currently affected by presumptive or registered vaccine objection.[21] More significantly, despite high overall childhood immunisation rates, nearly half of all parents have some vaccine concerns or are 'vaccine hesitant'.[22,23]

2.6 Vaccine Hesitancy

Vaccine hesitancy is a psychological state that describes a range of attitudes, beliefs and concerns about vaccinations, which results in a spectrum of vaccine decision-

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[‡] For the current Australian immunisation schedules see https://www.health.gov.au/health-topics/immunisation/immunisation-throughout-life/national-immunisation-program-schedule

making and behaviour by parents, including acceptance of all vaccines, accepting some vaccines, delaying or splitting combined vaccines, and refusal of all vaccines.[24–26] The WHO Strategic Advisory Group of Experts on Immunisation (SAGE) working group on vaccine hesitancy has defined the term:

> *Vaccine hesitancy refers to delay in acceptance or refusal of vaccination despite availability of vaccination services. Vaccine hesitancy is complex and context specific, varying across time, place and vaccines. It is influenced by factors such as complacency, convenience and confidence.*[24]

The reasons for vaccine hesitancy in primary caregivers of children primarily include parental concerns about the safety of vaccines, concerns about the number of vaccines given together, and a lack of understanding about the potential severity of diseases vaccines protect against.[22,27] Concerns specific to the HPV vaccine in academic health literature include parental anxiety about promoting sexual activity by condoning an immunisation against a sexually transmitted infection (STI).[27,28] A consistent finding about parental consent to immunisation is that a recommendation to vaccinate from a trusted health professional is effective in reassuring hesitant parents and the strongest predictor of vaccine uptake.[23,27,29–31]

Access to immunisation is also affected by social, logistical and structural barriers. While access issues were originally encompassed within vaccine hesitancy, Bedford et al. has argued that pragmatic reasons for under-immunisation do not reflect hesitancy, and in fact the terminology must make this clear in order to adequately target interventions.[32]

The adoption of the SDH lens to immunisation allows for both hesitancy and pragmatic barriers.[32] Despite its privileged economic position, Australia is not immune to the effect of the SDH on vaccine uptake.[13,33] Immunisation research concerning Australian populations has identified issues of access and lack of knowledge and information about immunisation in refugees and migrants,[34–36] Aboriginal and Torres Strait Islander Australians,[37–39] rural populations,[40–42] and low income or resource poor contexts.[42,43] Immunisation in Indigenous Australians has been one example of the success of targeted interventions following identification of specific barriers, with immunisation uptake of Indigenous children at 60 months surpassing that of non-Indigenous children in Australia by the end of 2015.[44] There is less known about barriers specific to adolescent immunisations in Australia.

2.7 Adolescent Immunisation

Historically, the focus of the global immunisation effort has been on immunisations in early childhood, which is a critical time to protect infants and children against infectious diseases.[8] However, the efficacy of some vaccines wanes over time, leaving adolescents and young adults with suboptimal immunity and the potential to impact population herd immunity.[45,46] The implications of this include a re-emergence of VPDs in adolescence and young adulthood, resulting in a portal for infection spread to infants under 12 months who are not yet fully immunised and more vulnerable to severe infection.[45] Other reasons for the introduction of a vaccine in the adolescent schedule include the need for catch-up vaccinations for individuals who have missed immunisations in childhood, or the introduction of a new vaccine, such as HPV.

Adolescent immunisation uptake lags behind early childhood rates globally.[47] In the United States of America (USA), the Healthy People 2020 guidelines has set a target of above 80% coverage for adolescent vaccination.[48] There are no clear guidelines in Australia. Some challenges specific to adolescent immunisations globally include: the lack of a robust infrastructure for delivery, especially in countries that do not have a school immunisation program; the lack of comprehensive registers to track and record uptake of adolescent vaccines; and the more fragmented nature of adolescent health care.[8,49,50] In high income countries such as Australia, as with childhood vaccinations, vaccine hesitancy does have an impact on adolescent immunisation coverage, with the major issues of vaccine hesitant parents for adolescent vaccines including underestimating the importance of the vaccines offered, and safety concerns.[51–53] However, as with most countries and regions, practical barriers or access issues are estimated to play the greatest role. The relative contribution of these factors in the adolescent population in Australia is unknown.

Logistical issues can arise because the vast majority of young people enjoy good health and do not regularly attend health care settings, which limits opportunistic preventive health care interventions.[49,50] While immunisations are likely to be a high priority for many parents of young infants, they are often overlooked in adolescence, which is a time of emerging independence, when parental control lessens and self-determination increases, including with respect to health-related decisions.[45]

2.8 Adolescent Vaccines Scheduled in Australia

At the commencement of this research in 2016, there were three government-funded immunisations recommended for all adolescents in Australia. These included dTPa, the varicella vaccine, which was available for the cohort of adolescents who missed the second varicella vaccine introduced at four years of age in 2009, and a three-dose course of the HPV 4-valent vaccine. These immunisations were scheduled at 12 to 13 years of age or the first year of secondary school in most states.

At the end of 2017, the varicella catch-up program ceased, and this corresponded with the introduction of the two-dose 9-valent HPV vaccine in 2018. Also introduced as state-funded, time-limited, one-year programs in 2017, 2018 and 2019 was the Meningococcal ACWY (Men ACWY) vaccine, initially for young people 15 to 19 years and subsequently given at 15 years. Information about these vaccines is briefly outlined below.

2.8.1 Diphtheria-tetanus-pertussis booster

The diphtheria-tetanus-pertussis (DTP) vaccine is given at two, four and six months of age, with booster doses given at 18 months, four years and in adolescence. Coverage at four years is close to 94% nationally and adolescent coverage in 2015 in Victoria was 90.76%.

Diphtheria

Diphtheria is a highly infectious disease caused by the bacterium *Corynebacterium Diphtheriae*, which prior to vaccination in the 1950s was the most common infectious cause of death in Australia. Diphtheria manifests via respiratory illness or skin infection and is spread by respiratory droplets and secretions or contact with infected skin lesions. Cardiac toxicity occurs in 5-10% of infected people and is the major cause of mortality.[54] Due to an effective immunisation campaign, diphtheria was almost eradicated in Australia by the 1960s, but isolated cases in travellers returning from countries where it is still endemic have shown the potential for re-emergence should the immunisation rate fall. For optimal immunity, the schedule in Australia recommends three doses of diphtheria vaccine are given in the first six months, with booster doses at 18 months, four years and adolescence. Uptake required for herd immunity is 75%.[54]

Tetanus

Tetanus is an infection that can occur in a wound contaminated by *Clostridium tetan,* which is a bacterium that lives in the environment. It is not an infectious bacterium and cannot be spread between people. Tetanus therefore cannot be reduced or eradicated through herd immunity and individuals need protection through immunisation to reduce their risk of infection. Tetanus is now rare in Australia, with about 10 notifications a year in the last few decades.[55]

Pertussis

Bordetella pertussis causes a respiratory illness known as whooping cough, which is highly infectious. Without immunisation every one case of pertussis is transmitted via droplets to 15 to 17 others.[56] The infection is characterised by paroxysmal coughing and apnoea in infants. Severe complications include pneumonia and neurological impairment. Since the inclusion of pertussis in the immunisation schedule, deaths from whooping cough in Australia are rare, but do occur, and in fact since the mid 1990s cases have risen.[56] This is due to waning immunity, which occurs between four and ten years, so a booster dose of the DTP vaccine is vitally important. Infants under four months are most at risk until they have received the first two doses of the vaccine, so they rely on herd immunity for protection.

2.8.2 Human papillomavirus virus vaccine

Human papillomavirus (HPV) is a virus transmitted by sexual contact, primarily genital skin contact. It is the most common STI worldwide, with 75% of sexually active individuals contracting HPV in their lifetime.[57] HPV is responsible for significant genital wart morbidity, and persistent infection with some strains can lead to cancerous changes.[38,58] HPV is present in 99% of cases of cervical cancer, but other genital, anal and oropharyngeal cancers affecting both women and men are also attributable to HPV.[58,59]

Since 2007, Australia has had a government-funded school-based HPV vaccination program for girls in early adolescence, usually in the first year of secondary school. Boys have been included in this program from 2013.[58] The vaccine (Gardasil®) was initially given as a three-dose course over six months, protecting against four strains of HPV: types 16 and 18, and types 6 and 11.[59] In 2015, 77.4%% of 15 year-old females and 66.4% of 15 year-old males in Australia received all three doses of the

HPV vaccine, as calculated through the HPV register.[60] Within 18 months of the vaccine introduction, there was a 50% decline in genital wart presentation to sexual health services in Victoria, Australia. Smith et al. (2015) also found a population level decrease in genital warts of between 70 and 90% in females in Australian hospitals between 2006 and 2011.[38] In addition, there was a small but significant reduction in high-grade cervical abnormalities in younger women who had received the vaccine.[61,62]

In 2018, the HPV program in Australia was transitioned to the 9-valent vaccine, protecting against an additional 6 HPV types including 31, 33, 45, 52 and 58. At the same time, the schedule was reduced to two doses over six months in line with data supporting the effectiveness of this. The effectiveness of this vaccine cannot be understated, with Australia set to eliminate HPV in the next 20 years.[63]

Nevertheless, there are particular barriers for the HPV vaccine, which are challenging on a number of levels. The HPV vaccine is one of only two vaccines protecting against a sexually transmitted virus. Therefore, unlike many other immunisations, the HPV vaccine prevents against disease occurring many years into the future, with a long lag time. Barriers for this vaccine include reluctance on the part of a parent to consider their adolescent as potentially sexually active in the near future and concerns about ‘condoning’ early sexual activity by consenting to the HPV vaccine. Decision-making for this vaccine can be affected by beliefs and values about sexual activity, as well as the lack of imminent risk from the diseases against which HPV immunisation protects.[52,64,65] A Cochrane Review which is underway to examine ways to improve adolescent immunisation uptake, while specifically aiming to assist in identifying interventions for LMICs, will extract evidence from all countries.[46] The protocol for this review outlines possible interventions, including specific immunisation education and information given to young people and their families, reminder or recall systems for missed vaccinations, financial incentives for vaccinations, feedback about coverage to vaccinators, legislation of vaccine requirement for school attendance and mass vaccination campaigns.[46]

2.8.3 Varicella vaccine

Varicella-zoster virus most commonly results in chickenpox, which is a virus characterised by flu-like symptoms and itchy red lesions on the body. It is contagious, spread by droplets or contact with the lesions. The majority of cases are self-limiting, but prior to vaccination, 1500 hospitalisations and seven to eight deaths occurred every year in Australia due to varicella complications such as pneumonia, meningitis and encephalitis.[66]

One dose of the varicella vaccine gives approximately 85% protection against contracting chickenpox, with up to 98% protection against severe illness with chickenpox.[66] The varicella vaccine was introduced to the Australian schedule in 2005 at 18 months of age, with a catch-up dose in early adolescence funded as part of the school-based program from 2006. This adolescent dose was only given to those who had not had prior immunisation or who had developed natural immunity from the disease to cover those children who missed the preschool chickenpox vaccination. This catch-up program was ceased at the end of the 2017.

2.8.4 Meningococcal ACWY vaccine

The Men ACWY vaccine protects against four of 13 serogroups of *Neisseria meningitidis,* an organism usually present in the nasopharynx, but with the potential to cause invasive meningococcal septicaemia. Although the overall incidence of meningococcal septicaemia remains low, at 1-1.5 per 100 000, the rapid progression of the disease process, high morbidity and 10% mortality rate ensures that prevention remains a public health priority.[67,68] While a vaccine for the serogroup C has been in the childhood schedule in Australia since 2003, a rise in invasive W and Y strains since 2014 has caused concern. As a result, states and territories in Australia, including Victoria, added time-limited Men ACWY vaccine to the immunisation schedule in adolescence in 2017 and 2018. Since April 2019, Men ACWY has been federally funded for infants at 12 months and adolescents in Year 10, or age equivalent.

2.9 Adolescent Immunisation Documentation in Australia

Until 2018, the HPV vaccine was recorded through the HPV Register, which documented all doses given through the SBIP, and doses given by community care providers and General Practitioners (GPs) if they notified the Register. From this Register, state and national HPV uptake rates were calculated using the doses administered as numerator and the estimated resident population by age provided by the Australian Bureau of Statistics (ABS) as denominator.[69]

Adolescent doses of dTPa, varicella and Men ACWY were not recorded on the national AIR register until 2018. Therefore, at the commencement of this thesis there was no national collection of adolescent immunisation coverage for these vaccines. The Department of Health and Human Services (DHHS) Immunisation Division in Victoria produces uptake data for these immunisations using records of the number of doses of HPV vaccine given as numerator and Year 7 enrolment data from the Department of Education (Victoria) as denominator. Prior to the AIR, other states in Australia had varying ways they calculated uptake for these vaccines. For example, Western Australia had a database to track school immunisations, which was recorded by individual rather than aggregate data and allowed for the generation of a paper record for each student.[70] New South Wales produced coverage rates from the school programme in a similar way to Victoria, but unlike Victoria did not include immunisations given by other health care providers. Consistent recording and tracking nationally is vital to determine not only uptake of adolescent vaccinations, but also to allow identification of residential areas and schools with low coverage.[69]

2.10 The School-Based Immunisation Program

Australia has delivered immunisations through schools since the 1930s, both as one-off mass vaccination campaigns and more recently as a routine program for scheduled adolescent vaccinations.[71] This collaboration between health and other community sectors, such as education, to achieve high engagement in complex population-based interventions is endorsed by WHO.[72] Other countries with coordinated SBIPs delivering adolescent vaccines as an alternative to health clinic-based immunisation include Canada, Malaysia, Norway, the UK and Spain. In these high-income countries, the provision of immunisations at school, either as a stand-alone program or in conjunction with community providers, results in higher adolescent immunisation uptake rates in the adolescent age group than countries with community provider immunisation alone.[49,50,73] With infrastructure and financial support, SBIPs also exist very successfully in some LMICs.[74,75] In other LMICs where school attendance is low or unpredictable, a SBIP is less effective if it is a stand-alone strategy to deliver adolescent vaccines.[76]

In Australia, state governments allocate federal and state funds to local government or regional organisations to provide, manage and coordinate immunisation days at local or regional schools.[77] On those days, immunisation nurses deliver the scheduled adolescent immunisations in the school setting. Differences in administration of the SBIP across states and territories are highlighted in Table 2-3.

Table 2-3 Differences in Administration of the SBIP across States and Territories in Australia

Jurisdiction	**Year Level Given***	**Administered By**
Australian Capital Territory	Year 7 – HPV, dTPa Year 10 – Men ACWY	Maternal Child Health Unit Immunisations given by Maternal Child Health Nurses
New South Wales	Year 7 – HPV, dTPa Year 8 – 2nd dose of HPV if not completed in Year 7 Year 10 – Men ACWY	Public Health Units within regional offices Immunisations given by Immunisation and Community Nurses
Northern Territory	Year 7 – HPV, dTPa Year 10 – Men ACWY, Pneumococcal for Indigenous students Year 10 and above – Influenza for Indigenous students on request	Community Health and Remote Health Units Immunisations given by Health Promoting School Nurses and Health Department Nurses
Queensland	Year 7 – HPV, dTPa Year 10 – Men ACWY	Public Health Units Immunisations given by Community Health Nurses, Immunisation Nurses or General Practice Nurses
South Australia	Year 8 – HPV, dTPa Year 10 – Men ACWY, Men B Year 11 – Men B (2019 only)	Local Government Health Services Immunisations given by Council Nurses and Community Health Nurses
Tasmania	Year 7 – HPV, dTPa Year 10 – Men ACWY	Local Government Areas Immunisations given by Council Nurses or outsourced to Immunisation Nurses through private organisations

Jurisdiction	Year Level Given*	Administered By
Victoria	Year 7 – HPV, dTPa Year 10 – Men ACWY	Local Government Areas Immunisations given by Council Nurses or outsourced to Immunisation Nurses through private organisations
Western Australia	Year 7 – HPV, dTPa Year 8 – HPV (2019 only), dTPa (2019 only) Year 10 – Men ACWY	Local Government Areas or Public Health Units Immunisations given by Community Council Nurses

Key: dTPa – Diphtheria, tetanus, pertussis vaccine booster dose; HPV – Human papillomavirus vaccine; Men ACWY – Meningococcal ACWY vaccine; Men B – Meningococcal B vaccine. *2019 Immunisation Schedule

The recommended age for the scheduled immunisations in adolescence falls either in the last year of primary school or first year of secondary school, and all states therefore use grade rather than age for ease of implementation of the program. While local governments in Victoria are mandated to offer a SBIP to schools through the *Public Health and Wellbeing Act 2008*,[78] schools are not mandated to take part. Indeed, schools provide access and assistance to enable this program to operate on a good-will basis.[77] This program therefore encompasses a unique intersection between three levels of government (federal, state and local) and the health and education sectors, which requires an assumption of reciprocal co-operation.[79,80]

Local government immunisation providers negotiate the immunisation day dates with schools and provide consent forms and information for distribution to parents. Parental consent is required for nurses to administer immunisations to any student, with written consent preferred, but verbal consent acceptable. In Australia, student consent is not sought, although this has been considered in other countries.[81] Student assent is assumed and without this, it is logistically and ethically difficult to administer a vaccine. It is not mandated for schools to provide education about immunisations and there are no nationally standard resources to do so.[71,82]

Since 2013, local governments have the authority through the *Public Health and Wellbeing Act Amendment 2013*[83] to contact families who have missed vaccinations offered through the school program. Although schools are not compelled to provide contact details for the students, they are encouraged to do so to facilitate follow-up of delayed and missed vaccines, and do not require express consent of families to share class lists with the immunisation providers. If students miss vaccinations, some councils provide extra catch-up days at the school. If this is not possible, parents are encouraged to visit their GP or attend a community immunisation session. These guidelines are the same for students attending all schools, whether mainstream or specialist education settings that enrol students with physical or intellectual disabilities.

2.11 Disability

The WHO estimates that 15% of the world’s population live with disability, with 3-4% facing significant challenges from related ill health, difficulties with communication and accessibility, stigma and discrimination.[84] An accurate estimate of the prevalence of disability is elusive, due to the absence of one comprehensive definition and the wide variety of experience. An example of this can be found in a study from Norway that compared 11 different measurements of disability in a population and found the disability rates varied from 10% to 25% depending on the tool used.[85] Across countries, the variance can be even greater and this may be due to the added complicating effects of language and cultural concepts of disability.[85]

While defining what is atypical is therefore dependent on context, disability is commonly described according to four areas of impairment: intellectual, sensory, psychological and physical. The severity scale generally used in population data collection is mild, moderate, severe and profound, according to the degree that the person needs assistance with core activities of communication, mobility and self-care.[84] In Australia, the ABS data set requires that a condition can only be categorised as a disability when the impairment is one that lasts six months or more and affects aspects of daily living.[86]

However, defining disability is more complex than classifying impairment. More commonly, in the last 15 years, definitions of disability go beyond the medical and biophysical aspects and suggest that disability is a social and cultural construct. This Social Model of Disability (SMD) contrasts with the biophysical/medical model, which views the individual with a disability as flawed and needing to be fixed.[87] The SMD is based on equality of the worth of each individual, and challenges the social constructs that may prevent full participation in society for people with disability. The United Nations Convention on the Rights of Persons with Disabilities (UN CRPD),[88] ratified by Australia in 2008, has the SMD as its framework, describing disability as arising:

> *...from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.*[88]

This definition distinguishes between impairment, which is the underlying medical condition, and disability, which is the interaction between the impairment and the social, cultural and environmental barriers that prevent good health, full participation and acceptance.

The complexity of defining disability is such that it has been the subject itself of a doctoral dissertation.[89] Within this research, Gronvik[89] describes five types of definitions of disability:

1. *Subjective – disability is defined by the person*
2. *Functional – based on physical and mental limitations*
3. *Administrative – based on criteria necessary for funding and welfare purposes*
4. *Social – based on the SMD, where the environment limits the person*
5. *Relational – based on the interaction between the individual and the environment*

Therefore, disability is defined by the purpose for which a definition is required. The social and relational definitions recognise the environment as pivotal in shifting a functional difference to a disability. This is reflected in the International Classification of Functioning, Disability and Health (ICF), which is a broad measure based on impairments of body function, activity limitations and participation restrictions, and it also encompasses environmental factors impacting on the individual.[90] This framework is endorsed by the WHO and is the internationally accepted classification system for disability in health-related contexts.[90,91] The ICF framework is represented in Figure 2-5.

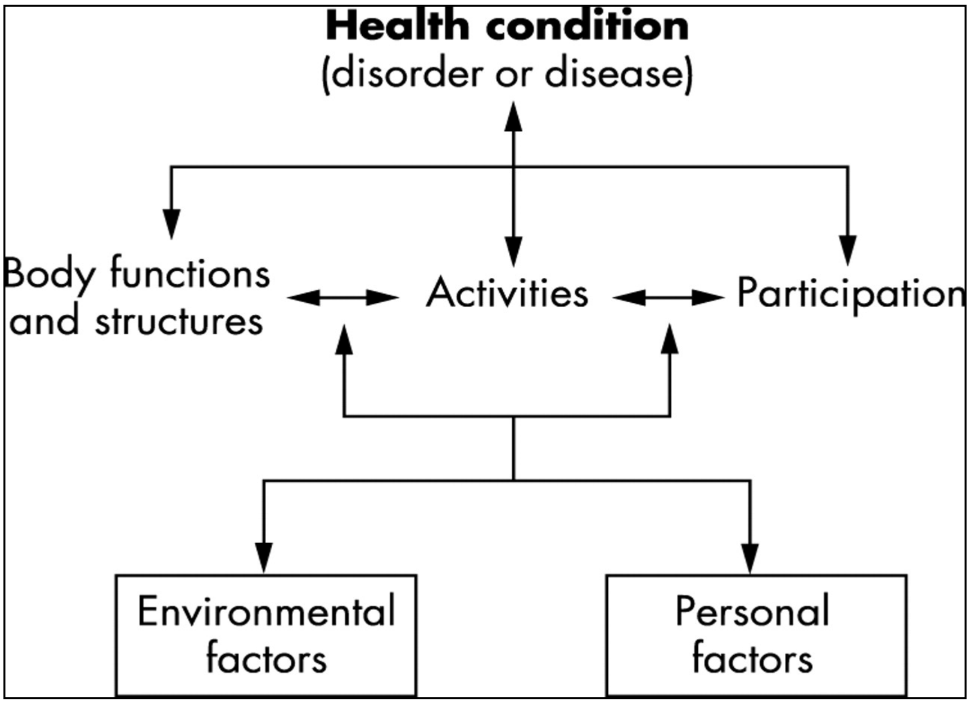

Figure 2-5 The Relationship between Body Functions, Activities and Participation in Health-Related Conditions as represented by the ICF Framework

Source: WHO. International classification of functioning, disability and health (ICF). Geneva, Switzerland: World Health Organization; 2001.

A full appreciation of the environmental and cultural influences on people with disability through history is required in order to interpret the definitions of disability in context.

2.12 Disability History and Disability Rights

For centuries, in most countries and cultures, those with a disability were deemed inferior, shunned and denied basic rights.[92] This stemmed from fear and misinformation; in particular, religious and occult beliefs of disability as a sign of evil.[92,93] The institutionalisation of people with disability emerged in the Middle Ages as a way to both protect and care for those who were deemed unable to care for themselves, but also to segregate the 'insane' from the general population.[92] This included those with mental and physical impairments, but also anyone who did not fit into mainstream society, such as criminals, alcoholics, prostitutes and vagabonds.[92,93] By the 17th century, there was emerging compassion for those with disability, but treatment and care were still harsh and rooted in a hierarchy that considered those with difference should be pitied and protected, but viewed them, nevertheless, as inferior.[92,93]

It was not until the mid-18th century that there was any systematic education of those with disability, supported by the ideals of the Enlightenment.[92] Relevant values to emerge from this period included new views about equality in society, individual integrity, humanism and the power of education and knowledge. Schools for the blind and deaf emerged throughout Europe, America and the UK, later followed by schools for the 'mentally retarded', which was a very broad term that at the time encompassed intellectual disability and mental illness. The rise of eugenics in 19th century compounded institutionalisation and brought with it sterilisation of those with disability, justified by the belief in the need to eliminate 'weakening' of the gene pool.[94] These beliefs persisted well into the 20th century, and indeed, sterilisation of females with disability and abuse and neglect in institutional care persisted through the late 20th century.[94,95]

Concurrently, an increasing social consciousness of disability rights was developing, in part due to the large numbers of veterans from the two World Wars returning home with visible disability. In 1948, the United Nations (UN) adopted the *Universal Declaration of Human Rights*,[96] which referred to rights, freedoms and liberties of all persons including those with disability. This began incremental steps towards a shift in thinking about people with disability as having equal rights, leading to the development of the UN CRPD[88] in 2006. The pathway to this important convention is detailed in Table 2-4.

Table 2-4 Major Events in the History of Disability Rights

Year	Event	Description
1948	UN Assembly adopted the Universal Declaration of Human Rights	Rights, freedoms and security to all people including those with disability
1950	UN Assembly meeting	Agreed to international standards for education, care and training for people with disability
1971	Declaration of the Rights of Mentally Retarded Persons	Focus on the rights of persons with intellectual disability in particular, particular to education. Still within a social welfare model
1975	Declaration of the Rights of Disabled Persons	Further promoted disability rights with a social model of participation and equal opportunity
1981	International Year of Disabled Persons	Promoted awareness of rights of those with disability, through events, conferences and education
1982	UN Assembly adopted World Program of Action Concerning Disabled Persons	Focus on how social and environmental barriers prevent full participation of people with disability
1983-1992	Decade of the Disabled Person	Established first global network of people with disability Established International Day of Disabled Persons Further promotion of rights of persons with disability through conferences, events and policy positions
1993	UN adoption of Standard Rules of Equalization of Opportunities for People with Disabilities	Overriding outcome of Decade of Disabled Persons
1993	World Conference on Human Rights	Development of Vienna Declaration and Program of Action – declared discrimination against persons with disability violation of human rights

Year	Event	Description
1995	World Summit for Social Development	Development of Copenhagen Declaration on Social Development – economic and social development requires equality and participation from all groups in society
Late 1990s	A number of international technical meetings regarding barriers to realising equal rights for people with disability	
2001	World Conference of Human Rights in South Africa	Program of action for realising rights of people with disability, resulted in Government of Mexico proposal to UN Assembly for a convention on rights of people with disability
2002-2003	Establishment of a Working Group to develop a convention on the rights of persons with disability	Draft convention written
2006	Convention on the Rights of Persons with Disabilities	Aimed for actions to promote inclusive development, equal opportunity and full participation of people with disability. Established a Conference of State Parties to assist to implement the Convention into policy and practice Australia signed in 2007 and ratified in 2008
2011	First World Report on Disability	Response to lack of data on people of disability to inform decision-making
2015	Member states of the UN adopted 2030 Agenda for Sustainable Development	Recognises disability as a significant factor in five sustainable goals – education, growth and employment, inequity, accessibility, data and monitoring and accountability. Disability intrinsically linked to the SDH. People with disability named as a disadvantaged group to be specifically monitored

2.13 Disability in Australia

In Australia, 4.2 million people (18.5% of the population) have a disability, of whom 1.2 million people (6%) have impairments categorised as severe or profound.[97] Approximately 7% of children under 14 have a disability, about half of which are severe or profound.[86] The areas in which people with disability need the most assistance are cognitive tasks, communication, mobility and self-care.

In 2009, the Australian Government commissioned a working group to inform the National Disability Strategy (NDS). The resulting report, *Shut Out*, detailed barriers in many areas for people with disability in Australia.[98] This included barriers to social participation, educational and employment opportunities, access to services and adequate funding.[98] This report provided the basis for the NDS, the key reform of which is the rollout of the National Disability Insurance Scheme (NDIS) from 2016.[99]

The NDIS shifted disability funding from a welfare block-funding approach to a whole-life individualised approach, in which participants have 'choice and control' over the way funding is used and services are provided.[100] It must be noted that while support for this shift in service provision and funding for people with disability was significant, the roll-out of the scheme has been, and continues to be, subject to criticism.[101] Nevertheless, the NDIS has been one of two key disability-related policy developments in Australia during the period of this thesis. The second main policy event, strengthened by the choice of service providers brought about by the NDIS, has been the increase in social and political awareness of systemic abuse of people with disability in institutional care,[102] which culminated in the announcement of the Disability Royal Commission in May 2019.[103] It was therefore within this political environment that data collection for this thesis took place.

2.14 Education of Young People with Disability in Australia

The *Disability Standards for Education 2005*[104] requires government schools in Victoria to make accommodations for students with disability and special needs. The *Victorian Education Training Reform Act 2006* mandates equal access to local government schools and equal opportunity for participation for all students.[105] The Department of Education and Training in Victoria (DET) has a number of policies to assist schools in providing appropriate and inclusive education.[106,107] This incorporates targeted funding for students with a variety of special needs within the Program for Students with Disabilities (PSD). While 15% of students in Victoria need some adjustment in schooling, only 4% receive targeted funding under the PSD.[107] The vast majority (85%) of these students have a primary diagnosis of Intellectual Disability (ID) or Autism Spectrum Disorder (ASD), with only 4% having a primary diagnosis of physical disability.[106]

International best practice prefers inclusive education over segregated specialist settings for young people with disability in terms of educational and social outcomes.[108,109] Before the 1980s, students with disability in Australia had limited accessibility to appropriate education that maximised participation and learning achievement. Victoria led the way amongst Australian jurisdictions with the report of the Ministerial Review of Educational Services for the Disabled (1984).[107] This provided for access for children with disability to their local government school and was subsequently supported by the *Disability Discrimination Act 1992 (Cth)*,[110] which legislated the right for children with a disability to attend mainstream education. Other key legislation and policies regarding education for students with disability in Victoria and Australia is presented in Table 2-5.

Table 2-5 Key Legislation and Policy for Education of Students with Disability in Victoria, Australia

Legislation, Government Policy, Standard or Review	**Key Content or Focus**
Disability Discrimination Act 1992 (Cth)	Commonwealth Legislation: It is unlawful for an education authority to discriminate against a person on the basis of disability in relation to enrolment in school, or to restrict or deny access to educational activities, including school curricula
Disability Standards for Education (2005)	Australian Standard: Provides for reasonable accommodations for students, covering participation, curriculum development, accreditation, delivery, student support services, elimination of harassment
National Disability Strategy 2010-2020	Australian policy: Targets set for outcomes of people with disability participating in inclusive high-quality education, including number of students with disability in mainstream schools and completing Year 12
Melbourne Declaration on Educational Goals of Young Australians (2008)	Australian policy: Outcomes of forum of education ministers. Includes disability in Goal 1 – equity and excellence in Australian schooling
Australian Education Act 2013 (Cth)	Commonwealth Legislation: Provides for a needs-based funding model and implementation of the National Plan for School Improvement and National Education Reform Agreement
National Plan for School Improvement 2013	Commonwealth Funding Plan: Outlines the budget and funding model for schools including targeted funding for students with disability
Education and Training Reform Act 2006 (Vic)	Victorian Legislation: Students with disability have the same entitlements as other students including attending their designated or other government school if there is sufficient accommodation to meet their needs
Equal Opportunity Act 2010 (Vic)	Victorian Legislation: It is unlawful to discriminate or treat a person unfavourably on the basis of disability in a number of settings including education

Legislation, Government Policy, Standard or Review	**Key Content or Focus**
Review of the Program for Students with Disabilities 2016	Victorian Review: Commissioned by the Victorian State Government as part of its education reform agenda. Provided 25 varied recommendations, most of which were accepted by the Government

Adapted from: Iacono T, Keeffe M, Kenny A, McKinstry C. A document review of exclusionary practices in the context of Australian school education policy. J Policy Pract Intellect Disabil. 2019 Dec;16(4):264-72.

Despite the legislation and policies put into place in the last three decades, the proportion of students with disability enrolled in mainstream schools has not significantly increased in this time.[111] The ideal of inclusive education in Australia has never been fully realised. All states and territories offer specialist school settings catering for students with physical and intellectual disabilities, with 448 stand-alone specialist schools in Australia, in addition to numerous specialist units attached to mainstream schools for students with disability.[111] Nearly half the students with significant learning needs due to disability in Victoria (47%) attend one of the 81 specialist schools, which cater for the education and wellbeing needs of students with disability, emotional or behavioural disorders.[107]

2.15 Specialist Schools in Victoria, Australia

There are a number of types of specialist schools that are defined by their enrolment criteria. Within this, there is some individual school flexibility in enrolment, particularly with regards to the level of intellectual disability. The enrolment criteria of different types of specialist schools in Victoria are outlined in Table 2-6.

Table 2-6 Types of Specialist Schools in Victoria, Australia

Type of Specialist School	Enrolment Criteria
Specialist Schools (SS)	Mild intellectual disability with an intelligence quotient (IQ) of 50 to 70
Special Development Schools (SDS)	Moderate to profound intellectual disabilities with an IQ of less than 50
Dual Mode Schools (DM) *(also referred to as Special Development Schools or Multi-Mode Schools)*	Mild to profound intellectual disability with an IQ less than 70
Physical Disability Schools (PD) *(also referred to as Special Development Schools)*	Physical disability or chronic health issue requiring ongoing allied health support
Autism-Specific Schools	Autism with intellectual disability
Sensory Specialist Schools	Hearing or vision impairment

A number of allied health and paramedical support staff, such as physiotherapists, speech therapists and occupational therapists are employed within the specialist school system to provide interventions to assist with disability aspects of functioning that impact learning for these students. School nurses are employed in each of the four physical disability schools in Victoria, which enrol the children most in need of daily health care intervention. Other specialist schools also employ a school nurse if their funding permits, but this is by no means universal. If no school nurse is employed in these settings, teaching or administrative staff are nominated to manage first aid and health care emergencies.

As with all public schools, there are preventive health programs that can be run in schools.[112] These can be run internally in collaboration with external health care providers. This type of intersectoral collaboration between schools and health care services can act to promote health equity.[113,114]

2.16 Health Equity for People with Disability

Article 25 in the UN CRPD declares that State Parties (to the Convention) shall:

> *Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes.*[88]

This highlights that without special attention to ensure there are no social, logistical, communication or education barriers to provision of good and equitable health care for people with disability, they are at risk of poor health outcomes. This complex relationship between social circumstances, environment, health and disability is illustrated in the fact that 80% of people with a disability live in LMICs.[115,116] Indeed *"poverty is both a potential cause and consequence of disability,"*[116] which is apparent also in affluent countries such as Australia, where nearly half (45%) of people with a disability live in poverty or near poverty.[117]

Australian research reveals a significant gap between the health of people with disability and the general population beyond factors relating to medical aspects of the impairments they experience.[96,118,119] Adults with intellectual disability in Australia are more likely to be overweight or obese, smoke, have cardiac disease or diabetes, and die prematurely from preventable disease than those without disability.[117–119] This gap is directly related to social inequity, including difficulties in acceptance in the community, and impaired ability to access education and opportunities for employment.

Access to primary health care is less than optimal for people with disability. Barriers include transportation issues, communication, lack of confidence and lack of knowledge about the health care system.[96,117,120] Barriers to breast screening and cervical screening in women with disability have been well described.[118,121–125] However, there is very little known about other preventative health care for people with disability. The multiple disadvantages experienced by people with disability signify the importance of investigating preventive health care, such as immunisation, in this group.

2.17 Disability Rights, Health and Immunisation

The importance of access to immunisation for people with disability in the context of the history of disability rights should not be underestimated. Organised and widespread immunisation programs have the potential to alter the morbidity and mortality, and therefore the strength, prosperity and quality of life, of populations. Although this potential is discussed in relation to LMICs, populations with low immunisation coverage within countries with high immunisation rates are easily overlooked. This compounds the health inequity for people with disability.

The intersection between disability rights, health and immunisation is clearly articulated in the UNICEF background paper *Disability prevention efforts and disability rights: Finding common ground on immunization efforts*.[126] This paper highlights the inequity in access to immunisations for children, young people and adults with disability internationally, and the impact of that on the health and wellbeing of people with disability. Groce and Lang (2012)[126] suggest this is due to a number of factors, such as inequitable access to health services, exclusion from health care initiatives, and a lack of understanding of the safety of immunisation for children with underlying disability.

In addition, the authors examine the practice of emphasising the prevention of disability by immunisation against communicable diseases, without equal emphasis in ensuring those who have a disability already are also immunised.[126] The subtext of this divide is that those with a disability derive less benefit or are less important in terms of ensuring immunisation, as they are already disabled. This bias has far reaching consequences for the health of people with disability, both in childhood and through to adulthood. The paper concludes that:

> *There are indications that (people with disability) are not getting immunized at the same rate as their peers without disabilities primarily due to social and cultural determinants…*[§] *The health and disability agendas should be brought closer together to ensure prevention efforts such as immunization, do not further stigmatize people with disabilities.*[126]

This paper is unique in highlighting the need to better understand the factors that influence immunisation practices for this population and for further research in this area as both a health and equity issue. However, the paucity of cited evidence on the uptake of immunisations with disabilities prompts the need for a comprehensive literature search to determine the current state of knowledge about immunisations in people with disability.

2.18 Chapter Summary

This chapter provides background to the fields of immunisation, particularly the SBIP in Australia, disability definitions and the relevant historical, cultural and political aspects. The intersection of immunisation for people with a disability is established as one of health and equity, and as important in the Australian context. This chapter establishes the need to understand the state of knowledge about immunisation for people with disability, and provides the context in which the literature search, and indeed the entire thesis, took place. The next chapter will be an in-depth exploration of the literature pertaining to adolescent immunisation health service delivery in specialist schools in Victoria, Australia.

[§] The conventional use of "…" in a quote was adopted throughout this thesis indicating that words were omitted from a direct quote, for practical purposes, where omission of words did not change the meaning of the quote.

3 LITERATURE REVIEW: IMMUNISATION IN YOUNG PEOPLE WITH DISABILITY

3.1 Introduction

This chapter reviews the literature on immunisation in children and young people with disability. This includes an overview of VPDs in people with disability, an explanation of the literature search strategy and an in-depth critical analysis of the relevant studies from this search. A discussion of the difficulty of the synthesis of this evidence and some important gaps in both the literature and government collection of data leads to the thesis aim and research questions. This review covers the literature up until February 2017, when data collection for Phase One, the first research study, began. Literature published after this time is appropriately appraised in Chapter 9 of this thesis. The chapter concludes by specifying the aim and research questions for this thesis.

This chapter formed the basis of a published review on immunisation in people with disability,[127] included for reference in Appendix C.

3.2 Consequence of Vaccine Preventable Diseases in People with Disability

An assumption within this thesis is that immunisation is an important preventive health intervention for all people, including those with a disability. From the principle of equity, this is logical. From a health perspective, there is also evidence to suggest that people with disability are at higher risk from VPDs. This is despite the fact that disability is not one of the descriptors included in the ‘special-risk’ groups in the Australian immunisation guidelines outlined in the government-endorsed *Australian Immunisation Handbook*.[128] These special risk groups cover a variety of populations that are known to be particularly vulnerable to VPDs and require different schedules or additional immunisation recommendations. Underlying disability, in particular physical disability or disability related to prematurity,[**] predispose an individual to acquiring illness and severe sequelae from viral and bacterial infections.[129] This includes all VPDs that have a respiratory or neurological component, including measles, mumps, rubella, diphtheria, tetanus, pertussis, varicella, Hib and influenza.

Data about morbidity and mortality from VPDs in people with disability can be found in reviews of VPD outcomes. The majority of these reviews concern influenza outbreaks. In a UK review of the 2009-10 influenza A H1N1 pandemic, 54% of the paediatric deaths were in children with chronic neurological disease, such as cerebral palsy (CP) and epilepsy.[130] In a review of the same pandemic in Canada, 11.5% of children admitted to hospital had neurological or developmental disorders, the second most common group after chronic respiratory conditions.[131] Two children in this review died; both had epilepsy, one with developmental delay and the other with CP.[131] This is mirrored in other reviews of influenza morbidity and mortality.[132–135]

There are fewer reviews of other VPDs, perhaps reflective of the significantly fewer cases of such diseases compared with influenza. Hjuler et al.[136] reported on the risks of invasive pneumococcal disease (IPD) in children with underlying chronic disease, which included some subgroups with disability. This study found that for children with neurological disorders, the adjusted risk ratio of IPD was 2.7 (CI 1.9-3.9). A disproportionate number of children with underlying disability also have a complicated course with varicella. In a prospective audit in the UK and Ireland, Cameron et al.[137] reviewed children and young people under 16 years hospitalised with varicella and found 13% had congenital abnormalities, Trisomy 21 or CP. Of the 112 cases, there were six deaths, three with physical disabilities.

[**] While ‘preterm infants’ is a category of ‘special risk’, this primarily gives guidance for the newborn and early infancy period, not the ongoing immunisation special needs of ex-premature children in terms of health and disability.

The literature on morbidity and mortality from acute infection from VPDs in people with disability clearly highlights the importance of immunisation in this population. One VPD that may prompt different assumptions about level of risk is HPV, as it is not an acute illness but a sexually transmitted virus with a long lag time until development of disease.[59] Preconceptions and prejudices in relation to the sexual activities and needs of people with disability can create barriers to acceptance of this vaccine.[138] Acknowledging the need to optimise uptake of the HPV vaccine for young people with disability requires recognition that their sexual health is important and relevant. Providing and promoting HPV vaccine uptake for young people with developmental disabilities is not only a matter of equality of access to health care, but is essential, because this population are as likely to explore their sexuality as typically developing adolescents.[139–143] Sexual risk is also disproportionately high in this population, particularly with regards to abuse of women with disability.[140,144]

As morbidity and mortality from HPV takes decades to develop, the impact of this virus in people with disability has not been measured. However, for women with disability, the low rate of cervical screening is a recognised issue, with many barriers described, including physical, logistical, communication issues and knowledge about the service.[118,121–125] This evidence of low rates of cervical screening further emphasises the importance of HPV immunisation for girls with disability.

In Australia, the absence of recommendations for people with disability in special-risk group guidelines has far-reaching consequences. Groups that are named ‘at-risk’ are the subject of data collection and research for evaluation purposes, and consequently are likely to attract research funding. However, research on immunisation in children and young people with disability is sparse, and finding this literature required a rigorous search strategy.

3.3 Search Strategy

In this thesis, the literature search undertaken on immunisation in young people with disability aimed to encompass any study including children or young people in adolescence with any disability, physical or intellectual, which occurs or is diagnosed early in life. One of the challenges in designing such a search concerned the number of terms used internationally to describe disability. A detailed list of disability and immunisation search terms was compiled in order to mitigate the possibility of missing literature due to terminology. An experienced developmental paediatrician assisted in compiling a list of disability search terms, incorporating both broad descriptors and specific diagnoses. This ensured that a comprehensive search of the disability literature was conducted. These terms were paired with immunisation keywords in order to find relevant articles within five databases: Pubmed, CINAHL, ERIC, Embase and Scopus. The full list of search terms can be found in Table 3-1. Reference lists of identified articles were also searched for other relevant studies.

Table 3-1 Literature Review Search Terms

Disability Term	AND	Immunisation Term
intellectual disability		vaccine*
developmental delay		immun*
mental retardation		vaccine hesitancy
learning disability		vaccine schedule
neuro disability		vaccine acceptance
physical disability		vaccine complacency
epileptic encephalopathy		vaccine refusal
hydranencephaly		vaccine decision-making
microcephaly		vaccine concerns
schizencephaly		vaccine delay
lissencephaly		vaccine communication
polymicrogyria		vaccine strategy
cortical migration disorders		vaccine recommendation
metabolic syndromes		vaccine preventable diseases
Cerebral palsy		Human Papillomavirus
Autism Spectrum Disorders		MMR
Prader-Willi		Hep B
Spina Bifida		DTP
Epilepsy		influenza
Cognitive impairment		varicella
Dravet’s syndrome		rotavirus
Angelman syndrome		Hib
Fragile X		Poliomylitis
Ohtara		Adolescent vaccin*
West syndrome		School vaccin*
Infantile spasms		
neurodegenerative disorders		
neuroprogressive disorders		
Aicardi-Goutières syndrome		

Infantile neuroaxonal dystrophy
Pantothenate kinase 2 deficiency
Tuberos Sclerosis
Leukoencephalopathies
Rett Syndrome
Trisomy 21
Trisomy 13
Trisomy 18
Cru-Du-Chat
Cornelia de Lange
Spinal muscular atrophy
Duchenne’s muscular dystrophy
Batten’s disease
Mitochondrial diseases
Neurofibromatosis
Turner’s syndrome
Noonan’s syndrome
PKU
Tay-Sachs disease
Beckwith-Wiedemann
22q microdeletion
storage disorders
Fredrich’s ataxia
Leukodystrophy
Niemann-Pick
dystonia
choreoathetosis
spasticity
quadriplegia
tetraplegia
diplegia
Fetal Alcohol Syndrome
Acquired brain injury
agenesis of the corpus collosum
Wilson’s disease
Familial Spastic Paraplegia
Charcot Marie Tooth disease
Cockayne syndrome
Alexander disease

All studies exploring or including specific findings pertinent to immunisation in children and young people with disability were included. Although studies on immunisation in adults with disability were consulted for context, these were excluded in this targeted literature search. Also excluded were studies focusing on disability that occurred, or was believed to have occurred, due to immunisation. There were no limitations on language or date for this search.

3.4 Immunisation in Young People with Disability

Twenty-four studies were found that examined immunisation in children and young people with disability.[145–167] Two studies were over 20 years old,[148,153] however the vast majority were published since 2008 (see Figure 3-1), which corresponds with the rise of the disability rights movement and increased awareness of equity for people with disability. Thus, the weight of evidence from studies found on this topic is current.

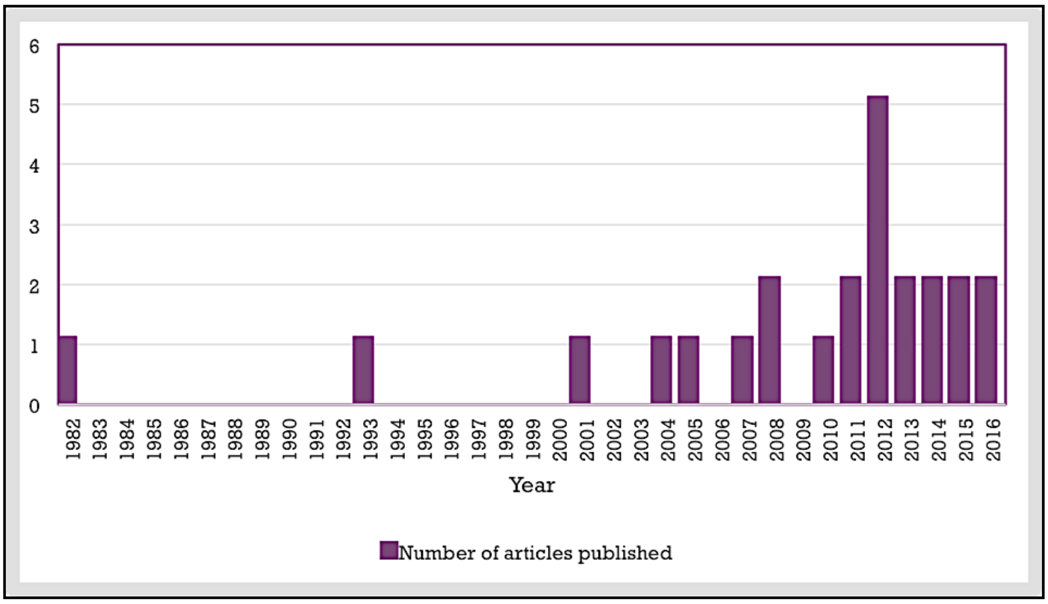

Figure 3-1 Number of Studies Published per Year on Immunisation in Children and Young People with Disability

Table 3-2 details the studies identified. The majority of the studies have immunisation uptake rates as a primary or secondary outcome measure, and 22 of the 24 studies (92%) were undertaken in high-income countries. These include countries in North America, Europe, Asia as well as Australia.[161,163] Therefore, the studies encompass a variety of immunisation schedules and service delivery methods. The studies also vary in how disability is defined, and the participants included. It is therefore difficult to gain a comprehensive understanding about experiences, behaviours, barriers and facilitators of immunisation in this population from these studies.

Table 3-2 Summary of Articles on Immunisation of Children and Young People with Disability

Year, Study, Location	Study Design/Data Collection Method	Research Aim	Participants	Disability or Definition of Disability	Immunisation	Relevant Results	Limitations
2016 **Cummings et al.** **USA**	Data linkage	To examine health services use among youth with ASD compared with those without ASD	8325 youth with ASD and 83,195 youth without ASD across the age range 3-17 yrs	ASD	Any immunisation with influenza vaccine uptake also calculated independently	Youth with ASD are significantly less likely to receive immunisations than those without disabilities or those with chronic disease	Could only access services by public health providers, did not include those provided by school and/or private health providers
2016 **Reiter & McRee** **USA**	Cross sectional study Secondary analysis of data from the Child Health Assessment and Monitoring Program – annual telephone survey on health-related	To examine the correlates of vaccination in youth with SHCN	604 youth aged 11-17 yrs with SHCN	Youth with SHCN	Tetanus Men HPV	In multivariable analysis correlates of immunisation in YSHCN include female gender older adolescents, those who had a preventive health check in the last year. YSHCN were significantly less likely to receive vaccines if they	Broad descriptor of special health care needs includes chronic health issues and emotional disorders Reliance on parent recall of vaccination status Absence of data on number of HPV doses given

Year, Study, Location	Study Design/Data Collection Method	Research Aim	Participants	Disability or Definition of Disability	Immunisation	Relevant Results	Limitations
	behaviours for children under 18					had no income reported for their household or had a parent with college education	
2015 **Okoro, Ojinnaka, Ikefuna & Onyenwe** **Nigeria**	Cross-sectional study, parent carer questionnaire and immunisation records	To determine the influence of socio-demographic factors and type of neurological disability on the immunisation status of children with chronic neurological conditions	168 families of children with chronic neurological conditions aged 6 mths to 5 yrs	Chronic neurological condition as determined by attending a neurology clinic with a condition that has persisted for more than 6 mths Main diagnoses CP and epilepsy	Not specified	Mother's higher education and father's higher income were the factors that significantly increase the immunisation coverage of children with neurological disorders. Those children with visually obvious disabilities were less likely to be fully immunised	60% of participants were aged less than 24 months
2015	Prospective	To document parental report	2138 parents of children with	Neurological or neurodevelopme	Influenza	50% of parents of children with	Dependant on

Year, Study, Location	Study Design/Data Collection Method	Research Aim	Participants	Disability or Definition of Disability	Immunisation	Relevant Results	Limitations
Smith, Peacock, Uyeki & Moore **USA**	survey	of influenza immunisation or intent to immunise in families of children with neurodevelopmental disorders Provider survey – to document physician recognition of high-risk influenza conditions	high-risk conditions, aged over 6 mths, including 1143 with neurodevelopmental disorders	ntal disorder: main diagnoses CP, ID, epilepsy		neurodevelopmental disorders immunised or were intending to immunise their child against flu Similar to general population Providers recognized CP as high-risk condition (74%), less so epilepsy (51%) and ID (46%)	parent report Recruited through members of a national disability advocacy group - reach across nation but specific subset of disability population Included intent to immunise in immunisation rate
2014 **Fisher, Audrey, Mytton, Hickman & Trotter** **UK**	Retrospective audit	To investigate factors associated with HPV initiation and completion in South West England	14,282 female students, aged 12-13 yrs 196 of these in non-mainstream schooling	Those attending non-mainstream schooling including specialist schools	HPV	Relevant finding – girls attending non-mainstream schools HPV initiation only 55.7% compared with 88.6% overall	Non-mainstream schooling also included young offender units, pupil referral units and home schooling, so not all in this cohort have disabilities

Year, Study, Location	Study Design/Data Collection Method	Research Aim	Participants	Disability or Definition of Disability	Immunisation	Relevant Results	Limitations
2014 **Remes Smith, Alvarado-Llano, Colley & Levesque Canada**	Retrospective cohort study Used data linkage – 4 databases	To identify individual and regional level determinants of HPV vaccine refusal in Ontario's Grade 8 HPV Immunization program	144,047 girls in Grade 8 aged 12-13 yrs in Ontario, Canada	Relevant disabilities included: autism and Trisomy 21, which were identified as significantly correlated with risk of missing HPV immunisation	HPV	49.3% refused HPV vaccination Associations with refusal – Trisomy 21, ASD, few physician visits, previous refusal of scheduled immunisations, living in areas of high deprivation	HPV status as per database Considered 'acceptor' if girl had any doses of HPV, so not necessarily full course
2013 **Cody & Lerand** **USA**	Questionnaire for parent/carers Internet-based survey of health professionals	To describe acceptability of HPV immunisation amongst parents of children with SHCN To examine parent and provider barriers to HPV vaccine	17 parents of girls with SHCN aged 9-16 yrs 130 providers (of 600) completed online survey	CSHCN	HPV	17% parents said they immunised their daughter against HPV 90% providers said they immunised against HPV, main reason why they did not was parent refusal	Broad descriptor of special health care needs includes chronic health issues and emotional disorders Looked only at girls with SHCN Relied on parent's recall re-immunisation status Small convenience

Year, Study, Location	Study Design/Data Collection Method	Research Aim	Participants	Disability or Definition of Disability	Immunisation	Relevant Results	Limitations
							sample Low response of providers
2013 **Greenwood, Crawford, Walstab & Reddihough** **Australia**	Retrospective audit using data linkage, ACIR and CP register	To compare immunisation coverage of children with CP with the general population coverage	449 children with CP aged under 7 yrs	CP	DTP MMR Hib Polio Hep B Varicella	19.2% of children with CP were not up to date with immunisations compared to 6.4-8% of general population	Based on ACIR data – underreporting of immunisation estimated up to 5%
2012 **Bazzano, Zeldin, Schuster, Barrett & Lehrer** **USA**	Cross sectional telephone survey	To determine if parents change or discontinue their child's immunisation schedule after ASD diagnosis	197 parents of children with ASD aged under 18 yrs	ASD as diagnosed by a medical practitioner	All immunisations	50% changed or discontinued immunisation schedule after diagnosis	Low response rate at 43% Relied on parent recall and report about immunisation practices
2012 **Pandolfi et al. (a)**	Prospective survey	To examine the effect of physician	275 families with of children aged 6 mths to	Mixed group of chronic disease and disability.	Influenza	57.5% overall influenza coverage, only	Mixed group of chronic disease and disability

Year, Study, Location	Study Design/Data Collection Method	Research Aim	Participants	Disability or Definition of Disability	Immunisation	Relevant Results	Limitations
Italy		recommendation regarding the influenza immunisation to families of children with chronic illness and measure the frequency of immunisation in this population	18 yrs with chronic diseases	Disabilities included – Trisomy 21 and a neurological disease including epilepsy and any neurological condition impeding respiratory function		25% in those with neurological diseases Higher (87-94%) who had physician recommendation for flu vaccine	Families recruited through specialty centre – already seeing specialists
2012 **Pandolfi et al. (b)** **Italy**	Cross-sectional study Audit of immunisation record and parent interview	To measure immunisation coverage and timeliness for children with Type 1 diabetes, HIV, Trisomy 21, cystic fibrosis and neurological diseases	275 children 6 mths to18 yrs from three Italian regions with chronic illness/disability	Mixed group of chronic disease and disability. Disabilities included Trisomy 21 and a neurological disease including epilepsy and any neurological condition	DTP Polio Hep B MMR Hib IPV Influenza	Low rates of immunisation at 12 mths, increased by 24 mths but below 90% for all immunisations MMR most likely to be delayed for children with neurological diseases. Most	Mixed group of chronic disease and disability Does not compare with control group Interview structure unclear Only quantitative results reported

Year, Study, Location	Study Design/Data Collection Method	Research Aim	Participants	Disability or Definition of Disability	Immunisation	Relevant Results	Limitations
				impeding respiratory function		common reasons for delay was acute illness	
2012 **Rosenberg et al.** **USA**	Online questionnaire	To examine immunisation beliefs and practices of families with a child with ASD	486 families with a child with ASD, 4-18 yrs	ASD – verified by health professionals	MMR DTP Polio Hep A and B Hib Rotavirus Varicella IPV	More likely to delay or omit immunisations if believed they played a role in ASD development Higher maternal education more likely to delay or omit immunisations for younger sibling of child with autism irrespective of belief of autism-vaccination link	Immunisations status by parent recall
2012 **Yen, Hsu, Loh, Fang, Wu, Chu &**	Cross-sectional survey, validated previously	To describe influenza immunisation uptake and determinants for	Parents/carers of 1055 adolescents with ID aged 12-18	ID	Influenza	23% had flu vaccine in last 3 yrs. Those with mod-severe disability with	Recruitment strategy unclear

Year, Study, Location	Study Design/Data Collection Method	Research Aim	Participants	Disability or Definition of Disability	Immunisation	Relevant Results	Limitations
Lin **Taiwan**	by authors	children with ID living in the community	yrs			regular health exams more likely to be immunised	
2011 **Tanabe et al.** **Japan**	Questionnaire sent to paediatricians	To determine factors influencing the advice from paediatricians about immunisation for children with severe handicaps and/or epilepsy	359 (of 680) paediatricians Asked specifically whether they would immunise in cases for febrile seizure, epilepsy or severe handicap	Severe handicap or epilepsy	Immunisations in general	Majority answered 'occasionally refuse' to immunise in all three scenarios. Most common reason duration since last seizure, majority would advocate waiting three months since last seizure. For handicap group main reason for refusal was daily epileptic seizures	Response rate 52.8% Only 32 doctors had paediatric neurology subspecialty Until 1996 Japanese guidelines suggested waiting one year after last seizure to immunise – no longer part of policy but need to consider this influence Stated aim does not match methodology
2011 **Yen & Lin**	Cross sectional	To determine Hep B	1111 teenagers 12-18 with ID	ID	Hep B	72.9% study participants	Immunisation status by carer

Year, Study, Location	Study Design/Data Collection Method	Research Aim	Participants	Disability or Definition of Disability	Immunisation	Relevant Results	Limitations
Taiwan	survey, part of larger survey into health of people with ID, parent report as proxy	immunisation coverage rates among community dwelling teenagers with an ID in Taiwan				immunised. Rate of non-immunisation twice that of general population Hep B immunisation correlated with higher household income, previously oral health exams	report 220 immunisation status unknown
2010 **Lin, Lin & Lin** **Taiwan**	Cross-sectional questionnaire	To examine the Hep B coverage rate and its determinants of children with ID in Taiwan	495 primary caregivers of children with ID, aged 3-24 yrs who attend three special education schools in Taiwan	ID	Hep B	74% had received the full Hep B immunisation. Incomplete Hep B immunisation was twice the general population Main determinants were lower	Taiwan's universal Hep B program gives all three doses by 5 mths of age – this research did not explain the relationship, given that ID is diagnosed later

Year, Study, Location	Study Design/Data Collection Method	Research Aim	Participants	Disability or Definition of Disability	Immunisation	Relevant Results	Limitations
						household income and older age of child	
2008 **O'Connor & Bramlett** **USA**	Data linkage – National Immunisation Survey and National Survey of Children with Special Health Care Needs 2000-2002 data	To compare vaccination coverage of children 19-35 mths with and without SHCN	17,994 children between 19 and 36 mths, 1283 (7%) with SHCN	CSHCN	DTP MMR Polio Varicella Hep B Hib Men	Generally no difference between the immunisation rates of CSHCN and those without Under-immunisation more likely in white affluent household	Broad descriptor of special health care needs includes chronic health issues and emotional disorders Immunisation coverage by parent report, verified by health care provider Data used now 15 years old
2008 **Samuels, Liu, Sofis & Palfrey** **USA**	Audit of immunisation rates before and after intervention and questionnaires to providers	To assess whether a medical model of care for CSHCN improves immunisation rates	Six general paediatric practices and 150 CSHCN 30 paediatricians	CSHCN	DTP MMR Polio Hib Hep B	Immunisation rates were already high, overall 83% and did not change after intervention Severity of	Broad descriptor of special health care needs includes chronic health issues and emotional disorders Difficult to determine

Year, Study, Location	Study Design/Data Collection Method	Research Aim	Participants	Disability or Definition of Disability	Immunisation	Relevant Results	Limitations
						illness, technologically dependent, non-English speaking background had no effect on immunisation rates	effectiveness of intervention as immunisation rates were already high (by USA standards) prior to intervention
2007 **Groce, Ayora & Kaplan** **Ecuador**	Retrospective audit and parent interview	To compare immunisation coverage of children with disability in remote parts of Ecuador with their non-disabled peers	32 children with disability and their siblings, mean age 13.6 yrs	A disability significant enough to impact on the child's daily life	Not stated	31/32 children with disability were up to date with immunisations, as were their peers	Limited quantitative and qualitative results beyond uptake rates published
2005 **Tillman, Tillman, Heininger, Lutschg & Weber** **Switzerland**	Retrospective case-control study	To examine the uptake and age of vaccination of children with chronic neurological deficits as compared to	100 children 1-16 yrs with neurological deficits and 200 age-matched controls	Various chronic neurological impairments Main diagnoses epilepsy, CP, severe developmental	DTP Polio Hib MMR Hep B	Children with chronic neurological deficits receive less childhood immunisations than healthy controls and at a	Difficult to follow the changes in the schedule over the period of the study

Year, Study, Location	Study Design/Data Collection Method	Research Aim	Participants	Disability or Definition of Disability	Immunisation	Relevant Results	Limitations
		healthy children		delay		later age Those who had congenital neurological deficits or a diagnosis in first 6 mths of life were particularly at risk of missing or delayed immunisations Pertussis the most likely to be missed or delayed compared to controls	
2004 **Haynes & Stone** **Australia**	Probabilistic data linkage	To determine the predictors of incomplete immunisation status of Victoria children at 12 and 24 mths	60,491 Victorian children born in 1998	Congenital malformations as defined by the Births Defects Register, Victoria, Australia		Congenital malformations not a significant predictor of incomplete immunisation at 12 and 24 mths	Congenital malformation broad classification from minor to severe Includes those with disability and those without

Year, Study, Location	Study Design/Data Collection Method	Research Aim	Participants	Disability or Definition of Disability	Immunisation	Relevant Results	Limitations
2001 **Tuffrey & Finlay** **UK**	Cross sectional survey of computer database of immunisation records	To compare immunisation status of children attending three special schools in Bath, England, with age and sex matched controls	136 children attending three special schools from 4-17 yrs, with severe physical difficulties, severe or profound learning difficulties or both. 272 controls	Severe physical disabilities or severe and/or profound learning disabilities	DTP Polio Hib MMR	59% of children from special schools fully immunised vs 83% of controls Significant difference found for pertussis, measles and rubella. No sex or age differences	Data from 2000
1993 **Raddish, Goldmann, Lawrence, Kaplan & Perrin** **USA**	Cross sectional survey Parent questionnaire, chart review, immunisation record review	To determine immunisation levels for among children with spina bifida compared to general population at 24 mths and 7 yrs of age, and describe influencing factors	120 children seen in myelodysplasia clinic of Children's Hospital in Boston, USA 4 mths to 18 yrs	Myelodysplasia	DTP Polio MMR	Children with spina bifida had lower uptake immunisations than general population At 24 mths 58% vs 79% At 7 yrs 81% vs 97%	Data from 1990 Excluded children with incomplete immunisation data

Year, Study, Location	Study Design/Data Collection Method	Research Aim	Participants	Disability or Definition of Disability	Immunisation	Relevant Results	Limitations
1982 **Tervo & Taylor** **Canada**	Retrospective audit	To determine factors associated with inadequate immunisation status in children with physical handicaps	98 children aged 2-20 yrs with physical handicap	Physical handicap – main diagnoses CP and myelomeningocele	Scheduled immunisations including MMR DTP Polio	Overall immunisation rate 63% 'lower than expected' Children with moderate to severe CP significantly less likely to be up-to-date with immunisations	Data nearly 30 yrs old Changes in schedule and understanding over time At the time of study pertussis was not recommended for those with neurological disorders

Key:

ACIR – Australian Childhood Immunisation Register

ASD – Autism spectrum disorder

CP – Cerebral palsy

CSHCN – children with special health care needs

DTP – diphtheria, tetanus, pertussis vaccine

Hep A – Hepatitis A

Hep B – Hepatitis B vaccine

Hib – Haemophilus influenzae type B vaccine

HIV – Human immunodeficiency virus

HPV – Human papillomavirus vaccine

ID – intellectual disability

IPV – invasive pneumococcal vaccine

Men – meningococcal vaccine

MMR – measles, mumps, rubella vaccine

Polio – poliomyelitis vaccine

SHCN – special health care needs

YSHCN – youth with special health care needs

mths – months

yrs – years

3.4.1 Coverage data

The majority of the studies measured immunisation coverage, with 16 of the 24 studies (67%)[146–148,151,153,154,156,158,161,162,164–169] calculating the uptake of one or more vaccinations in a population of children and young people up to age 18 years with a disability. Some studies measured immunisation coverage indirectly. Two studies did not specifically explore a cohort of people with disability but instead found that disability predicted incomplete vaccination, including in girls in non-mainstream schools,[157] and Trisomy 21 and ASD amongst school students.[159] One study explored whether infants with congenital malformations predicted low immunisation coverage.[163]

Almost all the direct coverage studies (13/16; 81%) found that children and young people with disability had lower rates of immunisation uptake across a range of different vaccines than their typically developing peers.[146–148,153,154,156,158,161,165–169] Only three studies found that children or young people with disability had similar rates of immunisation as typically developing children.[151,162,165] Groce, Ayora and Kaplan (2007)[162] reported a small study from Ecuador which found that 31 of 32 children with disability were immunised at the same rate as their typically developing siblings, despite poverty, isolated locations and difficulty accessing health care. The authors suggested that the specific culture, which valued children with disability, influenced immunisation practices.

The only other study of immunisation in children or young people with disability in a LMIC had quite different results, but supported the need to consider the cultural context of children with a disability.[166] This study was from Nigeria, and it explored the determinants of immunisation coverage in children six months to five years with neurological conditions attending an outpatient neurology clinic. The findings suggested that, apart from parental education and socioeconomic status, the degree of disability that was visually apparent negatively affected immunisation coverage. More research in LMICs may improve understanding of how different contexts impact health care decision-making and act as a barrier to delivering equitable preventive health care for people with disability.

A second study that reported no difference in coverage between children with and without disabilities was a data linkage study from the USA. This study found that Children with Special Health Care Needs (CSHCN) between nine and 36 months had immunisation rates similar to typically developing children.[165] These results must be interpreted with caution in the context of the definition of 'Children with Special Health Care Needs', which is commonly used in the USA. This is a very broad definition that includes children who require health or medical input above what would be typical, any child on prescription medication or with emotional or behavioural disorders or chronic illness, as well as those with a disability.[170] It is interesting that other studies from the USA have not replicated this finding with an older age range of young people with SHCN.[146,158] As it is likely that the cohort of CSHCN narrows after early childhood intervention and the period of assessment and diagnosis of disability, this suggests that once the category of CSHCN is more focused, a difference in immunisation coverage may be apparent.

A third study, also from the USA, found no difference in immunisation rates between children and young people with disability and typically developing children. This was a large study of influenza immunisation uptake in children with high-risk conditions, including neurodevelopmental disorders such as CP, ID and epilepsy. The results of this study found 50% of parents of these children had immunised or were intending to immunise their children against influenza, which was similar to the general population. It is difficult to compare these findings with studies examining coverage of other immunisations because in the USA, as in Australia, influenza vaccine is recommended for at-risk groups including children and young people with chronic illness. This applies to those with disability where there is impaired respiratory health, which is often present in children with CP, physical disability and other neurological conditions. Therefore, the expectation is that an aggregate group of children and young people with disability would have higher influenza vaccine coverage than the general population.

Nevertheless, this is not the case in any of the three studies exploring influenza immunisation,[151,167,168] although both Smith et al. (2015)[151] and Yen et al. (2012)[168] found that those with more severe physical disability were more likely to have received the influenza immunisation than those with milder disability. Interestingly, Pandolfi et al. (2012)[167] compared influenza immunisation coverage for a number of disease groups and found those with neurological disease were far less likely to receive the influenza immunisation than other at-risk groups, such as Type 1 diabetes and HIV. This suggests that perception of risk is less for those with respiratory compromise due to disability, rather than respiratory compromise due to a disease process. This belief is echoed in a study which found that although the majority of paediatricians (74%) recognised CP as high risk for influenza, only about half acknowledged the importance of influenza immunisation for those with epilepsy (51%) and ID (46%).[151] This was significantly lower than the 94% who recommended immunisation for children with asthma.[151]

Some studies did not aim to measure immunisation coverage. One such study explored overall health service use amongst youth with ASD and found that they were less likely to receive immunisations.[160] Another assessed whether enhanced primary care in the form of a dedicated nurse practitioner to coordinate the child's care improved immunisation rates for CSHCN, with no significant difference found.[150] Two studies examined parental decision-making about vaccines after a diagnosis of ASD in their child.[145,149] Both these studies concluded that parents were more likely to miss or delay immunisations after their child's diagnosis of ASD, and suggested that this may be due to persisting concerns about the disproved association between immunisation and ASD. However, even though these studies did not focus on immunisation coverage, they all measured outcomes numerically rather than qualitatively.

3.4.2 Qualitative data

While quantitative methods are vital in understanding immunisation coverage, qualitative methods are required to understand the issues relating to the immunisation of children and young people with disability. Qualitative research is more appropriate than quantitative data to determine the complex reasons for lower coverage. Despite this, only one study undertook qualitative data collection, and this study did not report the qualitative analysis in their published paper.[162]

Therefore, at present there is no qualitative research reported on immunisation in children and young people with disability and this highlights a clear knowledge gap. A wider search of the literature only found one relevant qualitative study of adults with disability, which explored their satisfaction with a program to immunise against Hepatitis B.[171] This study used qualitative interviews with adult clients with intellectual disability and questionnaires with care staff to investigate the logistics of Hepatitis B delivery, use of restraint and information needed about immunisation for this population.

There are also qualitative studies that examine the SBIP in the context of mainstream schools.[79,113,172–175] The majority of these studies use qualitative data from the immunisation nurse perspective to explore the implementation of HPV immunisation in the SBIP. Burgess et al. (2016)[113] refer to the issues of *"time, turf and trust"* in their discussion of the challenges relating to the school/health collaboration. More specific themes from these studies include clear communication, nurse workload, the logistics of immunisation day, peer support, distraction techniques and consent.[79,113,173,174] This qualitative analysis allows an understanding of the experience of immunisation and barriers to immunisation that is not available from quantitative studies. However, the issues in specialist schools may be quite different from those in mainstream schools, and to apply the findings from these studies without specific data from these schools would be misguided.

Within the body of research on young people with disability, there is a lack of both the in-depth qualitative research and the discernment of the perspective of multiple stakeholders that is apparent in studies of the SBIP in mainstream schools. In particular, the perspective of health care providers is essential for a complete understanding of the barriers and facilitators to immunisation service delivery in this population.

3.4.3 Provider recommendations

This literature review revealed scant research that explored the opinion and behaviours of health professionals in their role of providing advice about immunisations to families with children with disability. Three studies included paediatricians' perspectives on immunisation.[146,151,152] Only one study[152] focused primarily on providers; it examined paediatrician advice about immunisation for children with severe handicap or epilepsy in the Japanese context, where epilepsy was a contraindication to immunisation until the mid 1990s. This study had a response rate of 52%, with 10% of the these being paediatric neurologists.

Not one study was found that examined the perspectives and concerns of GPs or immunisation nurses about immunisation in people with disability. This lack of research limits the current level of understanding of influential factors regarding immunisation decision-making and service delivery, as well as the interventions that may be required by health professionals. Nevertheless, several studies that examined the perspective of families revealed the positive influence of health professionals in recommending immunisation in young people with disability.[151,167] In addition, Reiter and McRee (2016)[158] found that the strongest correlate of immunisation in youth with SHCN with disability was regular health checks.[158] The importance of health care provider recommendation is consistent with the literature regarding interventions to improve confidence and uptake in immunisations in the general population.[29]

3.4.4 Adolescent immunisations

While 13 of the studies found included young people in adolescence in the study participants,[146,147,151,153,154,156–159,164,167–169] only four studies focused exclusively on adolescent immunisations. There were no adolescent immunisation studies from Australia. The studies included one each from the UK[157] and Canada,[159] which both offer a SBIP for adolescent immunisation, and two from the USA,[146,158] where adolescent vaccinations are administered in the community setting.

Three of the studies focused only on HPV immunisation,[146,157,159] and one study included tetanus and conjugate meningococcal vaccine as well as HPV.[158] Reiter and McRee (2016)[158] found similar rates for tetanus immunisation but lower coverage of meningococcal and HPV immunisations in youth with SHCN, as compared with the general population. In the other adolescent specific studies, young people with disability had lower rates of HPV immunisation uptake relative to their peers,[146,157] or were associated with HPV vaccine refusal.[159]

3.4.5 Immunisation in young people with disability in specialist schools

Only two published studies examine immunisation in specialist schools, both from the UK. In South West England, Fisher et al. (2014)[157] explored correlates of HPV vaccine uptake in girls aged 12 to 13 years. After multivariable analysis, girls attending non-mainstream school settings were less likely to initiate or complete the HPV vaccine immunisation schedule (initiation: adjusted OR 0.16, 95% CI: 0.11–0.24; completion: adjusted OR 0.27, 95% CI: 0.17–0.44). The second study by Tuffrey and Finlay (2013) did not specifically examine adolescent immunisations but focused on childhood immunisation uptake in children and young people attending specialist schools aged four to 17 years.[156] However, elsewhere this research group referred to unpublished data on low uptake of the HPV vaccine for girls in specialist schools in this region (77%) relative to girls in mainstream schools (93%).[176,177] The authors of this commentary article suggest reasons for the lower coverage, including issues of informed consent or assent to the immunisation, and parental reluctance to consent due to safety concerns or a belief their child with a disability would not be sexually active.[177]

Regarding young people with disability in Australian specialist schools, there is no literature on the coverage, experience, barriers or facilitators of adolescent immunisations. In addition, there are no data specifically referring to immunisation in specialist schools maintained in government records. Although aggregate figures on school immunisations are collected by state governments for planning and evaluation purposes, the recognition of inequities in immunisation service delivery for vulnerable populations relies on the existence of disaggregate data. Aggregate immunisation uptake figures do not generally identify small populations at risk of under-immunisation, and therefore lower immunisation coverage in people with disability can be missed.

The issues regarding lack of recorded data for immunisation of young people in specialist schools in Victoria is significant. Uptake data are collected utilising the number of immunisations given as the numerator, and year level enrolment (Year 7 or 10) as the denominator. As the majority of specialist schools are ungraded, there is no year level enrolment number and so no such data are calculated. No consistent method is employed to utilise an age range for the denominator data, and therefore uptake of immunisation in specialist schools is not reported in the overall school immunisation rates in Victoria (private communication). Therefore, this population is currently absent in Victorian government data collection. The combination of a paucity of research and failure to include ungraded schools in routine data collection has wide ramifications for health equity, health service planning, allocation of funding and resources, and development of best practice for the immunisation of young people with disability in specialist schools.

3.5 Importance of this Thesis

There is a clear need for both local coverage data and qualitative research on immunisation for young people with disability to clearly identify the barriers and enablers to service delivery for this population. The studies that have been published focus on immunisation coverage in other countries and the overwhelming majority have found that this population are at risk of missing childhood and adolescent immunisations. However, with only two childhood immunisation studies from Australia, and a wide variety of settings, definitions of disability and methodologies used, it is difficult to ensure these data are relevant to specialist schools for young people with disability in Victoria.

As well as Victorian coverage data, crucially missing from the research is qualitative information on the experiences, barriers and facilitators of immunisation for young people with disability, particularly in terms of SBIPs in specialist school settings. Uptake only illustrates the potential scope of the issue, and this in isolation does not help identify the factors that influence decision-making and subsequently whether a young person with a disability receives an immunisation. Quantitative data do not provide comprehensive information about the reasons underpinning vaccine acceptance. There is not only a need for rigorous uptake data specific to specialist schools in the Australian context, but also qualitative data exploring individual and family decision-making about immunisation, and the policies and processes in the education and health system available to support this from the perspective of schools, immunisation providers and policy makers.

3.5.1 Research aim

The research aim of this thesis is:

> *To explore and describe acceptance and delivery of immunisation in specialist schools for young people with disability in Victoria, Australia.*

3.5.2 Study questions

The research questions for the studies within this thesis are:

> *What is the uptake of school-based, government-funded vaccinations in young people with disability attending specialist schools in Victoria, Australia, as compared to the general Victorian population, and what are the reasons for non-vaccination in this group?*
>
> *What are the socio-ecological determinants that prevent or enable immunisation for young people with disability in specialist schools in*

Australia?

3.6 Conclusion

This chapter has analysed the published research on immunisation in children and young people with disability up to February 2017. It has concluded that there is evidence to be concerned about coverage of immunisations in this population. However, local coverage data for adolescent immunisations, and an in-depth understanding of barriers and facilitators of immunisation in young people with disability, are both absent. The findings of this literature review have informed the development of the two phases of research within this thesis. The first phase, which aimed to determine the uptake of immunisations for young people with disability in specialist schools in Victoria, is reported in the next chapter.

4 PHASE ONE STUDY: THE UPTAKE OF ADOLESCENT VACCINATIONS THROUGH THE SCHOOL IMMUNISATION PROGRAM IN SPECIALIST SCHOOLS IN VICTORIA, AUSTRALIA

4.1 Introduction

This chapter outlines the first study in this thesis – the quantitative Phase One Study. The focus of this study was to answer the first research question, as outlined at the end of Chapter 3:

> *What is the uptake of school-based, government-funded vaccinations in young people with disability attending specialist schools in Victoria, Australia, as compared to the general Victorian population, and what are the reasons for non-vaccination in this group?*

This research has been published in a peer reviewed journal and is presented in this chapter as the published article:

O’Neill J, Newall F, Antolovich G, Lima S, Danchin M. The uptake of adolescent vaccinations through the school immunisation program in specialist schools in Victoria, Australia. Vaccine. 2019 Jan 7;37(2):272-9.

While all elements of the study are incorporated within this publication, including background, methods, results, analysis and interpretation, some sections are necessarily truncated as per the journal requirements. Therefore, the background presented in the article is a brief summary of the content detailed in Chapters 2 and 3 of this thesis. Furthermore, the methods section presented in the article includes only essential information; additional information pertinent to the research design and data collection is therefore outlined below. Results and discussion of results are presented in entirety in the publication.

4.2 Phase One Study Methods

Some information regarding the Phase One Study methods was not able to be included in the published article, and is therefore presented for completeness below. This section should be read in conjunction with the methods section within the publication.

4.2.1 Study process

The ethics protocol for this study is included in Appendix D. As outlined in the protocol, from December 2016 to January 2017, initial contact was made with the principals of all eligible specialist schools in Victoria via a letter outlining the aims of the study and including an Information Statement and Consent form (Appendix E). If the principals agreed to their school participating in the study, they were asked to return the participation form, using a stamped self-addressed envelope or via email. On this form, they were asked to identify the staff member who was allocated as the school immunisation coordinator, who then became the school contact for the purposes of the study. If no form was returned, a follow-up telephone call was made to the school two to four weeks after the initial paperwork was sent. A maximum of two follow-up calls were made. When requested, the letter, Information Statement and Consent Form were re-sent to the school via email.

School immunisation coordinators were asked to collect data for all young people enrolled at the school who were aged 12 or 13 on the first immunisation day of the year, whether or not they were offered immunisation. Also included was any young person outside this age range who was offered the adolescent dTPa or the HPV vaccination. This was in recognition that young people outside the scheduled age range might be offered these immunisations opportunistically, if the school or the immunisation providers were aware that they had previously missed an immunisation.

In 2017, the varicella vaccine was also offered at this age to adolescents who had not received a vaccine in childhood and who had no record of varicella infection. However, because not all adolescents under these criteria were eligible for the varicella vaccine, the comparison of uptake was not comparable between the two groups, and therefore, information for this vaccine was not collected. Some specialist schools also offered the annual influenza vaccine at school immunisation sessions. However, as this was not part of the SBIP and was Local Government Area (LGA)-dependent, this was not included in the data collection.

School immunisation co-ordinators were asked to enter data via a link to the data collection form on REDcap™ (Appendix D). The REDCap™ electronic data capture tool is hosted at the Murdoch Children's Research Institute, Melbourne. REDCap™ (Research Electronic Data Capture) is a secure, web-based application designed to support data capture for research studies. It provides:

1. *an intuitive interface for validated data entry;*
2. *audit trails for tracking data manipulation and export procedures;*
3. *automated export procedures for seamless data downloads to common statistical packages; and*
4. *procedures for importing data from external sources.*[178]

Data collection continued throughout the 2017 school year.

4.2.2 Outcome measures

The primary outcome measure for the Phase One Study was the uptake of dTPa and HPV vaccines in specialist school settings, as expressed as a percentage of the eligible population of 12 to 13 year olds.

Secondary outcome measures from data from schools included:

1. *Immunisation uptake by the degree of motor and intellectual impairment with:*

   Categorisation of motor function as:

   a. *Ambulant without aides*
   b. *Ambulant with aides*

   c. *Non ambulant*

Categorisation of intellectual impairment[††] as:

   a. *No impairment*
   b. *Probably no impairment*
   c. *Probably impaired, severity unknown*
   d. *Mild impairment*
   e. *Moderate impairment*
   f. *Severe impairment*

2. *Reason for non-vaccination if applicable;*
   a. *Up to date with vaccination*
   b. *Vaccine not available*
   c. *No consent form returned*
   d. *Consent form returned with consent for immunisation not given*
   e. *Not able to immunise due to student behaviour*
   f. *Immunisation not offered*
   g. *Not at school*
   h. *Other*

4.2.3 Ethical considerations

Ethics approval was obtained from The Royal Children's Hospital, Melbourne, Human Research and Ethics Committee (HREC 36326A) (Appendix F), and the research was approved by the Department of Education and Training Victoria (Appendix G).

4.2.4 Risk management

There were no identified risks to the schools or individuals participating in this study, apart from time and potential inconvenience relating to the requirement for the school immunisation coordinator to fill out the REDcap™ data collection form for

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[††] While determination of intellectual functioning is calculated from a standardised IQ test, many children with disabilities, particularly those who are non-verbal are unable to complete an IQ test. Therefore many children in specialist schools do not have a standardised test report on intellectual functioning. Thus the decision was made to use the categories of intellectual impairment based on the subjective professional assessment of the specialist school educator filling in the survey. While it is acknowledged these categories are not objectively and rigorously determined, this is reflective of the issues of data collection in this population.

each eligible student. It was estimated that each form took two minutes to complete and each school had between one and 40 eligible students. There were no foreseeable adverse events related to this study. Schools were informed that if they wished to withdraw from the study at any time, consent would be sought to use any data already collected. If this consent was refused, all data related to this school would be destroyed. No school withdrew from the study.

4.2.5 Data security and handling

The data on REDcap™ were only accessible to the study investigators through a secure password protected system. The immunisation coordinator at each school was able to access, view and enter information for students only in their own school. Data collected were not identifiable to individuals. The aim of this study only required aggregate data so the de-identification of schools was initiated at the analysis stage and maintained.

4.3 Published Study

The article below arising from the Phase One Study was accepted for publication in *Vaccine* on November 13, 2018 and published first online on December 3, 2018. It is reprinted below in its final published format with permission from Elsevier (Appendix H). Author contributions for this publication are as follows: study conception and design Jenny O’Neill (JO), Margie Danchin (MD), Giuliana Antolovich (GA), Sally Lima (SL) and Fiona Newall (FN); ethics protocol JO, with edits from MD, GA, SL and FN; recruitment of schools JO; checking and cleaning of data JO; analysis of data JO with assistance from Monsurul Hoq, Biostatistician, Clinical Epidemiology and Biostatistics Unit, The Murdoch Research Institute; interpretation of the data JO, MD, GA, SL and FN; initial draft of manuscript JO with editing and redrafting from JO, MD, GA, SL and FN. All authors approved the final manuscript as submitted.

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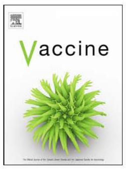

The uptake of adolescent vaccinations through the School Immunisation Program in specialist schools in Victoria, Australia

Jenny O'Neill [a,b,c,*], Fiona Newall [b,d,e,f,g], Giuliana Antolovich [a,c], Sally Lima [e,g,h], Margie Danchin [b,i,j,k]

[a] Department of Neurodevelopment and Disability, The Royal Children's Hospital, Melbourne, Australia
[b] The Department of Paediatrics, The University of Melbourne, Melbourne, Australia
[c] Developmental Disability and Rehabilitation Research Group, Murdoch Children's Research Institute, Melbourne, Australia
[d] Department of Haematology, The Royal Children's Hospital, Melbourne, Australia
[e] Nursing Research, The Royal Children's Hospital, Melbourne, Australia
[f] Clinical Haematology Research Group, Murdoch Children's Research Institute, Australia
[g] The Department of Nursing, The University of Melbourne, Melbourne, Australia
[h] Clinical Learning and Development Unit, Bendigo Health, Victoria, Australia
[i] Department of General Medicine, The Royal Children's Hospital, Melbourne, Australia
[j] Vaccine and Immunisation Research Group, Murdoch Children's Research Institute, Melbourne, Australia
[k] The School of Population Health, The University of Melbourne, Melbourne, Australia

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ABSTRACT

Background: As part of the National Immunisation Program (NIP) students in Australia receive adolescent immunisations through the School Immunisation Program at 12 to 13 years. For children with disabilities attending specialist schools, no vaccine uptake data is collected at this time point. We aimed to determine uptake of diphtheria-tetanus-pertussis (dTpa) and Human Papillomavirus (HPV) immunisations amongst young people with disabilities in specialist schools in Victoria.

Methods: A prospective cohort study was conducted in Victoria, Australia. Data was collected on immunisation days in the 2017 school year from specialist schools in Victoria. The school immunisation coordinator entered data online for eligible students for receipt of dTpa and HPV on each school immunisation day. Demographic data, motor and intellectual function of students and reasons for non-receipt of dTpa and HPV vaccine were recorded. Data were analysed using descriptive statistics.

Results: Of 73 eligible specialist schools in Victoria, 28 (38%) participated. dTpa was received by 63% (237/374) of participating students and HPV dose 1 (HPV1) was received by 66% (76/114) females and 67% (174/260) male students respectively. Three doses of HPV were received by only 41% (100/241) of students. The main reasons for missed immunisation were absence from school, lack of consent and inability to immunise due to the student's behaviour and/or anxiety.

Conclusion: This is the first study in Australia to report that uptake of adolescent immunisations in specialist schools for young people with a disability is significantly lower than in mainstream settings. Comparative data during the same time period for students in mainstream schools demonstrated higher uptake, at 89% for dTpa and 75% for three doses of HPV. These data highlight the inequity of receipt of school-based immunisations for this group of adolescents, the barriers to which could be more thoroughly explored through qualitative inquiry from a socio-ecological perspective.

1. Introduction

As part of the National Immunisation Program (NIP) in Australia, all young people aged 12 and 13 years are eligible to receive adolescent immunisations through the School Immunisation Program. In 2017, a booster dose of diphtheria-tetanus-pertussis (dTpa) vaccine, three doses of Human Papillomavirus (HPV) vaccine, and a catch-up dose of varicella vaccine (for young people who did not receive a dose in childhood and had no clinical history of infection) were offered in the school-based program. Signed parental consent is required for these immunisations to be given in the school setting by the Local Government Area immunisation nurses who visit the school [1]. For ease of administration, these vaccines are typically offered in the first year of high-school (Year 7) in Victoria. Vaccine

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* Corresponding author at: The Royal Children's Hospital, Flemington Rd, Parkville, Melbourne, Australia.
E-mail address: jenny.oneill@rch.org.au (J. O'Neill).

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uptake is determined by the number of doses given divided by the number of enrolled eligible students in Year 7. In 2016, 89% of eligible students attending mainstream schools received dTpa vaccine and 79% of females and 75% of males received three doses of HPV vaccine [2–4].

Mainstream schools in Victoria must accommodate students with any level of disability [5]. However parents of students with disabilities, who meet the criteria of an Intelligence Quotient (IQ) below 70, or high-level physical or behavioral support needs, can choose instead for them to attend specialist schools [6]. The decision to enroll a child in a specialist school is made by parents, often with specialist and educational advice, but is not mandated. The differences in the population of children attending mainstream schools with disabilities and those in specialist schools with disabilities, are not well described, with no statewide data collection of the demographics of these cohorts.

The specialist school settings are broadly divided into Special Schools, which enroll students with mild to moderate disability, and Special Development Schools, which enroll students with moderate to severe intellectual disability or high-level needs. In addition there are Multi-mode schools enrolling students with any level of intellectual disability or high-level needs (which are often also referred to as Special Development Schools), schools specifically for students with a diagnosis of Autism Spectrum Disorder (ASD), and schools for students with significant physical disability needing paramedical support.

Students in specialist school settings are typically grouped in classes according to ability and educational needs, but are not graded into individual year cohorts as seen in mainstream schools. As the majority of specialist schools have no Year 7 enrollment cohort, and therefore no figure to provide a denominator to calculate uptake of the school-based immunisations given at 12–13 years. As a result, data for adolescents with disabilities in specialist schools are not included in Victorian immunisation figures documented by the Department of Health and Human Services (DHHS) Victoria, nor is it possible to determine HPV uptake for these students from the HPV register.

The limited available evidence suggests that children with disabilities are at risk for under or non-immunisation. Lower rates of immunisation are recorded for children with disabilities for early childhood immunisations [7–9] and for the seasonal influenza vaccine [10,11]. Two studies from the USA and Canada on adolescent immunisation found that only 17% of children with special health care needs were immunised against HPV, and that having Trisomy 21 or ASD was significantly associated with missing HPV immunisation [12,13]. In a cohort of 72 Australian young people aged 14 with a range of disabilities, only 44.1% of females and 39.5% of males had received 3 doses HPV [14]. One unpublished audit in the United Kingdom, found that although parental consent for HPV vaccine was high at 77%, it was well below the 93% recorded in mainstream schools [15,16] and immunisation receipt was not recorded.

The potential for the population of young people with disabilities to be under-immunised is not only an equity issue, but has significant health implications. The consequence of vaccine-preventable diseases, in those with disabilities is likely to be more severe. This is particularly the case for people with significant physical disability, or disability related to prematurity, which can result in chronically impaired respiratory and neurological health [7,17,18]. In addition, the importance of HPV immunisation for young people with disabilities cannot be underestimated. Young people with disabilities are not only sexually active, but have a younger age of sexual debut and are more likely to experience unwanted sexual activity than their typically developing peers [19–21].

In this study we aimed to measure the uptake of school-based immunisations for young people with disabilities in the specialist school setting in Victoria, Australia. We also aimed to collect information on motor and intellectual function and reasons for non or under-vaccination to try and ascertain whether the type of disability influences immunisation receipt, and to identify the barriers and enablers to immunisation delivery. We hypothesised that the uptake of adolescent immunisations would be lower for students in specialist schools compared to mainstream school settings and would be predominantly due to lack of parental consent and behavioural factors and/or anxiety amongst students with disabilities.

2. Materials and Methods

2.1. Study population, recruitment and sampling

This prospective cohort study collected immunisation information on each of the three immunisation days in the 2017 school year for each consenting specialist school identified in Victoria. The principals of all eligible schools (n = 73) were sent an introductory letter and information statement in mid-December 2016 or late January 2017 outlining the study. If they consented to participation, they were asked to identify the school immunisation coordinator as the primary contact. A maximum of two follow up calls were made to schools that did not respond to the initial invitation.

On each immunisation day in 2017, the school immunisation coordinator was requested to enter data online for eligible students. Students were identified as eligible if they were aged 12 or 13 on the first immunisation day of the year. Data requested included: receipt of HPV and/or dTpa; age; gender; Aboriginal and Torres Strait Islander (ATSI) status; level of motor and intellectual function and reasons for non-receipt of dTpa and HPV vaccine. As not all adolescents were eligible for the varicella vaccine, uptake data for this vaccine was not recorded. Study data were collected and managed using REDCap^{TM} electronic data capture tools hosted at the Murdoch Children's Research Institute, Melbourne [22].

2.2. Inclusion and exclusion criteria for schools

Eligible specialist schools were identified through the DHHS Immunisation Section, Victoria. This included all Special Schools, Special Development Schools, Multi-mode Schools, Physical Disability Schools and Autism Specific Schools. The principal investigator checked the enrolment criteria of each school to ensure that the specialist schools enrolled adolescent students with physical and/or intellectual disabilities. Young people attending mainstream schools were excluded. Satellite units for young people with special needs attached to mainstream schools; schools for hearing impaired students and specialist schools for students with primary mental health or behavioral needs were also excluded.

2.3. Ethics

Ethics approval was obtained from The Royal Children's Hospital, Melbourne, Human Research and Ethics Committee (HREC 36326B) and the research was approved by the Department of Education and Training Victoria. Consent of the individuals were not required, as individual, school and Local Government Areas were not named, and only aggregate data was reported.

2.4. Data analysis

Statistical analysis of uptake rates was undertaken using Stata [23]. Analysis of the difference in proportions between specialist school uptake and mainstream immunisation uptake was undertaken using Chi-Square. The association between demographic

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variables and uptake rates was calculated using logistic regression, adjusted for age and clustering by school. Reasons for non-immunisation are presented as proportions of missed doses.

3. Results

3.1. Demographics

The demographics of consenting and non-consenting schools (28 [38%] vs 45 [62%]) are compared in Table 1. The schools that consented to participate were largely representative of specialist schools in Victoria although there were fewer medium size schools (32 vs 58%; p = 0.013) and schools from the South-Eastern region of Victoria (18 vs 38%; p = 0.026). There was no clear explanation for these differences.

3.2. Participant flow

Data was entered for 400 individual students, with 24/28 (86%) of participating schools completing data for all three immunisation days. Twenty-six records were excluded from students who received the third dose of HPV only, as a catch up dose from the 2016 school year. Complete data for the dTpa and first HPV immunisation dose (HPV1) was obtained for 374 students, with some attrition for the second and third HPV doses (HPV2 and HPV3) (Fig. 1). Hence there were 314 individual records entered for HPV2 and 241 entered for HPV3.

3.3. Immunisation uptake

The uptake rate for dTpa was 63% (237/374), and for HPV1 was 66% (76/114) for females and 67% (175/26) for males respectively. HPV3 completion was recorded for only 40% (28/72) of females, and 43% (72/169) of males from specialist schools (Tables 2 and 3). Uptake figures varied considerably by school, with schools reporting medians of 66% (IQR 38–85) for dTPa, 69% (IQR 43–80) for HPV1, 58% (IQR 33–75) for HPV2 and 43% (IQR 33–66%) for HPV3 (see Fig. 2). After clustering for schools, there was no significant difference in uptake of dTpa and HPV1 by gender, type of specialist school and degree of physical and intellectual impairment (Table 4). Students whose ATSI status was documented as "unclear" were statistically less likely to receive dTPa and HPV1 than those students who were not ATSI. However there was no significant difference in uptake for students who were confirmed ATSI.

3.4. Reasons for non-immunisation

The most common reason for missed doses of dTpa or HPV was absence from school with 38% (47/124) of missed dTpa doses and 117/391 (30%) of missed HPV doses attributable to absence on immunisation day (Table 5). Lack of consent card returned (31/124 [25%] for dTPa and 97/391 [25%] for HPV), and lack of consent given on a returned card (9/124 [7%] for dTPa and 52/391 [13%] for HPV) were also reasons for significant numbers of missed immunisation doses. Less common was inability to vaccinate the

Table 1
School demographics: consenting and non-consenting schools.

Demographic	Consenting schools (n = 28) n (%) Total students: 4,976	Non-consenting schools (n = 45) n (%) Total students: 6,298	p value
Type of School			
Special School	6 (22)	8 (18)	0.648
Special Development School	7 (25)	13 (29)	0.357
Multi-Mode School	11 (39)	18 (40)	0.476
Physical Disability	2 (7)	4 (9)	0.393
Autism Specific School	2 (7)	2 (4)	0.680
Student enrolment numbers			
<50 students	4 (14)	5 (11)	0.652
50–99 students	5 (18)	7 (16)	0.601
100–199 students	**9 (32)**	**26 (58)**	**0.013**
200–299 students	6 (22)	5 (11)	0.873
>299 students	4 (14)	2 (4)	0.911
Region of Victoria			
Metropolitan Melbourne	17 (61)	26 (58)	0.598
North Eastern	7 (25)	8 (18)	0.766
North Western	6 (21)	11 (24)	0.382
South Eastern	**5 (18)**	**17 (38)**	**0.026**
South Western	10 (36)	9 (20)	0.926
Student population			
Socio-economic index[*,^]			
Low	14 (50)	23 (51)	0.463
Low-mid	7 (25)	11 (25)	0.521
Mid	2 (7)	5 (11)	0.278
Mid-High	2 (7)	6 (13)	0.189
High	2 (7)	0 (0)	0.929
Missing data	1 (4)	0 (0)	0.846
English as a second language home[*]			
<10%	22 (79)	37 (82)	0.352
10–19%	6 (21)	8 (18)	0.648
ATSI student[*]			
<10%	25 (89)	37 (82)	0.807
10–19%	3 (11)	7 (16)	0.272
>19%	0 (0)	1 (2)	0.156

[*] 2015 data obtained from school annual reporting, available for 72/73 schools.
[^] As determined by family occupation.

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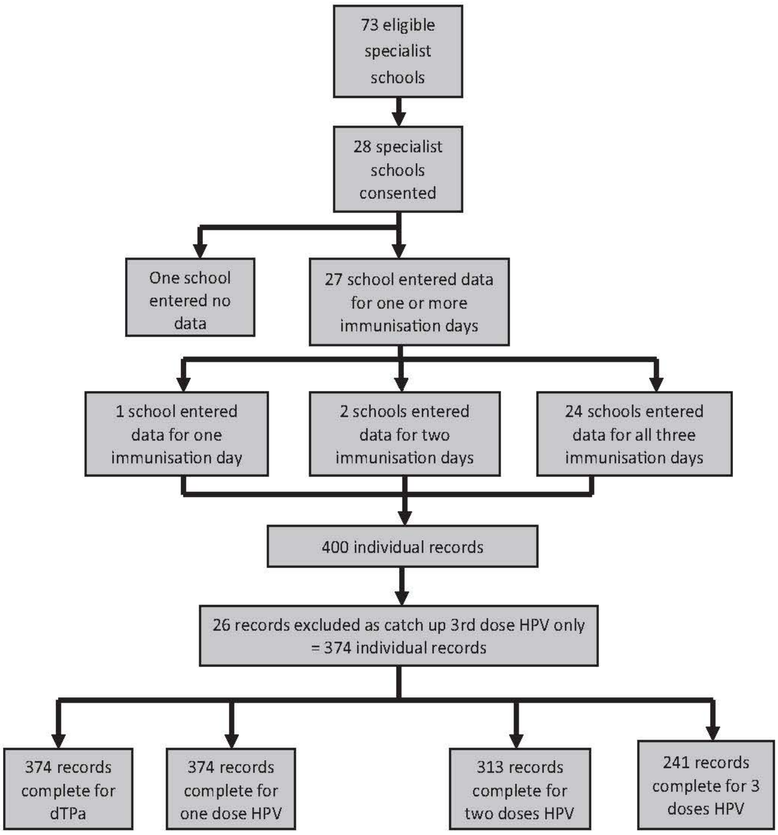

Fig. 1. Flow chart of participants.

Table 2
Uptake of dTPa vaccine as compared to Victorian data.

	Total number	dTPa Number (%)	OR (95% CI)
Victorian 2016 Year 7[*]	69,186	60,944 (89)	0.23 (0.19–0.29)
Specialist schools	374	237 (63)[*,**]	

[*] From data provided by DHHS Immunisation Victoria and DET.
[**] Includes those who received the dTPa immunisation on an immunisation day in 2017 and those who were up to date with dTPa.

student due to the student's degree of anxiety or distressed behaviour (91/124 [9%] for dTPa and 35/391 [9%] for HPV), however 49 of the 251 students who did receive their immunisation (19.5%) had a notation in this section that they were "very challenging" or "required extra support" or "became very distressed".

Reasons given in the "other" category for missed doses included, students who were enrolled also at a mainstream school so were attending there on immunisation day, were on excursions, or were at school but were unwell. There was no statistically

Table 3
Uptake of HPV vaccine as compared to Victorian data.

	Total Number	HPV 1 dose Number (%)	OR (95% CI)	Total Number	HPV 2 doses Number (%)	OR (95% CI)	Total Number	HPV 3 doses Number (%)	OR (95% CI)
Female									
Victorian Year 7[*]	33,675	29,545 (88)	0.28 (0.19–0.41)	33,675	28,566 (85)	0.19 (0.13–0.29)	33,675	26,640 (79)	0.17 (0.10–0.27)
Specialist Schools	114	76 (66)		96[**]	58 (52)		72[***]	28 (40)	
Male									
Victorian Year 7[*]	35,511	28,672 (84)	0.49 (0.37–0.63)	35,511	28,582 (81)	0.31 (0.24–0.41)	35,511	26,531 (75)	0.26 (0.19–0.35)
Specialist Schools	260	174 (67)		217[**]	123 (57)		169[***]	72 (43)	

[*] 2016, from the HPV Register.
[**] Missing dose 2 data includes: schools not submitting any individual data for that immunisation day (n=19, 5%), and individual student not having had any data reported for that day, although the school did submit other data that day (n=50, 13%).
[***] Missing dose 3 data includes: schools not submitting any individual data for that immunisation day (n=38, 10%), and individual student not having had any data reported for that day, although the school did submit other data that day (n=102 ,27%).

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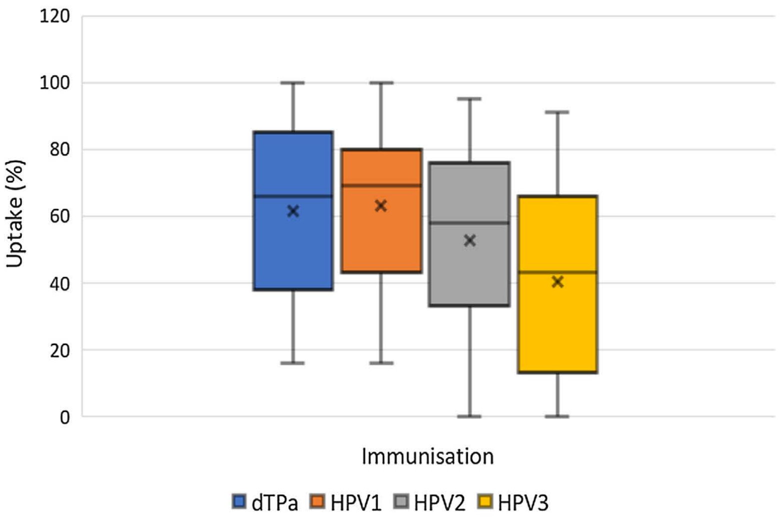

Fig. 2. Range of immunisation uptake across schools.

Table 4
Phase 1 Demographic association with uptake of dTPa and HPV.

Demographic	Total Number	Uptake dTpa n (%)[*]	OR	95% CI	Uptake HPV1 n (%)	OR	95% CI
Gender							
Female	114	68 (60)	Ref		76 (67)	Ref	
Male	260	169 (65)	1.26	0.69–2.28	174 (67)	1.01	0.54–1.88
ATSI status							
Not ATSI	352	227 (65)	Ref		239 (68)	Ref	
Unsure of ATSI status	12	3 (25)	0.18[**]	0.05–0.61[**]	4 (33)	0.24[**]	0.07–0.84[**]
ATSI	10	7 (70)	1.28	0.35–4.71	7 (70)	1.10	0.31–3.97
Type of School							
Special School	73	54 (74)	Ref		53 (73)	Ref	
Special Development School	82	42 (51)	0.37	0.12–1.18	43 (52)	0.41	0.14–1.24
Multi-Mode School	160	102 (64)	0.62	0.28–1.35	113 (71)	0.91	0.46–1.78
Physical Disability School	33	19 (58)	0.48	0.16–1.44	21 (64)	0.66	0.12–3.54
Autism Specific School	26	20 (77)	1.17	0.59–2.32	20 (77)	1.26	0.71–2.21
Physical impairment							
Ambulant without aides	330	210 (64)	Ref		222 (67)	Ref	
Ambulant with aides	18	10 (56)	0.71	0.28–1.80	11 (61)	0.76	0.32–1.82
Non-ambulant	26	17 (65)	1.08	0.25–4.64	17 (65)	0.92	0.11–7.69
Intellectual impairment							
No intellectual impairment	5	3 (60)	Ref		3 (60)	Ref	
Mild intellectual impairment	173	110 (64)	1.16	0.21–6.60	117 (68)	1.39	0.26–7.49
Moderate intellectual impairment	155	95 (61)	1.06	0.19–5.89	104 (67)	1.36	0.25–7.03
Severe intellectual impairment	41	29 (71)	1.61	0.28–9.21	26 (63)	1.16	0.22–6.10

[*] Includes those who received the dTpa 17immunisation on an immunisation day in 2017 and those who were up to date with dTPa.

[**] Statistically significant association p<0.05.

significant difference in reasons for missed immunisations for dTPa, as compared to HPV immunisation doses.

4. Discussion

This is the first study to describe immunisation uptake for young people administered vaccines through the school-based immunisation program delivered in specialist school settings in Victoria, Australia. We found dTpa and HPV uptake to be considerably lower in young people with disabilities in specialist schools compared to mainstream schools in Victoria. However, we did not find any association between vaccine uptake and gender, type of school or broad description of disability. The association between unclear ATSI status and lower uptake of dTPa and HPV1 in specialist schools, may reflect students that are less well known and at greater risk of under-vaccination, although the numbers were small. The most common reason for missed vaccination was absence from school, followed by lack of parental consent and inability to immunise due to the behavioural manifestations of anxiety.

The difference between specialist and mainstream school uptake data highlights how mainstream population data can mask poor immunisation rates in minority subpopulations. Although there is very little published research analysing dTpa uptake in adolescence, there is much published about HPV. It is well recognised globally that a government-funded school immunisation

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Table 5
Reasons for non-immunisation.

Reason	dTPa n = 124 students not immunised number (%)	HPV n = 391 doses not given number (%)	OR (95% CI)
Not at school	47 (38)	117 (30)	0.70 (0.46–1.07)
No consent form returned	31 (25)	97 (25)	0.79 (0.49–1.27)
Consent form returned but no consent given	9 (7)	52 (13)	1.96 (0.93–4.10)
Behaviour/refusal	11 (9)	35 (9)	1.01 (0.50–2.05)
Parents indicate they will take to a community provider/ GP	9 (7)	35 (9)	1.26 (0.59–2.70)
Other	17 (14)	55 (14)	1.03 (0.57–1.85)

program yields the highest uptake of HPV immunisation [24–26]. Australia has become a world leader in the provision and completion of HPV vaccination, initiating the program in 2007 for girls and in 2013 for boys [24]. The uptake rate for students in specialist schools is far below mainstream school uptake and HPV vaccine uptake in all 40 countries where government-funded HPV vaccines are provided through a School Immunisation Program, with the exception of Colombia [27]. Systems delivery and policies for school-based delivery of adolescent vaccines to specialist schools in Victoria, and more broadly in Australia need to be carefully evaluated.

Absence from school has been recognised as a barrier to delivery of immunisations through school-based programs in low to middle income countries where school attendance is poor [28,29]. However, it has not to date been described as a barrier in high-income countries where school attendance is generally high. Specialist schools in Victoria have twice the rate of student absenteeism as mainstream schools (12% vs 6% respectively) [30] on any given day, which provides challenges for the School Immunisation Program, especially for the HPV vaccine, which required three doses in 6 months. The change to a two-dose schedule, which occurred in Australia in 2018, may help to reduce missed vaccinations, especially if more catch up immunisation days are provided. However, the rate of missed immunisations due to absence in this setting is more than double the average rate (30% vs 12%) and the reason for the high absentee rate on immunisation days is not clear.

Lack of consent from parents for immunisation, including both failure to return consent cards and specific non-consent to the vaccination, was also a major reason for missed immunisation. Parent refusal of adolescent vaccinations, particularly HPV, is well documented with parents citing concerns about safety, low perceived likelihood of their child contracting HPV, and concern that the immunisation will encourage sexual activity [31,32]. It is unclear whether these concerns were held by parents of young people with disabilities in this study. Interestingly, there was no statistical difference in consent for dTpa compared to HPV, suggesting determinants of parental consent to adolescent immunisation in this population were not related to vaccination type. Reasons for non-immunisation in specialist schools may therefore be less about parental concern about specific vaccines and more about logistics, the process associated with vaccination and/or the behavioural concerns during immunisation.

Just under 10% of dTpa and HPV doses missed were reported to be due to anxiety and behavioural concerns. In addition 19.5% of students who received an immunisation were noted to require extra support or were upset at the time of vaccination. Distress of students on vaccination day, linked to anticipatory anxiety and needle phobia, is not unique to the specialist school setting [33]. Indeed a case of mass psychogenic illness triggered by anxiety at the prospect of receiving the HPV vaccination when it was first introduced at a mainstream school in Melbourne has been described [34–36]. A Canadian study found that 8% (79/1024) of children aged 6 to 17 were non-compliant with immunisation due to needle phobia, and 5% (45/883) of parents delayed or missed their child's immunisation due to the child's level of anxiety [37].

There is an absence of literature exploring the anxiety of young people with disabilities during immunisation. The behavioural manifestations of anxiety in children with intellectual disability and autism are more likely to be externalised than children without disabilities [38], and this may be a safety consideration for both students and staff when immunising in the school environment. The large number of students who are successfully immunised in specialist schools, but require extra support for distress is not captured in uptake figures. How this is managed by the immunisation teams, and the intensity of resources required, as well as the emotional impact on staff and students, requires further exploration.

For students who are not able to be immunised at school due to their anxiety or behaviour, the standard advice given is to attend their general practitioner (GP) for these immunisations. However GPs do not generally have more resources or experience administering immunisations to anxious young people who may have significant cognitive impairment than school immunisation nurses, and often refer onto specialist immunisation clinics in their state, if available. Assessment and immunisation under sedation can be arranged by specialist tertiary immunisation clinics, with high degrees of success [39]. However, many GPs and families may be unaware of this option or it may be logistically difficult to organise Clear referral pathways for students with disabilities who may need to attend such services to minimise distress and the potential for physical harm to both students and staff would be optimal.

Further research, incorporating qualitative inquiry, of the uptake of adolescent vaccinations in specialist schools in Victoria, Australia, is needed to understand the issues and barriers to implementation, provision and acceptance of immunisations in the specialist school setting. Qualitative inquiry could explore the multifactorial and complex determinants of under-vaccination, as well as the experience of vaccination for young people with disabilities in specialist schools [40,41] The strengths of qualitative research in understanding barriers to immunisation in defined, minority populations who are vulnerable to under-immunisation have been emphasised in a recent review of the Tailoring Immunisation Program (TIP), a program run in the World Health Organisation (WHO) European Region. The TIP program outlines a supported process to explore barriers and motivations to immunisations in populations with low immunisation coverage [42] and illustrates the growing recognition of the need for specific analysis and targeted interventions for some populations in order to provide equitable access to immunisation. A socio-ecological framework would enable exploration of the social, cultural and political constructs as well as individual and familial values and behaviours that may be barriers to vaccination in under-immunised minority groups.

There are some limitations to this study. Accurate data collection was reliant on the school immunisation coordinators to

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identify all eligible students. There was a wide variety of staff who undertook this role, including school nurses, teachers, administration staff, wellbeing coordinators and vice-principals, with variable knowledge about immunisation and motivation to undertake this role. Not all of the school coordinators in this study were present on the immunisation days, and while clear inclusion instructions were provided, it is possible some students who were eligible for adolescent immunisation were overlooked in data collection.

The uptake rates reported in this study may be an overestimate of true uptake rates for specialist schools. The School Immunisation Program operates in schools in Victoria on a good-will basis with no financial reimbursement, and therefore a participation rate of just over a third of specialist schools was not unexpected. The schools that participated were more likely to have the time and resources, or a dedicated school nurse whose primary focus was health rather than education, than those who declined. This may have translated into increased promotion and uptake of immunisation amongst participating schools.

Overestimation of uptake rates may be particularly evident in the figures for HPV2 and HPV3 where there was a significant decrease in numbers of individual entries, compared to dTPa and HPV1. This attrition included schools who did not submit any individual data for that immunisation day (HPV2: n = 19/375 [5%]; HPV3 n = 38/375 [10%]), therefore their immunisation status was unknown. It also included schools who only submitted data for immunised students (n = 50 [13%] HPV2: 50/374 [13%]; HPV3: 102/374 [27%]), therefore students with missing data were unlikely to have received an immunisation on this day but this was not explicitly stated.

5. Conclusion

This is the first study of immunisation uptake in specialist schools in Australia and is one of only a few studies globally examining adolescent immunisation in young people with disability. Young people with disabilities are at risk for under-immunisation with a significant disparity in uptake of dTpa and HPV in specialist schools compared to mainstream schools. Absence from school, lack of consent and behavioural issues were the main reasons for missed vaccination and warrant deeper exploration through qualitative inquiry. Such data can inform policy and new interventions to improve vaccine uptake for children with disabilities in congruence with the principles of equity in health care and the rights of persons with disabilities.

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Conflicts of interest

None.

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4.4 Conclusion

This chapter presents the published article that arose from the Phase One Study within this thesis, which is the first research to quantitatively measure uptake of adolescent immunisations in specialist schools in Australia. The primary outcome was a significant disparity between the uptake of dTPa and HPV in young people in specialist schools, as compared with the mainstream population. This finding has significant implications regarding the potential for VPD outbreaks in specialist schools and the health of young people with a disability. After clustering for schools, there was no significant difference in uptake of dTPa and HPV1 by gender, type of specialist school, and degree of physical and intellectual impairment. The most common reasons for missed immunisation indicated were absence from school, lack of consent form return or lack of consent, and issues with behaviour and/or anxiety on the immunisation day.

Phase One acted to inform Phase Two within the thesis in several ways. These included:

1. *Identification of key stakeholders within the SBIP to invite to participate in interviews and focus groups.*
2. *The design and questions included in the interview proforma, based on knowledge of the low coverage in specialist schools in Victoria and the most common reasons for missed immunisation.*
3. *The less important role of gender, type of specialist school, and type and degree of disability in determining successful immunisation, and therefore less emphasis on these aspects within interviews and focus groups.*

Crucially, Phase One emphasised the need for in-depth qualitative enquiry and demonstrated the breadth of reasons for missed immunisation. This supported the importance and significance of the Phase Two Study, and the need for the adoption of a broad ecological framework. This is discussed in Chapter 5.

5 COMMENTARY INFORMING PHASE TWO: ADOLESCENT IMMUNISATION IN YOUNG PEOPLE WITH DISABILITIES IN AUSTRALIA

5.1 Introduction

This chapter provides a synthesis of the Phase One Study within the existing research and highlights the gap that remains. This reinforces the importance and significance of a qualitative inquiry in the Phase Two Study utilising a broad ecological framework. This chapter is presented as a published commentary:

O'Neill J, Newall F, Antolovich G, Lima S, Danchin MH. Adolescent immunisation in young people with disabilities in Australia. Med J Aust. 2019 Sep 2;211(5):199-200.

5.2 Published Study

This commentary was accepted for publication in *The Medical Journal of Australia* on March 22, 2019, and was published on September 2, 2019. It is reprinted below in its final published format with permission from Wiley (see Appendix I). Author contributions for this publication are as follows: commentary concept Jenny O'Neill (JO), Margie Danchin (MD), Giuliana Antolovich (GA), Sally Lima (SL) and Fiona Newall (FN); initial draft of manuscript JO with editing and redrafting from JO, MD, GA, SL and FN. All authors approved the final manuscript as submitted.

Perspective

Adolescent immunisation in young people with disabilities in Australia

More research is needed to understand the barriers to optimal adolescent immunisation for students with disabilities

Jenny O'Neill[1,2]

Fiona Newall[2]

Giuliana Antolovich[2,3]

Sally Lima[1,4]

Margie H Danchin[2,3]

1 University of Melbourne, Melbourne, VIC.
2 Royal Children's Hospital, Melbourne, VIC.
3 Murdoch Children's Research Institute, Melbourne, VIC.
4 Bendigo Health, Bendigo, VIC.

jenny.oneill@rch.org.au

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The benefits of immunisation in preventing or reducing the severity of vaccine-preventable diseases and eliminating or reducing the risk of associated complications have been well documented. Importantly, immunisation is also a powerful means by which the inequity of poor health can be reduced, particularly in vulnerable groups that have a high burden of infectious diseases. This has been illustrated in immunisation research in refugees and other migrants, as well as in Aboriginal and Torres Strait Islander Australians, and in low income or resource poor settings.[1–5] However, there is a paucity of research about immunisation for people with disabilities, another medically at-risk and socially marginalised group.

Primary health care is less than optimal for people with disabilities, with identified barriers to health care including transportation issues, communication, lack of confidence and lack of knowledge about the health care system.[6] Adults with intellectual disability in Australia are more likely to be overweight or obese, smoke, or have cardiac disease or diabetes.[6] Barriers to breast screening and cervical screening in women with disabilities are well described; however, very little is known about other preventive health care interventions in this population, such as immunisations.[7] In particular, adolescent immunisation in young people with disabilities has largely been overlooked.

The potential consequences of vaccine-preventable diseases in those with disabilities are evident. A prospective audit in the United Kingdom and Ireland traced notified cases of complicated varicella admitted to hospital.[8] Of 112 cases, 13% had congenital anomalies, Down syndrome or cerebral palsy — significantly higher than the birth prevalence of anomalies of 2–3% across England and Europe.[9,10] Of the six deaths, four had pre-existing medical conditions, including three with physical disabilities.[8] Similarly, in a review of paediatric deaths in the UK from the 2009–2010 influenza A (H1N1) pandemic, 54% of those who died had chronic neurological disease, with cerebral palsy and epilepsy being the most common diagnoses.[11] These studies illustrate that people with disability are disproportionately likely to experience the most severe sequelae from vaccine-preventable disease, affirming the particular importance of optimising immunisation coverage in this population.

School-based immunisation for adolescents in Australia

The National Partnership on Essential Vaccines outlines the agreement between the Commonwealth and state and territory governments for the administration of the National Immunisation Program in Australia. Under this partnership agreement, the states and territories have the responsibility for ensuring access to and delivering vaccinations.[12] Currently, there are three government-funded immunisations recommended for all adolescents, which are offered to secondary school students through a school-based immunisation program: a booster dose of the diphtheria, tetanus and acellular pertussis (dTPa) vaccine; two doses of the human papillomavirus (HPV) vaccine; and the conjugated meningococcal ACWY vaccine from April 2019.[13] In February 2019, South Australia also introduced a state-funded meningococcal B vaccine through the school program for Year 10 and 11 students.[14]

Although delivery mechanisms vary in different jurisdictions, school-based immunisations are managed, coordinated and delivered by local teams of trained providers from local governments, primary care units or non-government organisations. The role of schools is to distribute and collect parental consent cards and provide support, appropriate space in the school timetable and the facilities in which the students can be immunised. The program therefore encompasses a unique intersection between the health and education sectors.

Immunisation uptake in adolescents with disabilities

In Australia, almost 290 000 (7%) of children under the age of 14 years have a disability, broadly defined as a limitation or restriction of core activity lasting more than 6 months.[15] There are only two Australian studies on immunisation uptake in adolescents with disabilities, both from Victoria.[16,17] One is a small audit of HPV vaccination status of 72 adolescents with a variety of developmental disabilities recruited through a tertiary centre.[16] This study found only 44% of females and 39% of males, aged 15 years, with disabilities, had received the three doses of HPV vaccine required as a complete course at the time. This was significantly lower than the corresponding aggregate Australian figures from the National HPV Vaccination Program Register in 2015, with 77% of females and 66% of males completing the HPV course.[16] The importance of HPV immunisation for this population should not be dismissed. People with disabilities have a young age of sexual debut, are more likely to experience unwanted sexual activity and are less likely to utilise health care services than their typically developing peers.[18–20] Young people with disabilities are therefore at higher risk of both HPV disease transmission and progression than young people without disabilities.

The second published study, which is from our research group, explores both dTPa and HPV immunisation uptake through the school-based immunisation program across 28 non-mainstream schools catering for students with physical and/or intellectual disability in Victoria.[17] Just over 43 000 (15%) of the students with disabilities in Australia attend the 472 non-mainstream schools that cater for the education and wellbeing needs of students with significant intellectual, physical, behavioural or emotional learning needs. While there are no national enrolment criteria for non-mainstream schools, eligibility to enrol in the non-mainstream schools that cater for disability is most commonly based on a diagnosis of intellectual disability defined by an intelligence quotient two or more standard deviations below average. However, different enrolment criteria apply for other types of non-mainstream schools, such as autism-specific schools, schools for hearing- or vision-impaired students, or schools for students with severe physical disability or significant chronic illness requiring paramedical support. Eligibility to attend non-mainstream settings therefore varies by individual school.

While most children with disabilities in Australia attend mainstream schools, the subset attending specialist schools reflects a highly vulnerable, more severely disabled group of adolescents. Although small, it is an important and often overlooked group with respect to public health interventions. Our study[17] found that 63% of participating students from specialist schools received the dTPa vaccine (compared with 89% in mainstream schools) and only 41% completed the full three doses of HPV vaccine required in 2017 (compared with 76% of males and 80% of females in mainstream schools). These are the first data in Victoria for adolescent vaccination coverage for students in non-mainstream settings.

Although immunisation coverage is collected by immunisation providers and aggregate numbers of students vaccinated are reported to the relevant state or territory health department, this does not include non-mainstream settings in Victoria. For mainstream schools, uptake is determined as the number of vaccinations given with the year level enrolment as the denominator. However, no such data are collected or readily available for students in many non-mainstream schools, as classes in schools for children with disability are often ungraded and a year level cohort is not identifiable. This reflects the invisibility of young people with disabilities in Victoria, and is likely to be similar in other localities in Australia.

Conclusion

The two Victorian studies indicate that young people with disabilities in Australia are missing their adolescent vaccinations.[16,17] While the second study provides broad reasons for missed immunisations, citing absence from school, lack of consent and student anxiety as the major issues,[17] what is needed now is in-depth exploration of the barriers to immunisation in this population. This will enable the development of effective interventions. The voices of immunisation nurses and managers, teachers in non-mainstream schools, parents of young people with disability, and those young people themselves, are crucial in understanding the issues that affect adolescent immunisation in this population. While uptake figures highlight the scope and significance of the issue, alone they do not explain the reasons for the discrepancy in coverage.

Qualitative research is needed to fully appreciate the barriers to and facilitators of immunisation in this vulnerable group, at the policy, systems, community, family and individual levels. It is only with such qualitative information, combined with accurate documentation of uptake figures for all schools, including ungraded schools, and a recognition that young people with disabilities are vulnerable to under-immunisation, that we can ensure adolescent immunisation coverage is optimised.

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5.3 Conclusion

This chapter serves to summarise the Phase One Study and introduce the Phase Two Study, with evidence of Phase One informing the design of Phase Two. Importantly, the commentary included in this chapter clearly outlines the rationale for the choice of framework for the qualitative Phase Two Study as the *Socio-Ecological Model*. The background, context and application of this framework will be discussed in the next chapter of this thesis, Chapter 6.

6 THE SOCIO-ECOLOGICAL MODEL

This chapter introduces the *Socio-Ecological Model* (SEM) as the framework used to structure and guide Phase Two of this research. This will include discussion of the overall philosophical stance of the thesis, and justification of the choice of the SEM, with consideration of other common frameworks used in public health and health promotion research. The SEM is explained in detail, including the origins of the SEM, how it has been applied in health promotion research, and the application of the framework in this thesis.

6.1 Theoretical Framework

The choice of a conceptual model or framework is central in any research, as it connects the methods, analysis and findings with the questions under focus. A conceptual or theoretical model is defined in a variety of ways as the theory, or set of theories, that explains phenomena or behaviour.[179] Furthermore, the conceptual or theoretical framework is the structure that guides the application of the theory to the research. In practice, these terms are used interchangeably. Thus, for the purpose of this thesis, ‘framework’ will provide an umbrella term to encompass both models and frameworks, where either can act as the lens through which the data are analysed and the research questions are explored and answered.

A research framework must be fit for purpose; the choice of framework is *“not arbitrary but reflects important personal beliefs and understandings about the nature of knowledge… how it exists in relation to the observer and the possible roles to be* *adopted and the tools to be applied consequently by the researcher."*[179] Thus, the framework must not only be congruent with the research aim and questions, but also with the philosophical viewpoint of the researcher.

6.1.1 Consideration of philosophical stance: Pragmatism

The motivation and purpose of the research determines the underlying philosophical stance. In this instance, this is to collect data that will contribute towards the understanding of adolescent immunisation in young people with disability and the development of recommendations to remove barriers and improve experiences. Given the paucity of research in this at-risk population, it is important not to assume that the experiences of young people attending specialist schools regarding immunisation and barriers to immunisation are similar to findings in other populations. Indeed, Phase One of this research revealed barriers to immunisation within this population that have not been previously identified as major factors in the SBIP in Australia, such as absence from school. As such, Phase Two of this research requires a multi-level inquiry that can capture such findings, with the use of a variety of data sources in order to answer the research questions. In this case, adherence to a particular epistemology or ontology is rejected as limiting the breadth of this inquiry. Therefore, pragmatism is adopted as the underlying philosophical stance.

Pragmatism allows for practicality to determine how knowledge is gained and thereby how research is designed.[180] However, beyond the 'practical pragmatism' of 'what works' is pragmatism as a philosophical stance.[181] Morgan (2014)[180] outlines the philosophical basis of pragmatism stemming from the work of John Dewey, who emphasises the central role of human experience and the cyclical nature of beliefs and actions in how humans construct meaning. Reality cannot be understood outside of one's actions. Therefore 'inquiry' does not have a starting point but is *"rooted in life itself – a life that [is] inherently contextual, emotional and social."*[180]

The question for pragmatic researchers is not about the nature of reality and knowledge, but about human experience. The 'practical' elements of pragmatism accept positivist and constructivist meaning, as well as inductive and deductive reasoning. However, inherent in the philosophy of pragmatism is a responsibility to consider different ways of answering a research question, and a recognition of the impact that choice will have on the understanding of the phenomena. A key tenant of pragmatism is acknowledgement of the value and the power of different methods of inquiry to construct meaning, and the value and power of those determining the research questions.[180] True to this philosophy, within the development of this research there was deliberate consideration of the conceptual framework chosen to answer the research questions, with respect to the context of the questions, the goal of the research and the position of the Researcher. As well as the choice of framework, the effect of a pragmatic stance is also illustrated in the mixed methods research design, as described in Chapter 7. The introduction of in-depth inquiry through a broad qualitative phase with many stakeholders with varying agendas aims to mitigate the inherent power imbalance that has resulted in the invisibility of people with a disability.

6.1.2 Consideration of frameworks

Immunisation fits into both the public health and health promotion arenas by being an intervention that proactively protects against disease, in both individuals and the community. Within public health and health promotion research, many types of conceptual or theoretical frameworks have been used, albeit with varying frequency. While the choice of framework depends on the research topic and research questions, in addition, within this thesis, the mixing of methods has enabled information from first quantitative phase to inform the choice of framework to best fit the second phase. Therefore, there were several considerations regarding the choice of a model and framework to guide Phase Two.

Phase One of this research, which established the disparity in adolescent immunisation coverage in young people in specialist schools as compared to mainstream schools, was required due to the absence of immunisation coverage data recorded from ungraded specialist schools in Victoria. This absence suggests issues at a systems level. Therefore, the framework in Phase Two that will further examine and explain low immunisation coverage should have the capacity to include systems level barriers. In addition, the broad reasons for missed immunisation revealed in Phase One highlight issues that are not prominent in mainstream literature on barriers to immunisation, including absence from school and student anxiety. Thus, any framework must also be flexible in its capacity to explore school, family and individual level issues, beyond the more commonly described consent issues. A framework that encompasses social, cultural and environmental levels of influence enables recognition of the role of the SDH with regards to preventive health care which, as discussed, is central to exploring the health of people with disability. With these factors in mind, a number of preventive health frameworks commonly used in the immunisation literature were identified and appropriately appraised to determine best fit for Phase Two. This appraisal is outlined in Table 6-1.

Table 6-1 *Consideration of Commonly Used Frameworks for Phase Two*

Model/ Framework Type	**Specific Model/ Framework**	**Brief Description**	**Ability to Include Policy/ Systems Level Issues/Barriers**	**Ability to Include Community/ Institutional Level Issues/ Barriers**	**Ability to Include Family Level Issues/ Barriers**	**Ability to Include Individual Level Issues/ Barriers**	**Limitations**
Integrative Models of Health	Health Belief Model[182]	Assessment of the individual perception of risk, severity, susceptibility, barriers and benefits, with an emphasis on the sense of personal agency, and identification of a 'cue to action' for behaviour change to occur	No	No	No	Yes	Focus on individual level, limited scope for consideration of other broader influences
	Theory of Reasoned Action/Planned Behaviour[183,184]	Assessment of the individual's strength of intent to perform the behaviour, through the determinants of attitude, perceived norms and self-efficacy	No	No	No	Yes	Focus on individual level, limited scope for consideration of other broader influences
	Protection Motivation Theory[185]	Focus on individuals motivation to protect oneself, determined by perceived susceptibility,	No	No	No	Yes	Focus on individual level, limited scope for consideration of other broader

Model/ Framework Type	Specific Model/ Framework	Brief Description	Ability to Include Policy/ Systems Level Issues/Barriers	Ability to Include Community/ Institutional Level Issues/ Barriers	Ability to Include Family Level Issues/ Barriers	Ability to Include Individual Level Issues/ Barriers	Limitations
		perceived severity, response efficacy and self-efficacy					influences
Patient-Provider Models	Shared Decision-Making[186]	A model of support and shared information based on evidence between provider and patient/parent in order to make a health-related decision	No	No – includes interaction with community providers but not specific community barriers	Possibly, where family is part of discussion	Yes	Focus on treatment decisions rather than preventive interventions, does not allow for exploration of broader influences
Implementation Science Models	Consolidated Framework for Implementation Research[187]	A multi-level implementation model, includes 39 evidence-based constructs within five domains – implementation characteristics, inner setting, outer setting, individual characteristics, implementation	Yes – within implementation process and outer setting domain	Yes – within inner and outer setting domain	Yes – within inner domain	Yes – within inner characteristic domain	Concentrates on implementation of interventions rather than identification of barriers and facilitators for a health intervention

Model/ Framework Type	Specific Model/ Framework	Brief Description	Ability to Include Policy/ Systems Level Issues/Barriers	Ability to Include Community/ Institutional Level Issues/ Barriers	Ability to Include Family Level Issues/ Barriers	Ability to Include Individual Level Issues/ Barriers	Limitations
		process, which impact on implementation of effective health care interventions					
	Theoretical Domains Framework (TDF)[188]	Identifies 128 constructs across 12 domains which are evidence-based determinants of behaviour from 33 psychological theories, to enable structured targeted interventions for health-related behaviour change	Partly – considers role of environment	Partly – considers role of environment	Yes – where family is involved in health care	Yes	Largely focused on the individual, but could be adapted to fit multi-level inquiry
Multi-Level Models for Health-Related Behaviours	The Socio-Ecological Model of Health Behaviours (SEM)[189]	Five levels of health influence, structured as rings – intrapersonal, interpersonal, institutional, community and policy.	Yes	Yes	Yes	Yes	Does not cater for levels of causation that are incorporated in the TTI model

Model/ Framework Type	Specific Model/ Framework	Brief Description	Ability to Include Policy/ Systems Level Issues/Barriers	Ability to Include Community/ Institutional Level Issues/ Barriers	Ability to Include Family Level Issues/ Barriers	Ability to Include Individual Level Issues/ Barriers	Limitations
		Considers influences within and between levels					
	Theory of Triadic Influence (TTI)[190]	Matrix model. Three levels of causation – ultimate, distal, proximal. Three level of influence, intrapersonal, interpersonal-social and cultural-environmental. Considers influences from stream, interaction between streams and feedback loops on behaviour	Yes	Yes	Yes	Yes	Higher levels of influence collapsed into one layer as compared to SEM. Complex to use

6.1.3 Integrative models of behavioural prediction

The first type of model considered for this research was an *Integrative Model of Behavioural Prediction.* In this category, three frameworks were identified as commonly used in health promotion literature and to address questions on barriers to immunisation. The first of these is the *Health Belief Model (HBM),* which is a behaviour change model and the most widely used in explaining health behaviour. The other related models are the *Theory of Reasoned Action* (or *Theory of Planned Behaviour*) model and *Protection Motivation Theory*. They are all similar in their focus on behavioural change intervention through use of cognitive processes and reward for the individual.

When applying these models to health promotion, the central tenet is that ability to influence determinants which enables the individual to change behaviour. This focus on individual level behavioural determinants has provoked critique.[191] While allowing for some influence of societal factors in terms of appreciation of the influence of the subjective norm regarding a particular behaviour, this is in respect to individual behaviour change. *Integrative Models of Behaviour Prediction* do not allow for change, which may be required in systems, policy, provider capability, setting or culture. For this research, where there is little known about the barriers and enablers of immunisation in this population, a framework that concentrates on individual factors that determine whether a young person with disability in a specialist school is immunised, is limiting and relies on assumptions of causality. An *Integrative Model of Behavioural Prediction* does not allow for identification of issues or opportunities for change beyond the individual level. Without adequate evidence for this topic, it would be remiss to assume that individual behaviour should be the focus, or the only focus, of this inquiry. Therefore, it is necessary to look beyond these behaviour change frameworks.

6.1.4 Patient-provider models

Patient-provider models, such as the *Shared Decision-Making Model (SDM),* focus on optimising communication between health provider and patient (or parent). This is key in immunisation research, in which recommendation for immunisation from a trusted health provider is established as a strong enabler to immunisation. Nevertheless, similar to the behaviour change frameworks, this framework focuses on individual decision-making. Thus, for the purposes of the Phase Two Study, this framework does not have the breadth to capture wider determinants of successful immunisation in specialist schools.

6.1.5 Implementation science models

Three main purposes of *Implementation Science Models* have been described:

1. *providing a framework for translating research into practice;*
2. *identifying the factors that affect the success of the implementation of an intervention; and*
3. *evaluating the intervention.*[192]

According to Nilsen (2015), both the *Theoretical Domains Framework (TDF)* and the *Consolidated Framework for Implementation Research (CFIR)* are examples of 'determinant frameworks', which work to identify influences on implementation outcomes.[192] While these frameworks can both identify barriers and enablers across multiple levels of influence, the primary purpose of this thesis is to evaluate the effectiveness of an existing program (the SBIP) in a particular environment (specialist schools), rather than designing or influencing implementation of an intervention. Therefore, while the scope of implementation science frameworks fit with the information from Phase One, their purposes do not adequately correspond with the aim of this thesis.

6.1.6 Mutli-level models for health-related behaviours

Two models that recognise multiple levels of influence on health have been examined. These are the *Socio-Ecological Model (SEM)* and the *Theory of Triadic Influence (TTI).* In contrast to integrative behaviour models, the SEM and the TTI are driven by systems thinking, which explains health decisions and behaviour as shaped by a complex interaction of the key domains central to health services delivery.[193] These frameworks allow for consideration of a wider context than the other models considered, and are thus the only ones that fit the criteria identified as important within the framework adopted for this thesis.

Within this category, the SEM and TTI were both considered applicable to this thesis. These two frameworks are very similar; the main differences are the matrix design (TTI) versus a layered ring depiction (SEM), and the inclusion of layers of causality in the TTI model. The latter adds an extra dimension to the TTI, but also a complexity in its application, which may account for the wider adoption of the SEM in preventive health, and in particular, in immunisation research.[193] An important limitation of the TTI in relation to this thesis is the collapsing of the higher levels of influence into one domain, as distinct from several layers in the SEM. This collapsing results in a tendency, when utilising the TTI, to concentrate on intrapersonal and interpersonal layers with a less thorough consideration of community, environmental and systems level issues and barriers. Due to the flexibility of the SEM to allow for an in-depth exploration of these broader layers, its capacity to cover the complexity and range of stakeholders in the SBIP, and its previous use in immunisation research, the SEM was the pragmatic choice of framework for the Phase Two Study in this thesis.

6.2 The Socio-Ecological Model

6.2.1 The origins of the Socio-Ecological Model

Although Urie Bronfenbrenner is most commonly credited with the development of the SEM, the origins of this framework can be attributed to many theorists from social ecology, behaviour change and systems change.[194] Ecology is the study of the relationship between organisms and their environment, and long before Bronfenbrenner, theorists were associating human behaviour with the reciprocal, cyclical patterns in nature. As early as 1936, Kurt Lewin, a German-American psychologist, discussed the concept of behaviour shaped by both nature and nurture, introducing the idea of the influence of the setting on behaviour and development.[194] This emphasis on the environment was further developed by social scientist Roger Barker and later James Kelly, who linked human development to the principles of ecology – in particular, the interdependence of systems, and concepts of adaptation and succession.[194] Seymor Sarason, an American psychologist and educator, is also credited with developing this field through his works on community psychology, and in particular, the importance of contextual factors that impact human behaviour.[195] Therefore, by the 1960s and 70s, understanding of the influence of social, cultural and organisational domains on human development through the person-environment relationship, and how this impacts on an individual's wellbeing, was well established. Bronfenbrenner adapted these ideas to explore and explain the process of child development.

6.2.2 Bronfenbrenner's Socio-Ecological Model of Human Development

Bronfenbrenner first proposed the 'ecological systems theory' to explain child development in early 1979.[196] His representation of this model was a series of nested circles, each representing a sphere of influence on the individual.[197] A version of this model is illustrated in Figure 6-1.

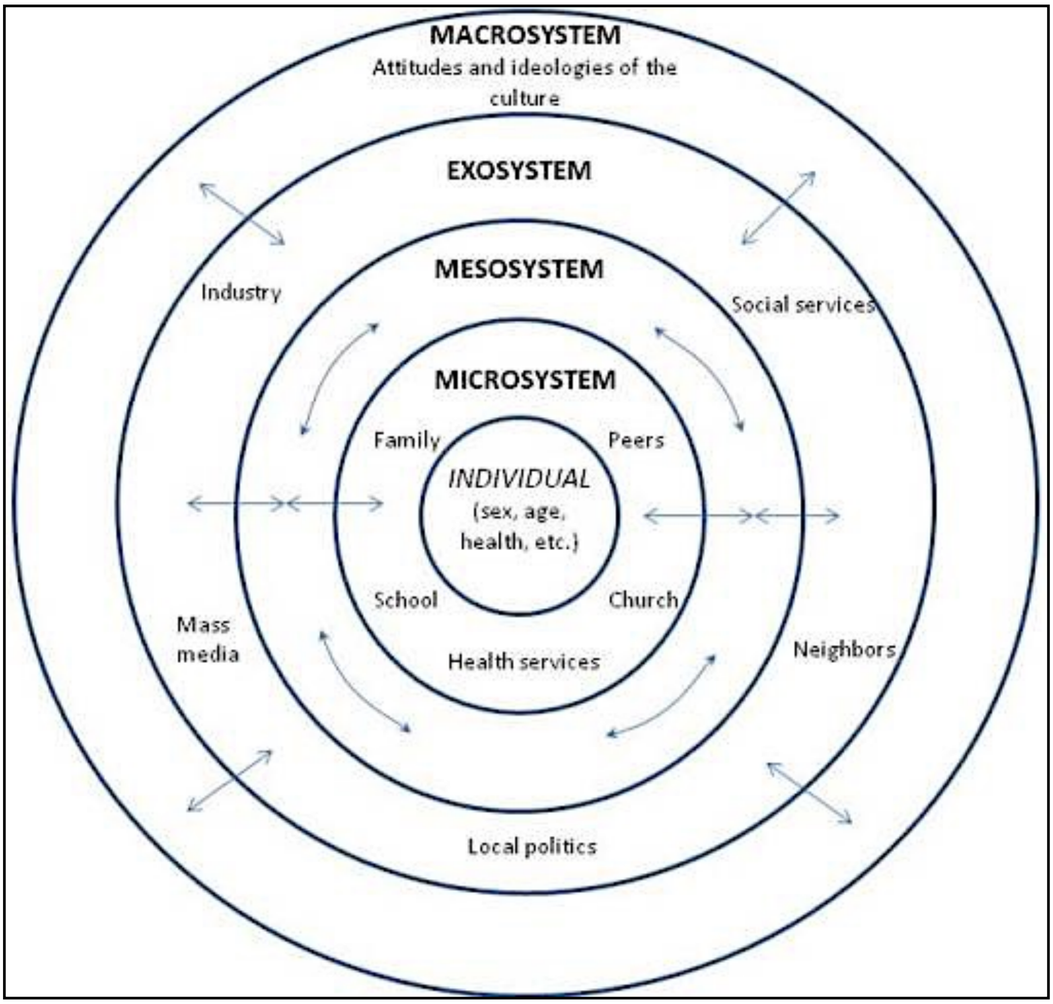

Figure 6-1 Bronfenbrenner's Socio-Ecological Model
Source: Wikimedia Commons CC-BY-SA-3.0

This representation is largely the same today, despite many interpretations and revisions of the SEM. Bronfenbrenner initially described four layers[196] in this model:

1. The *microsystem,* representing the child and the immediate environment in which there are daily interactions. This might include the parents, family and close friends or child carers, school or day care

2. The *mesosystem*, representing the interactions between parts of the microsystem
3. The *exosystem*, representing other people and places that are not part of the child's immediate environment but that have a role to play in their development. This might include neighbourhood events and people or parents' workplaces
4. The *macrosystem*, representing the wider influences that are remote from the child but still affect their development, such as the media, political and policy decisions, the climate and cultural and religious values

Bronfenbrenner continued to develop this work over some decades, critiquing his early schema as emphasising the influence of the environment disproportionally to individual determinants.[198] In the early 1990s, Bronfenbrenner proposed a revision of the ecological theory of human development, which he named the *Process-Person-Context-Time (PPCT)* model.[198] Studies utilising the PPCT model focus on the proximal process, which includes the small everyday reciprocal interactions that shape human development, influenced by individual characteristics in the context in which they occur, over time.[198] In this way, Bronfenbrenner has added emphasis on personal characteristics and the importance of time to his original model. Other theorists have further emphasised the importance of time in the SEM, which fundamentally looks at a dynamic process, including how things change and how things stay the same.[194]

A key concept in the SEM is the reciprocal nature between the various levels, which are not independent of each other but *"bi-directional… interactive and reinforcing."*[197] This is represented in Figure 6-1 by the arrows demonstrating flow between levels. Thus, the layers are not insular, but act upon each other, and the result of these interactions is the unique combination of influences within and across these domains. This is key in applying ecological theory to complex public health issues.

6.2.3 The use of the Socio-Ecological Model in public health

With the rise in interest in public health issues in the 1980s came a need to find a framework with which to explore complex population health problems with many stakeholders and levels of influence.[194] Efforts to combat issues such as smoking and alcohol consumption through a linear individualistic attribution of causality resulted in ineffective interventions. This initiated the move to ecological thinking in public health.

Kenneth McLeroy was among theorists who rejected individualistic health promotion models. McLeroy contended that such models overlooked the need for system, policy, environmental and cultural change, and he proposed a revision of Bronfenbrenner's representation of the SEM for health promotion.[189] McLeroy's *SEM of Health Promotion* spheres, illustrated in Figure 6-2, include:

1. Individual
2. Interpersonal
3. Institutional/Organisational
4. Community
5. Policy and Systems

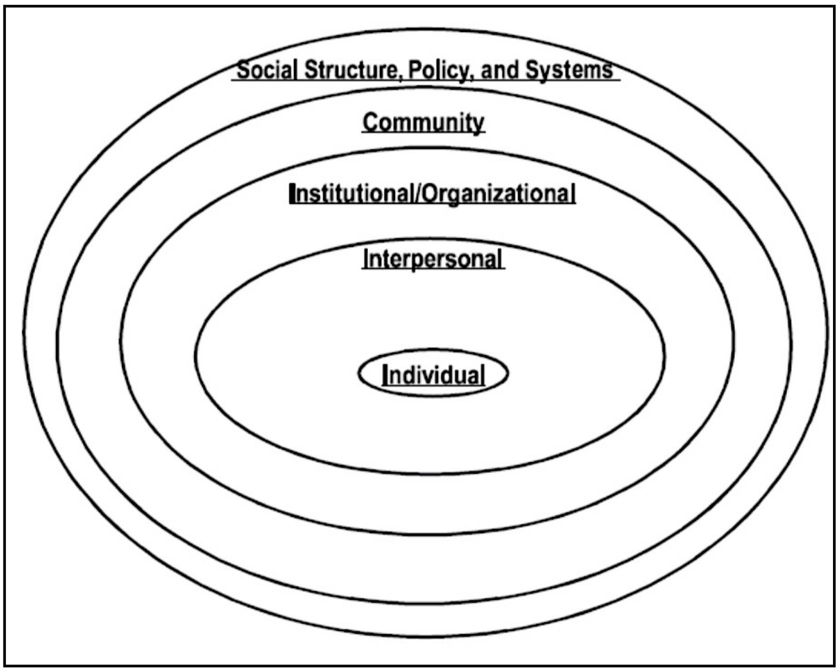

Figure 6-2 A Representation of McLeroy's SEM of Health Promotion

This representation of the SEM is used in public health research and health promotion activities. The appropriateness of this model in explaining and exploring health issues and the interplay with the environment, as well as social factors and disease distribution, has been recognised by national and international health organisations such as the Centre for Disease Control,[199] WHO[200] and UNICEF.[201]

Areas in which the SEM has been applied includes obesity research,[202,203] cervical screening,[204] Indigenous men's health,[144] adolescent health promotion[205] and smoking cessation.[206] Ecological theory has also been useful in analysing relationships between social inequity and health inequity,[207,208] which is a core concept in disability health. This ability within ecological theory to elicit a broad multi-level perspective, and also to allow for the core concept of inequity, makes it a good fit for research on preventive health care in young people with disability.

Despite established use in public health, health promotion, social inequity and health equity, at the commencement of the Phase Two Study in this thesis, the SEM framework had only been utilised in a few immunisation studies.[209–213] A systematic review published in 2016, in part focusing on immunisation and screening health promotion research using SEM, found only nine in 40 studies (23%) explored immunisation.[193] Another review[191] has examined the theoretical frameworks utilised in studies on HPV vaccination behaviour. Of 34 primary studies found that utilised a conceptual framework, the vast majority used *Integrative Models of Behaviour Prediction* (29/31, 94%), with none using the SEM.[191] This review critiques the use of individualistic models to understand HPV immunisation behaviour, on the basis that these models fail to acknowledge the wider determinants of health and how they influence uptake of HPV. However, it must be acknowledged that there is also criticism of the SEM as an effective framework in health policy.

6.2.4 Critiques of the SEM

Within the public health literature, critiques of the SEM focus on two main issues. The first concerns limited recognition of the importance of the interactions between levels of the SEM.[191] These interactions between the SEM levels constitute a key tenet of the framework. If well applied, the SEM is unique in capturing the multidimensional aspects of complex health issues, but also the dynamic and interactive nature of those domains. Limited recognition of the interactions between SEM levels can results in a loss of the depth of information and interventions that can emerge from the application of the model. If the model is applied in this limited way, the risk is that the findings can be stratified within SEM levels, any interventions that are recommended are not integrated, and complexity is missed. Consequently, the application of the SEM in this thesis included specific consideration of the dynamic interactive nature of this framework.

The second major critique of the SEM contends that it may be insufficient to guide multilevel interventions.[214] The SEM can be applied to the analysis of health issues and behaviour, as well as determining solutions or interventions; it is argued that this latter aspect is more difficult to do within the framework. While implementing an intervention is not the aim of this thesis, it is anticipated that an intervention or interventions will be part of subsequent future research, and it is reasonable to consider this critique. Any intervention that is complex and multi-layered with many stakeholders is challenging, and it is true that applying the SEM does not solve this complexity. However, it needs to be recognised that perhaps it is the issue which is complex, not the framework that is insufficient. The challenges of translating evidence of social and ecological barriers to health promotion into policy are well documented.[215] These challenges include issues with resources, political will, and a culture of individual rather than collective responsibility for health.

Stokols (1996)[216] has clear guidelines to suggest how community health interventions can be implemented true to the SEM framework. These include considerations such as developing interventions that enhance the control people have over their environment, and finding high-impact organisational and community leverage points to promote health beyond individual behaviour change. Stokols emphasises the need for multi-disciplinary input into interventions for complex problems, and proposes a method for working through the complexity that is inherent in health issues that fit the multiple dimensions of the SEM.[216]

6.2.5 Application of the SEM in this thesis

The spheres of influence on immunisation of young people with disability in the school setting are based on those set out in McLeroy's *SEM of Health Promotion* (see Figure 6-3). These are:

1. The young person with disability (Individual level)
2. The parents/guardian of the young person (Interpersonal level)
3. The specialist school where the immunisation takes place (Organisational level)
4. The local government immunisation nurses or contracted immunisation nurses who visit the school and perform the immunisations (Community level)

5. The government structures and policies that determine and oversee the SBIP (Policy level)

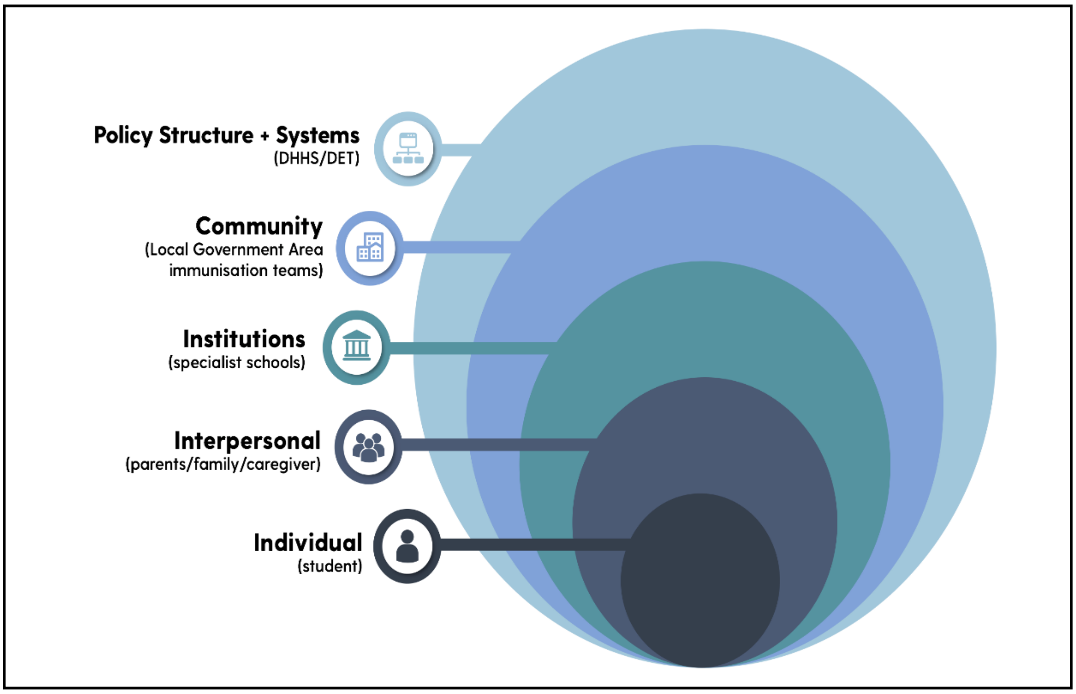

Figure 6-3 The SEM Framework Used in this Research

However, it is important, and a key aspect of the SEM, that these levels are not explored in isolation but that the interactions and impact of the interactions between the levels are captured. To represent this, the visual representation of the framework adopted for this research is one where the circles meet. Traditionally, the nested circles of SEM models are symmetrically placed inside one another and therefore, the only 'meeting' of the circles is with those on either side. However, other representations of this framework have all the circles meeting at one side, and while this has not been explained in the literature, it works to represents the interaction of all stakeholder groups with other stakeholder groups. Therefore, in Phase Two of this research there has been a deliberate decision in adopting this visual representation and applying it to data collection, analysis, discussion and recommendations.

6.3 Conclusion

This chapter has explained the philosophical stance of the research, the consideration of methodologies, and the rationale for the choice of the SEM as the framework to guide Phase Two of the research and ultimately, to inform intervention design to improve vaccine uptake in this population. In particular, the importance of the interaction of all levels of the SEM has been emphasised. This will be reflected in the next chapter, which sets out the qualitative methods for Phase Two of this thesis.

7 METHODS

This chapter discusses the design and methods used to address the primary qualitative research questions. As the Phase One methods are outlined in detail in Chapter 3, this chapter will focus on the mixed methods research design and the qualitative methods used in Phase Two. This will include sampling, recruitment, data collection and analysis tools, and the ethical considerations of the research.

7.1 Research Design

A two-phase, sequential, explanatory, qualitatively-driven mixed methods design was utilised to explore immunisation experience, barriers and facilitators for young people with disability in specialist schools in Victoria. The paucity of research in this area necessitated the in-depth exploration that the qualitative method allows. However, as previously discussed, there was not only a lack of immunisation research in this population, but also an absence of baseline data on uptake rates for specialist schools in official records, policies and government directives. This absence of uptake data added another layer to the research; it was vital to establish the scope of the issues in terms of immunisation uptake in order to frame the qualitative inquiry accordingly.

Therefore, to ensure completeness of the study, a mixed methods approach was chosen; if qualitative or quantitative inquiry was employed alone, the research question would be incompletely answered.[217] In addition, the mixed methods approach is particularly useful when exploring complex social and policy issues where there are a number of different stakeholders and interests. These aspects were important considerations in choosing mixed methods as the research design.

7.1.1 Mixed methods

While using both qualitative and quantitative methods to explore a research question is not new, ‘mixed methods’ as a methodology with its own set of rules, notation and rigour has only emerged in the last few decades. This is attributable to the increasing polarisation between quantitative and qualitative researchers in the 1980s and 1990s, which gave rise to this third paradigm that *“combines elements of qualitative and quantitative research approaches… for the purposes of breadth and depth of understanding and corroboration.”*[218] This paradigm challenges the notion that the culture and worldviews of qualitative and quantitative researchers cannot converge.[219] Indeed, mixed methods enable the strengths of different types of research to mitigate the limitations of each. Where quantitative inquiry can generate data that are generalisable beyond the group under study, qualitative inquiry can provide rich information about individual experience.

Although many variants of mixed methods designs have been described, there remain three basic types. [220] These are the convergent, explanatory sequential and exploratory sequential designs. Choice of design includes decisions about what relative emphasis of the different methods, timing of phases of the research, and integration of methods is needed in order to answer the research question.[221,222] According to Creswell and Plano Clark (2018),[220] the key tenets of mixed methods research are:

- collection and analysis of both qualitative and quantitative data
- one type of data builds on another or is embedded in another
- an organised research design that provides a method for conducting the study
- procedures are within a framework or theory

How these tenets are applied in each case is guided by the type of mixed methods study and the level at which qualitative and quantitative data is integrated.

7.1.2 Explanatory mixed methods design

The research design utilised for this study is an explanatory, sequential, mixed methods design, where the first phase was quantitative, followed by the qualitative phase. The aim of the qualitative phase was to explain the quantitative results. Traditionally, in explanatory mixed-methods design, the relative emphasis is on the first quantitative phase.[220,222] However, there are some exceptions to this rule, and in this study pragmatic consideration was given to which phase should be dominant.

The first quantitative phase was necessary in order to understand the scope of the issue and to inform interview and focus group discussion. However, the key aim of the study was to explore the experiences of, and barriers and facilitators to, immunisation for young people with disability in specialist schools in Victoria. Therefore, the qualitative element of the study was the focus; thus while this study was explanatory, the second qualitative phase was dominant. This variant to the explanatory mixed-method design has been defined as the *"case selection variant"*, *"preliminary quantitative input design"* or *"qualitatively-driven mixed methods."*[220]

7.1.3 Integration of the phases

Typically in sequential mixed methods designs, integration of the qualitative and quantitative methods occurs at two time points, as was done in this study. The first point of integration was to use the results of the first (quantitative) phase to inform the design of the second (qualitative) phase (see Figure 7-1). In this study, the uptake figures and the reasons for missed immunisation identified in Phase One were used to draft the interview topics and questions used in Phase Two. In addition, as one of the recruitment strategies, key informants were identified from the first phase and invited to participate in interviews in the second phase. Therefore, as is the usual procedure for explanatory mixed methods research, the design, recruitment strategy and data collection tools of the second phase of the project were not fully determined until the first quantitative phase was complete. This inability to map the full research project before starting is one of the challenges of mixed methods research.

The second integration of quantitative and qualitative phases occurred in discussion of the findings, where the implications of both phases of the study were considered as a whole, with both the breadth and depth that mixing methods facilitates. For this study, the quantitative phase shaped and supported the qualitative phase, and the qualitative phase allowed in-depth explanation of the quantitative phase. Integration of these phases are displayed in Chapter 9 through a joint display table and further elaborated through the narrative weaving, which enables data from each phase to be connected by the main themes or integrated inferences.[223–225] In this way, mixed methods produces discussion of findings that has depth and breadth beyond each stand-alone study phase.

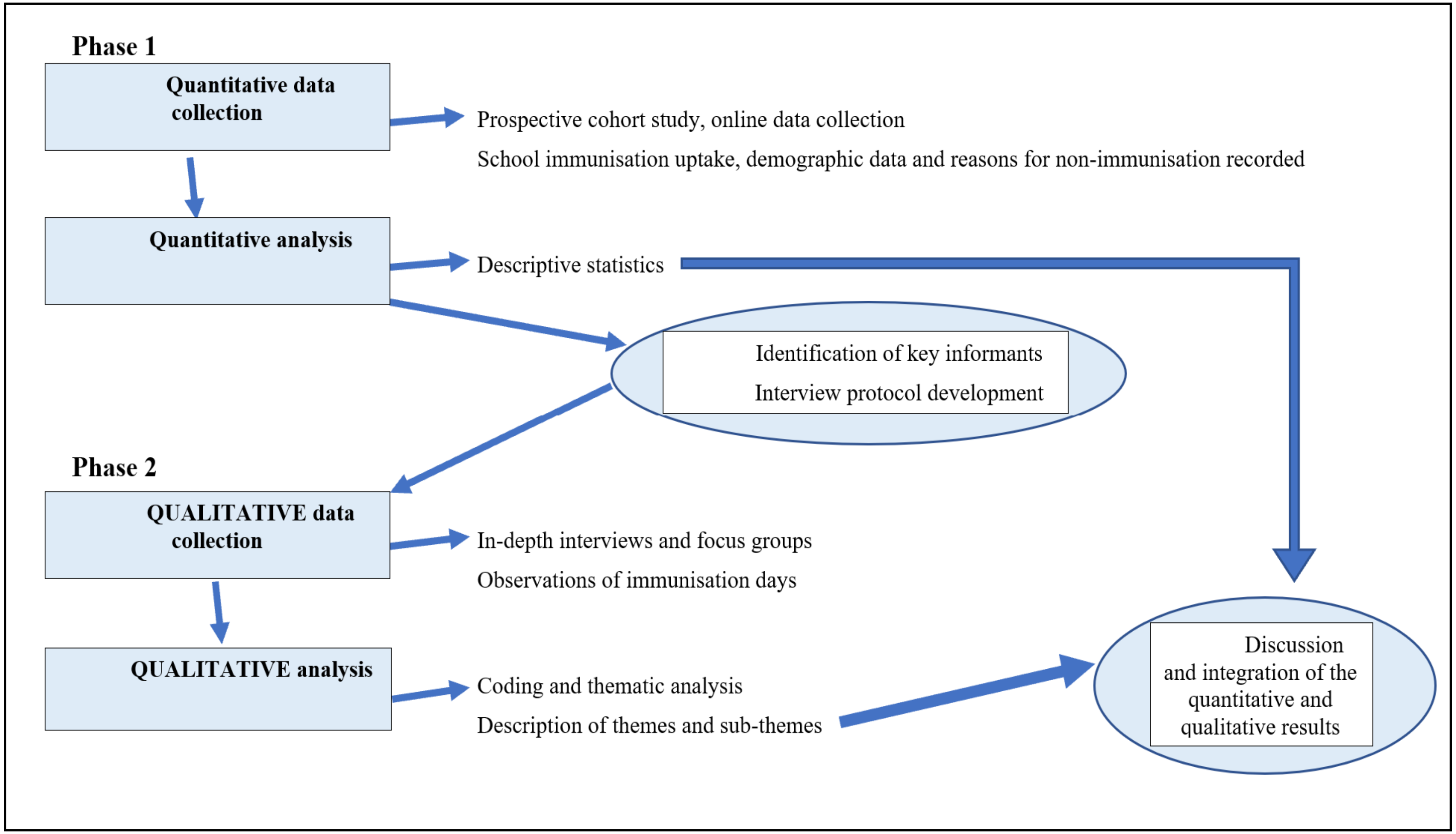

Figure 7-1 Explanatory Mixed Methods Research Design, adapted from Creswell & Plano Clark (2018)

7.2 Phase Two Data Collection

Phase Two was required to answer the main study objectives. This phase consisted of interviews and focus groups with key informants and other participants from each level of the SEM, as it applies to the school immunisation program in specialist schools. In addition, data were collected through observations of immunisation sessions in a number of specialist schools in Victoria. The protocol outlining this is included in Appendix J.

7.2.1 Research question

The research question for this phase of the study was:

> *What are the experiences of, concerns with, barriers to and facilitators of acceptance and delivery of school-based immunisation for young people with disability in specialist schools in Victoria, Australia?*

7.2.2 Study objectives

The primary objective was:

> *To explain low immunisation coverage with reference to specific socio-ecological determinants that prevent or enable immunisation for young people with disability in specialist schools in Australia.*

Secondary objectives were:

- *To describe implementation of SBIP in specialist schools*
- *To understand of the role of teachers, nurses, managers and policy makers in the SBIP in specialist schools*
- *To understand factors impacting on decision-making about immunisation and the process of administering immunisation to young people with disability in specialist schools*
- *To develop an understanding of the experience of young people with disability undergoing immunisation in specialist schools*

7.2.3 Study outcomes

Consistent with qualitative inquiry, outcomes for this phase were not objective measures, but were the prevailing themes from the interviews, focus groups and observations. The primary outcome was a description of the understanding of specific socio-ecological determinants that prevent or enable immunisation for young people in specialist schools. Secondary outcome measures were the themes relating to other aspects of the SBIP in specialist schools.

7.2.4 Recruitment

Recruitment for this phase was defined by the structure of the SEM used as the lens for this research, as described in Chapter 6. Recruitment was achieved primarily through a stratified purposive sampling strategy. Initially, data collection was planned to be only via interviews and focus groups (see protocol Appendix J). However, an early amendment allowed for observations of school immunisation days (see Appendix K). The Information Statement and Consent Form for observations is included in Appendix L.

Interviewees were recruited with respect to the SEM. The stakeholders in three layers of the SEM (policy, community and institutions) were identified through background reading and discussion with the research team, as well as interactions from Phase One. In addition, snowball sampling was incorporated at a policy level, where it was important to capture all key stakeholders from the small number who have specific knowledge about policy issues regarding school immunisation in Victoria.

Initially, recruitment at the Local Government Area (LGA) and school level was based on maximum diversity sampling. Six Victorian LGAs were identified by the Researcher based on diversity of: location (metropolitan, regional, and where applicable rural); population; a range of immunisation uptake levels (as recorded for mainstream schools); socioeconomic levels (as measured by index of relative economic advantage and disadvantage); and type of specialist schools. The immunisation managers, immunisation nurses and specialist schools within these LGAs were sent an Information Statement and Consent Form with an invitation to participate in an interview or focus group (see Appendices M, N and O). It became clear very quickly that while immunisation teams were keen to participate, it would be very difficult to ensure that participants from the school level for each identified region were represented. Therefore, the amendment to the study protocol included an application to extend the invitation to participate to all immunisation teams with specialist schools in their region in Victoria, as well as all specialist schools in Victoria (see Appendix K), in order to maximise participation. At the family and individual levels, a convenience sample was obtained.

7.2.5 Inclusion and exclusion criteria

For policy stakeholders, inclusion criteria included employment with either DHHS Immunisation Section or DET and some involvement in, or specialist knowledge relevant to, the SBIP.

For the community stakeholders, all LGAs in Victoria with one or more specialist school(s) in their region were included. Exclusions in this stakeholder group included LGAs without specialist schools in their region, and schools that were invited to participate in Phase One of the research and who indicated that they did not want to participate in the research at all.

For school observations, inclusion criteria included specialist schools that enrol young people with physical and/or intellectual disability who had a scheduled immunisation day in May/June or October/November 2018. Excluded were mainstream schools, satellite units for young people with special needs attached to mainstream schools, schools for hearing impaired students, and specialist schools for students with primary emotional and behavioural issues.

For parent participants, inclusion criteria included primary carers (including biological parents, adoptive or foster parents, and grandparents) of young adolescents attending a specialist school in Victoria and eligible for adolescent immunisations in the last 12 months, whether or not they received them.

For young people, inclusion criteria included any young person who attended a specialist school and was eligible to receive their adolescent immunisations in the last 12 months, whether or not they received them, and were able to participate in a verbal interview.

Exclusion criteria for all participants included the need for an interpreter to participate, as interpreters were not available for interviews or focus groups. Exclusion criteria for young people with a disability included the use of non-verbal communication systems, as the interviewer required verbal answers to questions.

7.2.6 Timing of recruitment

There were two recruitment waves. The first was April to May 2018 and the second was October to November 2018. This was to correspond to the majority of immunisation day dates for the two immunisation days offered to schools in 2018, which were required to cover the two-dose schedule for the HPV. All other adolescent immunisations in 2018 were also offered on one of these days. Some LGAs offered more than two days to schools to accommodate catch-up immunisation days. Waves of data collection were best suited around immunisation days, as interviews of both LGA immunisation nurses and managers and school immunisation coordinators could be conducted face-to-face on those days. Therefore, convenience determined the timing of interviews. Interviews that were not attached to immunisation observation days were scheduled to take place by phone or face-to-face at a mutually agreeable location, most commonly the participant's place of work.

All participants from the policy stakeholder group were interviewed in the first wave of data collection. The numbers in this group were low, and logistically it was best to carry out these interviews within a short space of time. Contact details were identified in Phase One of the research for key informants at the policy level. Potential participants were contacted via email or phone to explain the research. If the participant agreed, the Information Statement and Consent Form (see Appendix P) were sent electronically to the participant, and a time and location was mutually agreed. Interviews were offered face-to-face at the participant's place of work, or by phone.

Recruitment of parents and young people was in process for the entire 2018 year, as there were a number of different strategies used to attempt to recruit this hard-to-reach group. This included advertising with disability-specific organisations and groups, such as The Association for Children with a Disability, Amaze Victoria, Down Syndrome Association and the Cerebral Palsy Support Network. Specialist schools that agreed to participate in Phase Two were asked to place an advertisement about participating in the research for parents and young people in their school newsletter (see Appendix Q) and/or send a letter home with students to parents inviting participation (see Appendix R). In addition, parents were made aware of the study through promotion in the Neurodevelopmental and Disability Outpatient

Clinics at The Royal Children's Hospital, Melbourne. A direct phone number and email address was included on all the promotional material. If parents or young people were interested in participating, the Information Statement and Consent Form (see Appendix S) were sent to parents and interviews were conducted by phone or face-to-face outside the school or hospital setting.

7.2.7 Sample size

The adequacy of sample size in qualitative research has been the subject of much debate.[226–229] Unlike quantitative studies, statistical significance or power is not relevant, therefore qualitative research does not seek to recruit a certain sample. The gold standard of sample size in qualitative research is often attributed to a concept originating from grounded theory, that of 'data saturation.'[226] Data saturation refers to the point of data collection where no new information is discovered. The actual extent to which data collection and analysis continues to achieve data saturation is not fixed, despite many researchers attempting to quantify it. While Guest, Bunce and Johnson (2006) have suggested six to12 interviews should be adequate for data saturation,[228] Creswell and Plano Clark (2018) has a wider range of five to 25.[220] Francis et al.(2010) propose a method of calculating saturation for interview data by starting with 10 interviews and stopping when no new themes are identified over three interviews (10+3).[230]

Critics of the concept of data saturation argue that, in fact, it is impossible to predict or determine the point where there is no new information to be gained from data collection.[229,231,232] As Braun and Clarke (2019) discuss, the application of the concept of saturation must be congruent with the nature of the qualitative inquiry.[232] In this Phase Two Study, a broad iterative inquiry approach was adopted, based on Reflexive Thematic Analysis,[233,234] in response to the scant knowledge and previous research on the topic. Within this approach, a more appropriate measure of sample size was whether the amount of data answered the research question *"with depth and maximum opportunity of transferability of findings."*[226] Depth refers to the richness of information and its appropriateness in relation to the research question, and transferability allows for the findings to be meaningful. Therefore, true to the iterative nature of qualitative research and the choice of semi-structured interview format, there was no pre-determined sample size for Phase Two. Recruitment continued until all eligible participants in that domain were invited to participate, or when it was determined there was depth and adequate transferability of the data for that group of stakeholders.

There were some extra considerations in determining sample size. The first was the framework adopted, which required adequate representation from stakeholders at all levels of the SEM. The second was related to the limits of the sample available. For example, as there were a small number of relevant people to interview in the policy area on school immunisation, this number was pre-determined.

7.2.8 Interviews and focus groups

Only interviews were offered to policy stakeholders, immunisation managers and immunisation schools co-ordinators, as at these levels, these stakeholders are key informants on immunisation for the state government, local government or school, respectively. Key informants act as expert spokespeople for their group or population and therefore, in-depth interviews are the most appropriate method of gaining a comprehensive understanding of their perspective.

Focus groups were offered to immunisation nurses as an alternative to interviews. This was in recognition of their role in the SBIP as members of nursing teams and the value of hearing their views within a team context. Interviews were offered as an alternative for nurses who wished to participate outside the focus group, or for smaller teams that only had one or two permanent nurses.

Both focus groups and interviews were offered to parents. A focus group was included because it was considered that the group dynamic of parent discussion would add depth to the discourse and enable more parent voices to be heard. However, pragmatic scheduling considerations were the priority for parent participants, who all chose interview format.

Interview and focus group guides were developed to ensure consistency in data collection, while tailoring topics to each relevant SEM level. The semi-structured nature allowed for themes and topics to be initiated by participants, thereby ensuring the discussion was participant driven and not reliant on preconceived themes. Broad topics covered included: the experience of the participant in their role in the SBIP in specialist schools; the perceived barriers and enablers to immunisation in specialist schools; and particular concerns of the participants in their roles about immunisation in specialist schools. As data collection and analysis took place concurrently, interview guides were continuously revised in response to reflection on each interview, discussion with supervisors and the information from preliminary data analysis. The initial interview guides for each interview/focus group, and examples of revised interview guides, can be found in Appendix T.

7.2.9 Observation sessions

Observation sessions at immunisation days at specialist schools were organised through the LGA immunisation team managers, who obtained permission from the relevant specialist schools. Notes and reflections from these observations were written up as vignettes immediately after the sessions. These vignettes were coded manually and then aligned to the final themes they reflected. In this way observations were checked for "fit" with the coding and theming of focus groups and interviews and thus the data was triangulated, increasing the rigour of the analysis process. These observations provided a proxy understanding of the young person's experience through examination of verbal discussions, body language and facial expressions.

7.3 Data Analysis

Interviews and focus groups were recorded and transcribed by an external transcriptionist, who signed a confidentiality statement. De-identified transcriptions were uploaded into QSR International NVivo12 software,[235] which was used to organise data as it was coded and themed. Data were analysed using the thematic analysis process as developed and described by Braun and Clarke (2006),[233] and further developed and renamed Reflexive Thematic Analysis by Clarke and Braun (2019).[234] Thematic analysis was the chosen data analysis method as it provides a systematic approach for identifying themes in qualitative data, and flexibility in terms of the research question, methodology and philosophical assumptions underpinning the research. Thematic analysis can be applied to various types of projects, and using this method allows proposed research outcomes to be defined by the researcher rather than the method of analysis. This is congruent with a pragmatic approach to applying methods that are the best fit for the research question.

Braun and Clarke (2006)[233] describe six stages of thematic analysis, which were all followed. These stages are set out in Table 7-1. True to the iterative method of this type of analysis, no code-book or pre-determined codes were used. Codes were identified *in vivo* and themes were developed with close reference to the data.

Importantly, there was a deliberate decision not to use the SEM framework during the initial coding and theming. This was in part in order to ensure no predetermined boundaries limited the findings, given the paucity of knowledge in the area. This was also to be consistent with the focus on respecting the importance of not only the layers in the SEM, but also the interactions between the layers. Thus, to understand the complexity of how the layers interact on the issue of SBIP in specialist schools, and to avoid creating siloed themes, this initial analysis took place independent to the SEM. After theming, the SEM framework was then applied in order to identify the relevance of each theme and subtheme for which mix of stakeholder groups. In this way, the true interactions creating barriers or enablers could be understood.

Table 7-1 Stages of Thematic Analysis, adapted from Braun and Clarke (2006)

Thematic Analysis Stage	Activity	Specifics
Reading and familiarisation	Reading and re-reading data noticing relevant aspects. Keeping a record of impressions of data and conceptual ideas about data.	This stage is not systematic but 'stream of consciousness' ideas and thoughts about data. Should not be relied on as basis of analysis but as an adjunct to the next steps. Reading is *active, analytical and critical*, reflecting on what data means beyond the surface.
Coding across entire dataset	Identifying everything of interest to the research question and recording a brief phrase or word that labels each chunk of data.	The same data can be coded in as many different ways as is relevant. Codes can reflect the actual content of the data (data derived codes), often using participant language, or they can reflect the interpretations or implicit meanings of the data (researcher-derived codes). Codes can be renamed as the process is undertaken.
Searching for themes	Looking for patterned responses or meaning broader than codes. Reviewing codes and collated data, identifying similar codes, overlap or close relationships and considering what the central concept is relating to the research question.	Themes have a central organising concept related to the research question. Themes can be revised and considered with subthemes, but must make sense on their own and relate to the other themes in some way.
Reviewing themes	Checking phase to ensure data fit within the themes. Returning to original transcripts and coding and re-reading data and considering if there is a good fit with themes.	Themes may need to be reviewed and refined several times with reference to the original data to ensure themes are based in evidence.
Defining and naming themes	Writing a few sentences about each theme to define the focus and boundaries. Reviewing theme names with reference to this description, considering if they are memorable and informative. Identifying extracts and quotes that illustrate each theme.	Analysis continues into this stage, reviewing and ensuring the themes describe the meaning of the data beyond what the extracts say.

7.4 Rigour

Rigour or trustworthiness in qualitative research is most commonly determined through the four concepts of *credibility*, *transferability*, *dependability* and *conformability*, as described by Lincoln and Guba (1986).[236] This was ensured in Phase Two through triangulation of data collection methods and participant viewpoints (credibility, conformability); thick, rich description evidenced by the raw data (credibility, transferability, conformability); and a clear description of methods and process (conformability).[236,237] Crucially, underpinning all these elements of trustworthiness is the concept of *reflexivity*.

7.4.1 Reflexivity

Reflexivity is a form of critical self-reflection: *"…the process of a continual internal dialogue and critical self-evaluation of researcher's positionality as well as active acknowledgement and explicit recognition that this position may affect the research process and outcome."*[238] Being *reflexive* acknowledges the researcher as a tool and the importance of their world-view in shaping and understanding the data.[238]. Examples of aspects of the researcher that may influence the research are socio-demographic factors, such as gender, race, religious orientation, and personal attributes, such as values, beliefs, experiences and background.[238] Maintaining a journal is one way to practice reflexivity. Other reflexive practices employed in this thesis have included peer discussion and review after interviews and observations, regular supervision, and transparency within translation of the Researcher as to the Researcher's background, values and assumptions.

This reflexivity was particularly important during data collection. During this phase, it was acknowledged that discussing immunisation is often politically and emotionally charged. Developing rapport and a non-threatening environment for interviewees was vital, as was being aware of the need for neutral responses to remarks about immunisations that were in opposition to the Researcher's pro-immunisation stance. The variety of stakeholders participating in interviews and focus groups also resulted in a need for reflection.

The Researcher, as a nurse, was very conscious during the process of data collection that she was able to develop rapport quickly and was most comfortable interviewing other nurses. This included both immunisation nurses and school nurses. One technique the Researcher used was self-disclosure, introducing herself as a paediatric nurse with many years of experience in disability, but no background in immunisation. This allowed the nurses interviewed to use professional jargon, including acronyms understood among nurses. The disclosure of having had little experience in immunisations diminished any expectation that the Researcher was an expert in the area, and allowed the field of expertise to remain in the interviewee's arena. This was one way the Researcher emphasised that there were no preconceived assumptions in the research, the way the program was run, or in relation to the barriers or facilitators of immunisations in specialist schools.

Less familiar to the Researcher were the school immunisation coordinators, who were not nurses and had no health care experience, and mainly functioned in schools that did not have a school nurse on staff. This group held a variety of teaching or administration positions in the school, and through reflection, the Researcher became aware that the guide for these interviews often needed to be modified. This was sometimes due to the interviewee having little understanding of the immunisations given or of issues surrounding immunisation, such as policies and funding. It was more difficult to develop rapport and to elicit the depth of information from these interviewees.

The Researcher had established skills in creating rapport with parents of young people with disability and the young people themselves, developed during a decade of clinical work in this field. Through reflection, the Researcher also determined that the particular type of parents who self-selected to participate were quickly engaged and enthusiastic about the interview. This level of enthusiasm was present with some but not all other stakeholder groups that were targeted and invited to participate for their inside knowledge or as key informants. The Researcher considered the potential for an imbalance in power relationships in interviews with parents, but no evidence of this emerged through body language or within the interview dialogue. Again, this may be due to the type of parent who self-selects to participate in research.

Although interviews in the policy stakeholder group were the easiest to recruit, they were the most difficult to conduct due to the lack of previous interaction within the Researcher's professional role. This was mitigated somewhat by the small number of relevant policy personnel, and their close interest and participation in the information gathering stage of the research and in Phase One. This allowed the Researcher to comfortably interview these individuals and also tailor interview questions to their particular roles and areas of expertise.

The importance of reflexivity was also acknowledged through the data analysis process which occurred in conjunction with data collection. Reflexive journaling and regular discussion with the supervision team were tools utilised to ensure a critical lens was applied to the Researcher's pre-conceived ideas of equity, disability and healthcare in order reflect the meaning intended by the participants.

7.5 Ethical Considerations

Ethics approval was obtained from The Royal Children's Hospital, Melbourne, Human Research and Ethics Committee HREC 36326B, (see Appendix U) and the research was approved by the DET Victoria (see Appendix V).

Signed consent was obtained from all participants prior to the interview or focus group commencing. In the case of school immunisation co-ordinators, signed consent was also obtained by the principal of the school, as per DET research in schools requirements.

Signed consent was obtained from the immunisation team managers of LGAs for the Researcher to attend immunisation sessions at specialist schools with the immunisation team. When this consent was received, the principal of the school involved was informed of the planned observation and received an Information Statement with a copy of the DET approval for the research via email. Verbal consent to enter the school and observe the immunisation session was obtained at the start of each immunisation session from the principal or proxy at the school.

7.5.1 Risk management

There were minimal risks to participants involved in this study. The risk of psychological distress when recounting thoughts and experiences of the immunisations of young people was considered. If this should occur, the plan was to stop the interview or focus group and allow the individual(s) to have a break. The choice would be given to the participant whether to continue the interview or focus group. If the participant continued and appeared to recover, further support would be offered by way of a follow up phone call from the Researcher within the next week. If the participant declined to continue or continued to appear distressed, the

Researcher would encourage follow up by the individual's GP or employee wellbeing scheme (for professionals). For parents, the risk of the discussion about their choice to vaccinate or not vaccinate their children provoking uncertainty was considered. If this should occur, details of the Immunisation Service at The Royal Children's Hospital, Melbourne would be given to the parent so that they might access the clinic and review these decisions with a paediatrician or a senior nurse specialised in immunisation.

For the Researcher, safety was ensured when travelling to different locations by:

1. Notifying the research team of all interviews and focus groups, including time, date and locations
2. Having a charged mobile phone on person at all times
3. Organising to notify a member of the research team via text message when entering an interview and on leaving

There were no foreseeable serious adverse events for this study. Distress of any individuals taking part was discussed with the research team and, if referral to supports was required, the Research and Ethics department at The Royal Children's Hospital was to be notified and advice sought as to whether any further action was needed. At any time, participants were free to withdraw from the study without consequence, however this did not occur.

7.5.2 Data security

Audio-recordings, transcriptions and demographic data were stored electronically on a password protected computer with locked cloud back-up, only accessible to the research team and the external transcriptionist. Transcriptions will be kept for seven years after completion of the study. The study computer was continuously in the possession of the Researcher, who worked between The Royal Children's Hospital and her home.

Participants were given an alias, which was assumed on all transcriptions and analyses of data. A spreadsheet was maintained with allocation of alias so that the data were re-identifiable for the purposes of rechecking of data and meaning with participants if necessary. This spreadsheet is password protected and will be kept for seven years after completion of the study. No identifiable data have been or will be included in any publications or presentations. This includes identifying individuals, schools or LGAs.

7.6 Conclusion

This chapter has explained this research as a two-phase, sequential, explanatory mixed methods study, and the rationale for this choice. The methods of the qualitative Phase Two Study in this thesis have been outlined, including sampling, recruitment, data collection and analysis and ethical considerations. The next chapter will discuss the results from the Phase Two Study.

8 QUALITATIVE DATA FINDINGS

8.1 Introduction

This chapter presents the qualitative findings from Phase Two of the research. This is the outcome of analysis of the data collected from 40 interviews and two focus groups with participant stakeholders in the SBIP in specialist schools in Victoria, as well as data from observation of immunisation days at 10 specialist schools. Themes and subthemes are presented with reference to direct quotations and observations, to ensure participants' voices have been honoured throughout the process of data analysis. Findings are then summarised with reference to barriers and facilitators of the SBIP in specialist schools in Victoria, as set out in the research questions.

8.2 Recruitment

Interviews and focus groups were conducted in two main waves of data collection. The first took place from February to May 2018 and the second took place from October to November 2018. This allowed for the initial coding and discussion of data from the first wave to inform the second wave. Some challenges emerged regarding recruitment of parents (discussed below), which resulted in recruitment for this group continuing into 2019. School observations were undertaken in the second half of 2018.

In this Phase Two Study, particular consideration was required for the recruitment of several different participant groups. The approach, sample size and particular challenges, including gatekeeping of each of these participant groups, is discussed below.

8.2.1 Policy participants

Qualitative data collection for the policy level consisted of five key informant interviews from the DHHS Immunisation Section, Victoria and DET Victoria. These key informants were identified through the initial planning of the study, with individuals from these departments providing background information about the SBIP. Therefore, participants in this stakeholder group were well informed about the study, and rapport with the Researcher had already been established by the time of recruitment. All five participants in this group agreed to interviews without reservation. The sample was determined by the number of key informants who had a role in supporting the SBIP, excluding those on leave at the time. The small number reflects the reality of the workforce in this area at the state government level in Victoria.

8.2.2 Immunisation team members and school immunisation coordinators

For recruitment at the level of the immunisation teams and schools, an initial maximum diversity sample recruitment strategy was trialled, as discussed in Chapter 7. This strategy highlighted that while immunisation teams were very keen to be part of the research, specialist school immunisation coordinators were more reluctant. Extending recruitment to all immunisation teams and specialist schools in Victoria maximised school participation.

Local Government Areas and their contractors varied in their requirements for the immunisation team manager role. The majority of the immunisation team managers were senior registered nurses, who had a dual role of managing the logistics of the program and administering immunisations. Other teams had managers who were not health qualified, and who therefore managed logistics of the program but did not participate in immunisation. During the data analysis, a decision was made to differentiate based on qualification. As such, ‘Immunisation Manager’ referred to those who had an administration role only, and ‘Immunisation Nurse’ included all nurses, whether or not they also had administrative responsibilities.

While the quality and content of the Immunisation Manager interviews were different than Immunisation Nurses, given they were not directly engaged with the clinical role, their unique perspective on practical and logistical aspects of the program was valuable. Immunisation Managers were also the contact point for the Immunisation Nurses in the team, many of whom were casual or part-time employees. The importance of interviewing Immunisation Managers was therefore twofold – they provided understanding of the logistical considerations of the program and access to the rest of the team.

Although focus groups were offered for immunisation teams, the large number of casual and part-time employees made this difficult, and many smaller regions only had two immunisers. This resulted in only two focus groups being conducted, although in five other regions, Immunisation Nurses chose to be interviewed in pairs (see Table 8-1).

School Immunisation Coordinators were staff members allocated to the role of liaising with the immunisation teams to facilitate the immunisation program in the school. Where a school employed a registered nurse, this was part of their role. When there was no registered nurse, the background and position of the allocated staff member varied (see Table 8-1). Although principals were directly sent information about the study and were required to give consent for School Immunisation Coordinators to take part, research-related paperwork most often bypassed the principal. Frequently, the School Immunisation Coordinator initially received the paperwork and then arranged for the principal's signature. There were no direct questions about the study or particular interest in the study shown by principals. This reflects their minimal role in the SBIP, which consolidated the decision to interview the School Immunisation Coordinators only as key informants for specialist schools.

As discussed in Chapter 7, the sample size for immunisation team and school participants was determined by pragmatic considerations, true to the principles described in Braun and Clarke's Reflexive Thematic Analysis.[234] In recent writing, Low (2019)[231] argues that there is never a point where no new data emerges; he suggests that this is a *"logical fallacy"* and sufficiency of data to map patterns and meaning should instead determine sample size. Accordingly, after the first wave of data collection and initial coding, it was determined that more School Immunisation Coordinators were needed to fulfil sufficiency of data collection. Logistically, this could be achieved by interviewing after observation at school immunisation days, as rapport was more successfully established with school staff through face-to-face interaction. Immunisation Managers and Nurses who were present on these days were also offered interviews. The number and quality of interviews with immunisation team participants ensured a depth of data, which enabled themes to be fully developed and rich in description.

8.2.3 Parents and young people

One of the challenges in recruiting parents was the absence of a research database of young people with disability that facilitated access to them and their families. Therefore, the initial recruitment strategy was to advertise at specialist schools for participation of parents, with or without their child's participation. Many schools that agreed to staff participating in the study, declined to advertise for participation of parents, either in their newsletter or via a notice home with the student. Understandably, these schools were trying to limit the amount of research families with children with disability were asked to participate in, and they also considered that families should not be approached for participation through the school. As immunisation is often a sensitive topic with polarising viewpoints, it is possible that schools were also hyperaware of introducing this research in the school environment. As a result, only three schools agreed to advertise the study in their newsletter, and only one parent participant was recruited through these advertisements. This protective role schools adopted, in which they acted as a gatekeeper to families, was not anticipated.

Subsequently, other recruitment strategies for parents were undertaken. Several disability organisations were approached to promote the study in their newsletter or social media pages, including the Association for Children with Disability, Cerebral Palsy Support Network and Down Syndrome Victoria. Amaze's research database of families with children with autism was accessed to send an invitation to participate to eligible families. Twenty paediatric practices across Victoria were also requested to advertise the study in their clinic waiting areas. However, these strategies also failed to elicit any inquiries from families.

During this time, two families were recruited through word-of-mouth, but it was not until a subsequent ethics amendment (see Appendix W) for eligible families to be approached through clinics at a tertiary paediatric centre, that another four parents were successfully recruited. Initial coding and review of these seven parent interviews revealed there were clear patterns emerging from the data, and within the recruitment constraints, the sample was deemed sufficient. Within this, there is recognition of the homogeneous characteristics of the parents interviewed, with all having consented to school vaccinations without question. This is discussed more below in the theme *"competing priorities"*.

Despite these efforts, no young people were interviewed for this study. To interview a young person required parental consent, and all seven parents who expressed interest and were subsequently interviewed declined an interview for their child, due to their child's expressive and/or receptive language constraints. Therefore, data from observations of immunisation sessions became even more valuable, in terms of providing a proxy for the immunisation experience of the students.

8.3 Participants Demographics

Demographic data for participants in interviews and focus groups are presented in Table 8-1.

Half of the interviews (20/40, 50%) and both focus groups were conducted face-to-face. All face-to-face interviews were conducted at the participant's place of work. The remainder of the interviews were conducted by telephone. The mode of interview was the participant's choice. Six out of seven parents (86%) preferred a phone interview, citing convenience. Interestingly, the length of the interview did not differ greatly by mode, with face-to-face interviews lasting for an average of 25.63 minutes, and phone interviews an average of 29.67 minutes. The length of interview varied greatly with no discernible pattern between SEM groups. The longest and shortest interviews were both with Immunisation Nurses; the longest was 65 minutes in length and the shortest just over eight minutes. When interviews were undertaken with Immunisation Managers, Immunisation Nurses and School Immunisation Coordinators, at the end of a school observation session, there were occasionally time restraints, which resulted in shorter interviews. With no such constraints, it is not surprising that interviews with policy participants were the longest, with an average of 44.95 minutes, followed by parents at an average of 25.68 minutes.

The majority of School Immunisation Coordinators were employed at their schools as nurses. Details of gender, age and disability type of children of parent participants is also included in Table 8-1. All parents had children who were offered immunisation at school in the last year.

Table 8-1 Demographic Details for Participants in Phase Two

SEM Group	Name*	Type of Interview P=Phone F=Face-to-Face	Length of Interview in Minutes	Additional Information
Policy	Georgia	F	34.16	
Policy	Nina	F	NA**	
Policy	Mallory	P	51.48	
Policy	Elinor	F	38.17	
Policy	Ming	F	56.00	
Immunisation Manager	Taylor	F	12.31	
Immunisation Manager	Mary	F	38.17	
Immunisation Manager	Leanne	P	15.00	
Immunisation Manager	Rory	F	23.50	
Immunisation Manager	Phuong	P	19.35	
Immunisation Nurse	Serena	P	25.34	
Immunisation Nurses	Yvonne and Mel	F	46.28	
Immunisation Nurse	Clare	F	08.33	
Immunisation Nurse	Maree	P	30.10	
Immunisation Nurses	Peta and John	F	27.08	
Immunisation Nurse	Fiona	P	37.88	
Immunisation Nurse	Jordana	F	38.01	

SEM Group	Name*	Type of Interview P=Phone F=Face-to-Face	Length of Interview in Minutes	Additional Information
Immunisation Nurse	Alana	P	41.19	
Immunisation Nurses	Kate and Martha	P	26.34	
Immunisation Nurses	Niamh and Livinia	F	14.45	
Immunisation Nurses	Caitlin and Rylee	F	18.52	
Immunisation Nurse	Rose	P	65.46	
Immunisation Nurse	Beth	P	40.11	
Immunisation Nurses	Focus Group 1	F	38.31	4 participants: Kasey, Amelia, Rita, Lee
Immunisation Nurses	Focus Group 2	F	18.04	3 participants: Caitlin, Linda, Meg
School Immunisation Coordinator	Mandy	P	26.48	School nurse
School Immunisation Coordinator	Zara	F	NA**	School nurse
School Immunisation Coordinator	Fatima	F	17.03	School nurse
School Immunisation Coordinator	Jane	F	14.33	Wellbeing officer
School Immunisation Coordinator	Trish	F	18.04	Administrator
School Immunisation Coordinator	Philippa	F	14.04	First aid officer
School Immunisation Coordinator	Sarah	P	57.04	School nurse
School Immunisation Coordinator	Anna	P	16.38	School nurse
School Immunisation Coordinator	Amy	F	24.11	School nurse

SEM Group	**Name***	**Type of Interview P=Phone F=Face-to-Face**	**Length of Interview in Minutes**	**Additional Information**
School Immunisation Coordinator	Athena	P	25.09	School nurse
Parent	Julie	F	37.35	Daughter, 15 yrs, ID
Parent	Stephanie	P	36.20	Son, 17 yrs, ASD, ID
Parent	Lara	P	21.46	Son, 17 yrs, CP
Parent	Freya	P	12.15	Son, 16yrs, CP, epilepsy
Parent	Shelley	P	21.25	Daughter, 12yrs, mitochondrial disorder, seizures
Parent	Kathryn	P	16.22	Daughter, 16yrs, ID
Parent	Andy	P	35.14	Son, 15 yrs, ID, ASD

Key: ASD – Autism Spectrum Disorder; CP – Cerebral Palsy; ID – Intellectual Disability; *All names are pseudonyms; **Interview not recorded

8.4 School Observations

Details of observations of school immunisation sessions are presented in Table 8-2. Typically, schools had two or three immunisation team members who immunised students one at a time, except School 5, which had two immunisation teams concurrently immunising. In addition to immunisation team staff, the School Immunisation Coordinator was present for the entire session at each school, and a classroom teacher and one or two aides were usually present. Where specific examples from observations are described in this chapter, all student and staff names are changed.

Most schools had a separate waiting area for students after the immunisation. School 5 had students waiting for immunisation, having immunisations and waiting after immunisations all in the one large room. This resulted in a chaotic and noisy environment.

A total of 197 students were observed across the ten schools for immunisation. They were all students with consent and present at school on the day. There may have been other students who consented but were absent from school or refused to come to the immunisation area. The number of eligible students without consent was unknown to the Researcher. One school consented only to observation in the waiting area and did not allow the Researcher into the immunisation room, and therefore, these student immunisations were not directly observed.

A total of 6/197 (3%) students had parents present. Of the students observed during immunisation, 39/176 (22.2%) had significant issues related to immunisation. In particular, 27/176 (15.3%) were distressed during their immunisation, characterised by any of: excessive crying, screaming, struggling and/or requiring more than five minutes to calm down and/or the use of restraint by staff, defined as holding beyond hand-holding or steadying the injection arm. For the remaining students in this cohort with significant issues (12/176, 7%), immunisation was abandoned due to their distress.

Table 8-2 Details of Immunisation Sessions Observed at Schools

School Number	Metropolitan / Regional	Immunisation Team Members Present	Students Presented for Immunisation	Students with a Parent Present	Students Immunised, but with Significant Distress	Students Unable to be Immunised
1	Regional	2 nurses, 1 admin	20	2	4	3
2	Regional	2 nurses	9	0	1	1
3	Regional	2 nurses	10	0	0	0
4	Regional	2 nurses	8	0	2	0
5	Regional	4 nurses, 1 admin	34	0	6	1
6	Metropolitan	2 nurses	16	0	4	1
7	Metropolitan	2 nurses, 1 admin	18	0	2	0
8	Metropolitan	2 nurses, 1 admin	21	2	NA*	NA*
9	Regional	2 nurses, 1 admin	38	2	10	1
10	Regional	3 nurses	23	0	0	5
Total			197	6/197 (3%)	27/176 (15.3%)	12/176 (6.8%)

*Researcher was only permitted in the waiting area, did not directly observe immunisation

8.5 Themes and Subthemes

Themes and subthemes were developed from an iterative process using Reflexive Thematic Analysis,[233,234] as described in Chapter 7. As stated, the SEM framework was set aside for the early phases of analysis to ensure data whereas analysed iteratively. Once initial coding and theming was complete, the SEM was then applied to understand the barriers and facilitators to immunisation in specialist schools, within and between each stakeholder group. Therefore, the role, or absence of a role, of each group of participants was explored in reference to each theme and the subthemes within. There were five final themes and 13 subthemes. These are outlined with the relevant interaction within the SEM in Table 8-3.

Table 8-3 Phase Two Findings: Themes, Subthemes and Interaction within SEM

Theme	Subtheme	SEM Level Interaction
An invisible population	A school is a school The power of data	All levels
Searching for support		Policy (DET/DHHS) and Community (immunisation teams)
Going the extra mile	Teamwork is the key Being flexible Never stop trying It's hard yakka	Community (immunisation teams) and Institutions (specialist schools)
Competing priorities	It's not top of their list to worry about It's easier at school Immunisation decisions are complex	Community (immunisation teams), Institutions (specialist schools) and Interpersonal (parents)
Trust takes time	A familiar face helps We can't prepare them Anything could happen Crossing the line	Community (immunisation teams), Institutions (specialist schools), Interpersonal (parents) and Individual (students)

The community layer of immunisation team members emerged strongly in all themes, suggesting this stakeholder group as central to the SBIP. It is noted that this group had the largest number of participants. Their interest in participating in the research was clear, with most of these participants providing rich detailed descriptions and answers to interview questions. This, in turn, reflects their key role in facilitating the SBIP, their unique immunisation focus compared to other SEM stakeholders, and their central and widespread influence. This emerges strongly in the discussion of themes and subthemes. In contrast, the outer layer of the SEM (policy) and the innermost layer (individual) only each appear in two of the five themes. This suggests a less present role in the SBIP, despite the students as the stakeholders in the innermost layer being the subject of the immunisations.

8.6 An Invisible Population

The theme of *"an invisible population"* refers to the absence of immunisation guidelines and policies that include and acknowledge young people in specialist schools with disability. Participants from *all levels* of the SEM acknowledged that this population is not considered within the structure and policies of the SBIP that currently exist. As such, young people with disability are currently invisible in immunisation policy and programs.

This invisibility manifests in two broad ways that are discussed in the subthemes:

1. The treatment of all schools as the same in the context of the SBIP: *"a school is a school"*; and
2. The lack of data, or access to data, specific to immunisation in young people with disability that impacts the ability to affect change on policy, funding or resourcing: *"the importance of data."*

8.6.1 A school is a school

The subtheme of *"a school is a school"* represents the constraints of the SBIP as a program to fit mainstream secondary schools. As Ming (policy) explained, *"for the purpose of the specialist schools, we don't differentiate at all within the Department"*. The central tenet is that the SBIP, while set up to provide equal opportunity for immunisation for all young people, in practice is not equitable. Interestingly, the policy participants, presumably who have the most influence in this high-level policy domain, discussed the shortcomings of the system extensively. Mallory (policy) reflected on the equal/equitable dichotomy with regards to funding of school immunisations:

> *You know, we fund equally across the board. So, we just give that subsidy payment of $9.00, whatever it is, for each jab in the arm. And that is irrelevant to the setting that you're administering that jab, you know? ….Like I don't think that we fund equitably. So, I don't think that we look at these particular settings and say, "Well, there's a heck of a lot more work that needs to be going into administering a program in this particular setting." And it might be tricky to do that. Like when you look at all of the number of complexities in different schools, maybe it would be a challenge for us to do that, right? Like how would we fund individually in each different school setting? And how would you then develop a model to do that, right? You've got special schools and the complexities that might go with that, and then the range of different complexities at special schools.*

Thus, policy participants recognised the difference between mainstream and specialist schools, and that immunisation funding is not adequate for the workload in specialist schools, and they acknowledged the complexity in adjusting for difference.

The concept of difference, in this case disability, being in the *"too hard basket"* (Yvonne and Mel, immunisation nurses) reverberated through all layers of the SEM. Immunisation Nurses had a very clear picture of practical differences in the act of immunising in specialist schools as compared to mainstream schools:

> *It's probably more of an intimate situation… so you don't have the big hordes of groups coming through, it's just generally like a one-by-one basis. And then you usually would have two nurses to spend a bit of time on one child at that one time. And you don't push them through as quickly because you need to spend a bit more time with them to reassure them and just to make sure that we are safe as well as the student. So, in some ways it's a slower process but we sort of need to be a bit more thorough really, in terms of everybody's safety. But in saying that, we don't go through the questions, like we might in a mainstream school as well. But generally, we don't ask them many questions, we just have to assume that the parents have consented and signed, and all the information is correct.* (Maree, immunisation nurse)

In addition to practical and logistical difference, Immunisation Nurses acknowledged the different reasoning and decision-making that is involved when immunising young people with disability. As Serena (immunisation nurse) stated:

> *You've got unwilling, unconsenting participants that are fully grown, which is quite different. In an ordinary school situation that wasn't a special school, we would never immunise children that are objecting the way that we would in the special school.*

Peta (immunisation nurse) also emphasised this difference: *"You can't treat it like a mainstream school. You do have to go in there with a different mindset. Even though you are offering the same thing."* This was in contrast to the Immunisation Managers, who were the only group of participants who expressed a belief that the SBIP was fit for purpose for all schools. This may reflect the well-defined administrative role of the Immunisation Managers, which does not extend to clinical aspects of immunisation. Their emphasis is on the administrative tasks of the SBIP, and these tasks need to be completed for every school:

> *We go through the same process of contacting them, asking them for numbers in the relevant age groups, taking the consent cards down to them, getting them back from them, arranging dates and times. It's exactly the same process.* (Leanne, immunisation manager)

Although all other participants across the SEM levels agreed that there were differences in immunising in specialist schools as compared to mainstream schools, any attempt to adjust for this appears to be unspoken and unwritten. Immunisation Nurse Serena stated that she had *"never had any discussions about anything different. It has never been mentioned in my seventeen years of immunising, anything different about special schools"*. Yvonne and Mel (immunisation nurses) explained how they do consider the differences, while maintaining the pretence that indeed, a school is a school:

> *We have always traditionally just offered pretty much everything we could [at the specialist school]… in an attempt to vaccinate those kids up to speed regardless …At times I don't suppose that it was even on the schedule really. The Health Department had that "don't ask don't tell" mentality. They were happy to turn a blind eye for us to use the vaccines to catch these kids up but just don't tell anyone, basically.*

For parents, inequitable policies and structures are phenomena they experienced throughout a variety of health encounters, not just immunisations, and this was expressed with a degree of resignation:

> *I think these things are, you know, in any public health system these things are a bit of a sausage factory and, you know, you are either this kind of sausage or that kind of sausage or you're one of the ones who can't be served at this shop and off you go.* (Andy, parent)

Therefore, the SBIP is a standardised program for all schools and does not allow for equitable adjustments. The fact that there are differences in schools that affect the program is understood across all levels of stakeholders, but it is accepted that these differences are too difficult to adjust for, or are simply the consequence of minority groups. This is where the power of data is vital.

8.6.2 The power of data

The subtheme of *"the power of data"* reflects the need for evidence to recognise inequity and to influence policy. High level immunisation data are predominantly focused on vaccine uptake figures. Georgie (policy) critiqued this focus, explaining immunisation uptake data as a powerful political tool, rather than an actual health outcome:

> *So, we have an interesting government approach that it is all about coverage rates and I have tried to explain to them that that is actually an input and it is not an outcome. An outcome is reduction of disease.*

Georgie continued to explain that despite the different focuses of stakeholders, data are central in influencing government:

> *Data is just so powerful… I think the only way to get support and movement is to say look at this, because if you don't say it, if you don't put those hard numbers in front of people, the Minister won't [listen]… yes that's the way to do it.*

Although DHHS Immunisation Section stakeholders stated that they recognised *"there may not be year levels like mainstream year levels for specialist schools, and [we are] very lenient in how we see a vaccine goes out in that regard"* (Ming, policy), this was disputed by Kate (school), who explained that *"all our data goes by year levels so I kind of try and bunch them into a year level according to their age* *for the data, but it is a bit tricky."* Specialist schools need to determine eligibility based on age, and according to recommended age ranges, students are eligible across two years, which causes confusion, as Mary (immunisation manager) explained:

> *The only thing that frustrates me with the special schools, in terms of what Department of Health want, are statistics. That really frustrates me. I'll give you an example. Here, these three will be part of that age group. Yet, I can't offer it because they had them two years ago. So statistically-wise, I don't like the way they ask us enrolment numbers and things like that. If I include them and I say… we had given it two years ago, and I can't really say "elsewhere" because I've given it. So that's the only thing that's not really clear with Department of Health enrolment numbers.*

So while immunisation information is requested by the government, the accuracy and reliability in ungraded schools is compromised. As Mallory (policy) stated:

> *I would have absolutely no idea, in those alternative setting schools, what their coverage rate is really either. So I don't think we're doing a good job at looking at these populations of youth across the board and setting up particular programs to be funding them. Like, I don't think that we're doing a very good job in general at doing it… for some of these special groups, the data's been so invisible for so long.*

In this context, the lack of data, which is a result of the invisibility of young people with disability, then acts to reinforce the conditions that create this lack of visibility.

While policy participants spoke about data solely in the context of immunisation, immunisation teams also spoke about the difficulty collecting measurable data about their workload. This is particularly pertinent when immunising in specialist schools that require more time and resources. Rose (immunisation nurse) said, *"We can't measure an outcome from that so there is not really any work. No not any work! …They can't make it into a KPI because it is not measured."*

School Immunisation Coordinators spoke about data in the context of the importance of keeping their own records of student immunisations for more practical purposes:

> *Some might say, you know, that they just declined, which means they just didn't want it and whether they've not returned, so I keep all that data just for my records because sometimes the parents will call in two years later and I will say, "No you declined it" or "You didn't return the form" or*

> *whatever, so I can go through it with them.* (Anna, school immunisation coordinator)

The importance of School Immunisation Coordinators keeping their own records of immunisations was partly explained in the context of the difficulty in determining if a student has been immunised. Schools do not have access to the AIR and HPV registers. When Amy (school immunisation coordinator) was asked if it would be helpful for schools to have access to these registers, she responded:

> *Oh that would be terrific. One, we would be able to catch-up on people who come to us. We will be able to send the transcript to many people [who] come to me asking what did they get done? And it's only because I keep records of what they've done… because they have to fill forms out for all the Centrelink or another organisation… but if I had, yes, I would love that. That would be terrific.*

Parents spoke of immunisation data in the context of their individual child's record rather than data to drive policy, funding or resources. Interestingly, Stephanie was the only parent who seemed aware of the existence of the AIR, but was not confident in its accuracy:

> *After a while my husband and I would say, did he ever have that vaccination? And sometimes we would check on the Immunisation Register. Sometimes it is put on that, but the flu vaccinations don't ever get put on that, so it is a bit hard to tell.*

The other parents did not discuss the Immunisation Registers. In fact, they seemed largely unaware of their ability to access their child's immunisation record. Andy (parent) stated:

> *Being able to muster [the information] would be easier… if his record somewhere had that information on hand already, so I didn't have to traipse around to his GP and the Council and everywhere and figure out what he's got and what he hasn't.*

For parents, the power of data was described as being able to easily determine what immunisations their child is due for and when. For parent Lara, the difficulty keeping track of this information was in fact a key factor in her choice to take her child to a tertiary care hospital for adolescent immunisations, instead of the SBIP: *"…because everything is up to date, they've got it all on their computers and it [is] just easier* *then."*

Therefore, lack of data impacts the clarity about individual records and aggregate data at the parent, school and immunisation team level. In addition, the issues with collecting accurate data on immunisation in young people with disability compounds the invisibility of this population and also the support needed to meet the extra challenges of immunising in specialist schools. This is illustrated by the theme *"searching for support."*

8.7 Searching for Support

The theme of *"searching for support"* refers to the interaction between *policy* (state government Departments of Health, and Education and Training) participants and *immunisation team* (local government or local government contractors) participants. This theme discusses resources within and between state and local government teams to manage a large program, and how the perceived lack of support for the SBIP from the Victoria State Government affects the morale of local immunisation teams. This tension is particularly heightened in the context of the challenges in the SBIP in specialist schools.

There is no individual allocated to oversee the SBIP in either in the Victoria State Government Departments of Health or the Department of Education and Training. Despite this, Georgie (policy) listed the significant role of the Department of Health in assisting local government with the SBIP. This includes infrastructure, such as funding, software and paperwork, as well as advice and safety surveillance, and a point of contact for schools and parents for any immunisation issues that arise. Georgie summed this up: *"We try and take a lot of pressure off local governments… that's the way I see the support around the whole school program."*

However, this appears to be at odds with the perceptions of immunisation teams regarding support. None of the immunisation team participants interviewed expressed that there was any supportive communication from the Victorian State Government Departments with regards to the SBIP. Many immunisation team participants voiced an acceptance that *"we just basically run our program and then that's about it"* (John, immunisation nurse). Some of those in the policy level agreed with and justified this sentiment, referring in particular to the *Public Health and Wellbeing Act*[78] that mandates local governments to provide an immunisation service for children and adolescents living in that municipality. In recognition of LGAs' responsibilities according to this Act, Ming (policy) stated that the Department of Health *"try not to manage the schools too much. It's tends to turn into Big Brother a little bit."* Elinor (policy) explained further:

> *[Local governments] are quite autonomous, because 79 local governments run different services out there. Some councils do the job for other councils, that sort of thing. Or they've got a contractor that comes in, so they're quite autonomous in that.*

Rose (immunisation nurse) was very vocal about the low priority of the SBIP within her own LGA, as well as the DHHS Immunisation Section and DET, and the impact of this on the morale of immunisation teams:

> *If there was someone that was in the Department [of Health] that had a liaison with Department of Education that may be able to work with these schools and help… give the immunisation some sort of priority in the school… It just feels like we are these little tiny teams trying to do big programs without very much support from a government level. And within our Councils we are not seen as an important service. We don't bring in a revenue and we generally are a high-risk group so we, you know, we have risk of needle sting, we've got all those things that they deem as a risk because that's what Council's about. They're not about necessarily providing the immunisation program so the school program, I think, is very undervalued probably from Council, and it definitely doesn't appear from the state level either, that the schools programs are of any importance. If they don't have someone dedicated in DHHS for looking after school programs, what does that say from the government?*

In addition, Rose expressed frustration that her requests for assistance with aspects of the SBIP went unheard and unanswered:

> *There is no definitive assistance. If you've got a school that is identified as really low coverage, nobody rings you and says is there something we can do?…I asked at a couple of the DHHS, the region meetings, something about is there something that you guys can help with? And nothing, and so I actually think I am becoming a little bit disillusioned at times.*

This lack of connection with and assistance from the Victoria State Government in managing the SBIP was reiterated by other immunisation teams. Mel (immunisation nurse) discussed the same issue in relation to searching for support from the DET:

> *I don't know if it's Education Department level, the support for the schools to promote the program in the specialist schools and perhaps provide the resources so that the maximum number of staff do understand the importance of the program and what they can do to support the program to make it a little bit more uniform across the board, and also maybe how to get past their own personal prejudices. If a student's family has elected to be immunised then we sort of need to help facilitate that.*

Beth, a regional Immunisation Nurse, had attempted to implement a program to catch-up childhood vaccinations alongside the SBIP for students in non-mainstream schools in her region. This was an intervention that was beyond the requirement of the SBIP, but one that, interestingly, policy participant Mallory suggested would be future best practice:

> *We need to at least start, and we are having discussions about it, is piloting some projects in some of these alternative settings: special schools, flexible learning centres, English language schools, etc., where there's more comprehensive catch-up being delivered to students in those schools, where we know that the coverage isn't great, and it reflects the whole NIP Program and not just the adolescent vaccines.*

Despite this, Beth, like Rose, felt her request for support from the DHHS Immunisation Section was unheard:

> *Yes we were trying to get extra funding… I did write to [the Department of Health] and I was trying to get some funding to do this, but I didn't get any replies either, so we just went ahead… I really needed another nurse in here. I just killed myself… because it is really hard to check, well now we won't have the HPV register, but you've just got to try and tally those children up all the time with the registers, so it is quite exhausting.*

Ming (policy) provided a different perspective on this disconnect between state and local government in supporting the SBIP in specialist schools:

> *We rarely hear any issues around specialist schools for whatever reason. It may be that they don't think that it's an issue that needs to be dealt with at this level. They might think it's something that they deal with internally. But no, we rarely hear any big problems with any of the kids with disabilities*

> *within schools or at any specialist schools. I mean that could be a matter of putting it out there and saying, "Tell us if there are issues."*

Another consequence of this lack of communication is that extra work that is put into the SBIP when administered in specialist schools is unaccounted for and reliant on goodwill. This is discussed in the theme *"going the extra mile."*

8.8 Going the Extra Mile

The theme of *"going the extra mile"* refers to the process of immunising students with disability in specialist schools. This theme focuses on the interaction between two levels of the SEM – the community level of *immunisation teams* and the organisational level of *schools.* The core tenet is how these groups *go the extra mile* to immunise in specialist schools.

The factors within this theme are described within four subthemes. The number of subthemes reflects the breadth and depth of rich descriptive data from participants about the process of immunising in specialist schools. These subthemes are:

1. The importance of a close working relationship between immunisation teams and schools: *"Teamwork is the key"*;
2. *"Being flexible"* in how the immunisation day runs and how and where immunisations are given in specialist schools;
3. The value of persistence and tenacity in immunising young people with disability: *"Never stop trying"*; and
4. The physical and emotional toll of going the extra mile in specialist schools: *"It's hard yakka."*

8.8.1 Teamwork is the key

Teamwork within the immunisation teams was referred to many times as a key factor in a successful immunisation day:

> *We've got a good team and we've all worked together for quite a long time… If somebody says, uh oh!..., you look, and you just stop what you're doing, and you look, and you see what is happening over there. Yes, we are no heroes. We are a team.* (Alana, immunisation nurse)

There was also agreement by Immunisation Nurses that immunisation days in specialist schools were easier to organise, ran smoother and were less stressful when there was a strong relationship between immunisation teams and the schools. Caitlin and Rylee (immunisation nurses) discussed how they *"love coming to [the special school]"* specifically because of the school staff:

> *The staff are so fabulous… So supportive of one another. The staff are just absolutely brilliant. Supportive not only of the kids, but supportive of us as well which is really, really important and that makes it go just so smoothly, even if it is really challenging or confronting like it was first round. We both remarked how it was really challenging but the staff are just so exceptional really, really are exceptional.*

Martha (immunisation nurse) echoed this:

> *I really enjoy going to the local special school. The staff there are fantastic, and I think we have a good relationship with them… I've got a really good relationship with the main sort of admin person and she sets up the appointments and sends all the cards home and follows up with them... And they seem to like us coming, like they don't sort of complain about it.*

Yvonne and Mel (immunisation nurses) had two very different experiences at the specialist schools in their region. They described the relationship between their immunisation team and one of the specialist schools as a very strong partnership, and their relationship with the other specialist school as less than ideal:

> *We find at [one specialist school] that the students are more immobile. But I don't know, it's just a whole different vibe isn't it? There's a lot of staff and the program is really well supported so we do get a lot of support from admin and principals… they usually come with their carer so each student will come with an adult whether they are walking or they are in a wheelchair and so you've got them to liaise with and they're very supportive of their student that they are with, which is in complete contrast to [the other specialist school]…we are sort of unsupported. There might be a carer there, but they are hands off. The students are very mobile and strong, and we don't feel like there is much support from the school as whole in terms of rolling out an immunisation program, so whether people don't believe in immunisation or believe that immunisation has caused issues in these children or there is just an unsaid something… So we get this real contrast of experiences.*

One factor that was noted as helpful in building a relationship with the school was the consistency of staff. When *"it's the same people, like they have been there a long time… it is easy because we've all been doing it a while"* (Peta and John, immunisation nurses). Immunisation Nurse Jordana discussed the importance of *"combined collaboration with the teachers,"* and how this is the key to the success of a session.

The School Immunisation Coordinators reciprocated these thoughts, both of the importance of a working relationship with the immunisation teams, and how this generally evolved over time:

> *It's so often with those nurses we've got to know them over the years and that has been really valuable… we have had really good relationships, as I say, that are built up with the staff and because we've been able to do them in smaller numbers, they often comment "oh this is so different to doing it in a mainstream school" because there is that different relationship.* (Athena, school immunisation coordinator)

In addition, School Immunisation Coordinators expressed appreciation when the Immunisation Nurses understood young people with disability, and were aware of their differing needs:

> *The two nurses that have come are absolutely brilliant. They are so good with the kids and they understand them. One of them has been coming, oh, ever since the program has been running here which is even before I took it over in 2014, so she knows. She knows they've got disabilities and her approach is just brilliant. It's just great. So without them we wouldn't get anywhere near as far as we do.* (Philippa, school immunisation coordinator)

Overwhelmingly therefore, immunisation teams and schools spoke about teamwork as essential to the smooth running of the SBIP, especially in specialist schools. This included the communication between local governments and the schools and a shared understanding of the varying needs of students with disability, which required flexibility. This is discussed in the next subtheme *"being flexible."*

8.8.2 Being flexible

Another aspect of immunisation days discussed both by immunisation teams and School Immunisation Coordinators was the necessity of *"being flexible."* This was recognised by Immunisation Nurses who were experienced in immunising in specialist schools:

> *It can take a lot of time you know, managing backwards and forwards you know, they might come in and out and we basically are looking at each child as individually rather than like just a bit of a train process in that sense.*
> (Peta and John, immunisation nurses)

Jordana (immunisation nurse) discussed not being able to have a definite plan for the day:

> *I think the time spent there, like you know, you can't have a set plan when you go there, well you can, you can have a broad plan, but you just have to allow for someone running off down the corridor and out into the garden and give them time. And you do, sometimes you can spend half an hour with one client and you will eventually get them there, and you can usually immunise them.*

Other immunisation team participants mentioned how they adjust their schedule to fit the needs of students with disability. For instance, Mary (immunisation manager) ensured she scheduled a specialist school on a Thursday, as a parent requested to be present for the immunisation and that was their day off. Yvonne and Mel (immunisation nurses) started the immunisation session at one of the specialist schools they visited later in the morning, after realising that there were many children who did not come to school on time, and Immunisation Nurses Peta and John, as well as Niamh and Lavinia and the nurses in Focus Group 1, all spoke of immunising in classrooms if students were more comfortable there than in the designated immunisation room.

School Immunisation Co-ordinators appreciated when immunisation teams *"read the play pretty well and [are] pretty flexible"* (Mandy, school). In return, however, School Immunisation Coordinators explained they are also flexible in supporting the immunisation teams:

> *We have a lot of problems with getting consents and notes returned ...and we might have a 20% return by the cut-off date, and if they were not flexible with their dates it wouldn't be as successful I don't think in terms of uptake. As it is, because I tend to get notes back and I'm a bit flexible and I just say, "alright give them to me and I'll drive them over after work and drop them*

> *off at [the LGA]" and I do that a lot.* (Mandy, school immunisation coordinator)

For schools, this flexibility is an extension of their role in the lives of their students, particularly with respect to their health care. School Immunisation Coordinator Sarah described this as a necessary, but unrecognised, part of her job:

> *For certain families we most definitely attend appointments with families, either during school hours or occasionally outside of school hours, but that is to ensure that these kids actually get to the appointment… I probably strongly believe there would be many, whether it be at a Departmental level or at a school level that would say "well you prove to me how this helps the kids interface with the National Curriculum. If it doesn't help them interface with the National Curriculum then it is outside our scope." But I would argue, the school in a child's life is a real epicentre of their interaction with the broader community and you know, societal expectations and all those sorts of things, so their health will impact on their ability at some point and some level with being able to access the National Curriculum, so if you don't have that foundation stone sorted then really, you are behind the eight ball before you start.*

Athena (school immunisation coordinator) also discussed student health and wellbeing as a school responsibility by default:

> *Yes it is the whole wellbeing of the child, because often there are no other professionals. Or other professionals may be involved short term but there is no long-term monitoring of these children, and if it is not sort of picked up at the school level then often there is no one else to pick it up.*

This illustrates how specialist school staff go the extra mile in many ways, not just for the SBIP. This appreciation of the link between education and health care, and in particular the value placed on immunisations, also underlies the subtheme *"never stop trying."*

8.8.3 Never stop trying

Both immunisation teams and schools discussed the persistence and tenacity, to *"keep trying… never stop trying"* (Beth, immunisation nurse), that is required to maximise immunisation of students in specialist schools. This is, in part, due to the number of students missing immunisation day due to a high absentee rate in specialist schools, where *"the actual school attendance is so unpredictable"* (Sarah, school immunisation coordinator). Even when students are at school with parental consent for the immunisation, it may not go ahead if students are very anxious or have challenging behaviours, so successful immunisation occurs only after repeated visits, where *"it is just maybe catching that child at the right time on the right day"* (Beth, immunisation nurse). This was illustrated by student Alex in Observation Box 1.

Box 1: Observation from School 2

Students come in in groups of two and three. It is generally calm, with students verbally protesting but sitting on the chair and accepting their snake lolly when immunisations were done. The two nurses have been to the school many times and chat easily with the staff and the students as they come through.

Jason is about the fifth boy to come in, he is small and was crying. He sits down protesting "No!!!"

The door opens, and another boy bounces in with a cheery smile and a teddy under his arm. "This is Alex," says Wendy (nurse). They explain Alex "hasn't quite let us give him his immunisations yet, but we will keep trying." Alex sits by Jason and puts his arm around him during the immunisation "You know what?" he says to Jason, "you are BRAVE".

Alex stays and watches the next two immunisations repeating, "you are BRAVE" to the students as each was done. Wendy turns to Alex "Are you ready to be brave?" Alex jumps up, "Oh god no!" he says and exits out the door.

Wendy turns to the observer and says, "That's good for Alex, we couldn't even get him to come near us last year."

Towards the end of the session Alex makes a reappearance. "Ready now Alex?" Wendy says. Alex shakes his head and hangs back, but then darts to the chair and sits down for a split second. "Come on Alex," says Wendy "you'd make your mum very happy if you had this done." Alex shakes his head again and darts out the door.

Fifteen minutes later all the other immunisations are complete, and the nurses pack up. Just as they are closing the last case Alex comes back in. "I'm ready!!!" he announces. Wendy glances very briefly at the equipment that has just been packed away but doesn't hesitate as she starts to open the case again, "Great Alex, can you sit down?"

Alex jumps back, "No I've changed my mind!!"

Wendy sighs, "Alex you'd make me a very happy woman if we could leave today knowing you had your needle."

Alex disappears out the door. A minute later he is back and holds out the teddy. "Teddy is ready!!"

"Do you want me to give teddy his needle?" says Wendy.

Alex nods and carefully Wendy lies teddy down, holds his arm and immunises him with an empty syringe. Then she places a Band-Aid on teddy's arm and hands him back to Alex. "There, teddy was very brave! Now is it your turn Alex?"

"No!!" says Alex and disappears.

The school immunisation coordinator comes in. Wendy says, "We immunised Alex's teddy but not him. We will try again next time. We will keep trying and eventually he will do it."

Immunisation teams were well aware that *"if we could do more visits we could catch more children"* (Beth, immunisation nurse), and within resource and logistical constraints, they often provided extra visits to specialist schools. They also described catching up adolescent immunisations for young people in specialist schools beyond the scheduled age:

> *We also go the following year, if they've missed their final dose of HPV in year 7, we might do it this year which we certainly wouldn't offer that to any other mainstream schools.* (Jordana, immunisation nurse)

Catching up missed immunisations in specialist schools is resource and time intensive. Martha (immunisation nurse) described the process of determining catch-up and then encouraging follow through:

> *I went and checked all their records and then I sent like individual letters with the appropriate consent cards. So we had a few kids this morning who had missed their third dose of HPV like last year, so I went and checked all the records to see if they had had it or not and then I sent home the HPV card and I would write on it, you know, dose one was given, and dose two was given, only due dose three or whatever, and then I wrote in the letter as well, you know, that we are catching up with some vaccinations that were missed at the end of last year and they only need this one to catch-up with or whatever.*

Apart from the increased workload, immunising young people with disability can also have an emotional toll on Immunisation Nurses who build a relationship with students through multiple attempts at immunisation. Rose (immunisation nurse) emotionally recounted one such experience she had:

> *I reckon I took a card for a kid, I think I took it for three years… we were chasing him in the end for Hep B and the bloody program had finished, [but] I still took a Hep B every time and this child… I said, "shall I stop bringing his card?" …and [the school nurse] said "no, because mum and dad really want him to be immunised and if he needs the immunisation this year we'll immunise him", and I said, "all right" and anyway we did immunise him in the end. We did get his full course in - and he died six months later.*

As a contrast to the general trend to *"keep trying"* to immunise students, Philippa (immunisation nurse) described a time where she refused to keep trying, a decision she made based on the time and resources she had already spent without success:

> *I had one instance where the mum said, "what about next time" and I said "no." She said, "you're refusing?" and I said, "I am refusing. An hour and a half, we got nowhere. If you want your student to have the immunisation you're going to have to take them to the doctor."*

Although there were many examples of immunisation teams refusing to keep trying to immunise an upset student, this was the only example in the data collected of an immunisation team refusing to try again to immunise a student at the next visit. The intensity of immunisation encounters in specialist schools contributes to a significant physical and emotional toll on staff, discussed in the next subtheme.

8.8.4 It's hard yakka

The overall sentiment from both immunisation teams and schools was that school immunisations in specialist schools are not easy: *"It's a really hard day and it's a really hard yakka for everyone to get it done"* (Amy, school immunisation coordinator). For immunisation teams, it can be both physically and emotionally challenging, despite there being far fewer students to immunise in a specialist school as compared to a mainstream school. Moira (immunisation nurse) in Focus Group 2 stated:

> *I always find it wearying… not so much [because of the school], because it is small. There are three or four kids there, but I come away from here feeling physically and emotionally a bit drained.*

Peta (immunisation nurse) found immunising in specialist schools *"daunting,"* and this was also reflected by Maree (immunisation nurse), who explained:

> *I think I probably went there in my first year and I walked out feeling a bit like, oh gosh, shaking, going, "Wow, that's confronting!" But even now sometimes I feel like that too.*

It was unclear from these nurses if it was actually the disabilities of the students that were daunting and confronting, or whether it was the process of immunising young people who may have limited communication and receptive understanding. Caitlin and Rylee (immunisation nurses) also used the word *"confronting,"* but primarily in reference to the experiences of the students:

> *First round definitely it is more confronting for the children, for the students. It is a brand new school for a lot of them and they are very nervous and scared… They were really nervous and really challenged and they challenged us, and yes it was confronting for them.*

Interestingly, Jordana (immunisation nurse) also used the word *"confronting"* but qualified this quickly by stating that despite this feeling:

> *Not one of us has ever walked out of there feeling really upset. We've walked out of there feeling, you know, it's a warm fuzzy feeling, you know, that you walk out and you go, gee, those kids, what they've got going on in their lives it's something that I can't even fathom and where they've come from and what their future is, but right here and now we have given them that little boost maybe.*

Serena (immunisation nurse) was very frank about how difficult she found immunising in specialist schools. This was, in part, due to the threat of physical injury in this environment, but also in relation to the moral distress she experienced:

> *I find the special schools particularly challenging. The physicality of it I find challenging and unfortunately it makes me, I am uncomfortable. I am uncomfortable with the coercion and the restraints and the general setting. The fact that I almost never come out of a special school without being physically hurt… And so I think I come in with the preconceived idea that I*

> *am going to get hurt and I don't know whether that is a good way to come into a school situation.*

School Immunisation Coordinators also described the challenges of school immunisation days, which were managed alongside their regular workload:

> *It is hard work because I actually do my job as well, so I might run to a seizure or I might run back to see where they are up to and try to keep things moving along.* (Amy, school immunisation coordinator)

This was difficult enough for Schools Immunisation Coordinators who were registered nurses and therefore appropriately absorbed the immunisation role, but not all schools had a trained health professional to assume this responsibility. For those schools, where a teacher or admin staff coordinated immunisations, it was considered that this would be even more challenging:

> *So I really think without someone like me [a nurse] to be liaising with the Shire, to be liaising with parents, to have the knowledge to explain the pros, cons and options, I think for a lot of specialist schools this would be very troublesome. It would be really hard.* (Sarah, school immunisation coordinator)

Mandy (school immunisation coordinator) suggested that, like the immunisation teams, school staff can find immunisation day exhausting and stressful. The experience of the day, rather than immunisation uptake, is how she measured success:

> *I think I also would judge success on whether at the end of the day the immunisers and our own teachers and staff are scarred and felt like they needed to go home and drink a bottle of red, or whether they got through the day and you know, it's busy, and it's stressful, and it's a bit crazy, but I think mostly they felt like it was manageable.*

This subtheme illustrates the personal consequences of going the extra mile for immunisation teams and schools. The willingness to do this to administer the SBIP reflects the way in which these groups attempt to support immunisation of students with disability, often in the context where the parents of these young people have many other competing priorities.

8.9 Competing Priorities

The theme of *"competing priorities"* refers largely to parental consent for immunisations and the factors that determine whether this is achieved. This theme focuses on the interaction between three levels of the SEM – the community level of *immunisation teams*, the organisational level of *schools* and the interpersonal level of *parents.* The central finding is that for parents of young people with disability, immunisation has to compete for their attention with many other priorities. This is not only due to the additional needs of their child, but also social stressors. In addition, there are a number of factors that influence consent.

There are three subthemes under this theme:

1. The lower priority immunisation has for parents of young people with disability: *"Not top of their list to worry about"*;
2. The logistical benefits of providing immunisations at school for these families: *"Easier at school"*; and
3. The variety of factors and influences on consent and administration of immunisations in specialist schools: *"Immunisation decisions are complex."*

8.9.1 Not top of their list to worry about

Participants discussed two different types of issues that took precedence over immunisation for families. The first was *"the number of kids that have life threatening things going on all the time. You know, it's just not the top of their list to worry about immunisations"* (Stephanie, parent). In this context, the priority was the all-consuming or very complex health and wellbeing needs of the young person related to their disability. This was discussed by parent participants largely in the context of other families, as all the parent participants interviewed in this study were invested in ensuring their children were up-to-date with immunisations, regardless of their child's medical needs. Despite this, Andy's son had missed immunisations due to significant behavioural challenges, and Andy therefore explained very eloquently why immunisation was currently not a priority:

> *I wouldn't bother thinking about it, because it's hard and hard on him, and if he hates the process, then he just hates the doctor and I don't want that. So basically there is always this, you've always got to try and [leave] certain*

> *doors open to him… He is currently very excited about hospitals and doctors and things. He likes them generally. But if that door slams shut with a bad experience, a frightening experience or pain experience somewhere that is unnecessary, then that will just shut the door to everything… It's that balance between choosing immunisations over maybe something else that you are able to do at the moment.*

The second and more prevalent issue related to prioritising immunisations was discussed by Immunisation Nurses and School Immunisation Coordinators. This was the social context of the families with children in specialist schools:

> *Some of the kids unfortunately come from really complicated social backgrounds and separated families and you know, perhaps parents with disabilities themselves or intellectual disabilities themselves, so it is not a priority. I think in the scheme of all that they've got going on in their life, an immunisation is not a high priority.* (Jordana, immunisation nurse)

Many participants referred to the prevalence of inter-generational disability among families of children in specialist schools. Sarah (school immunisation coordinator) discussed in detail the effect this has on not only immunisation, but on overall student wellbeing:

> *If you've then got that, what I keep talking about, the intergenerational disability, you haven't got proactive parents. You haven't got parents that have sort of worldly experience that make them think "you know what I'm going to go and get myself an OT or I need to go and talk to a doctor about this, this is just not right." So yes it is those kids that aren't immunised, aren't whatever, and is just through, and I say this with respect, it is through ignorance and that's not fair because you don't know what you don't know until somebody tells you that you didn't know it... So I think that is why a lot of our kids sort of aren't part of these programs.*

As well as *"parents with intellectual disabilities,"* several other social issues were listed by Mary (school immunisation coordinator) as reasons for poor consent card return, including: *"Parents who don't read diaries. Limited interest. Parents who have substance abuse issues. [Students] in out of home care."* Fatima (school immunisation coordinator) described consent card return in a school environment with many non-English speaking families as: *"A tad challenging. Many of the families couldn't read the paperwork to start with. A lot of Arabic-speaking families* *where the Mums don't read Arabic or English, so we had some problems there."*

School Immunisation Coordinators were consistent in describing families of students in specialist schools with significant and multiple social disadvantage. The issue of consent in this context was not described as unique to immunisation: "*We have a persistent problem of people not returning forms for anything unless it's got food involved"* (Fatima, school immunisation coordinator).

Following up consent cards added to the School Immunisation Coordinator workload considerably, although this was identified by most as important:

> *I do think that like the follow up contact with parents, whether it is sort of from a constant person or who it is from, but actually checking in with parents who haven't returned forms as to sort of why not? Do you need more support and how can we help you to give you that support? So it is about the relationship between the school and the parent.* (Sarah, school immunisation coordinator)

In response to literacy and language difficulties, one school had trialled Immunisation Nurses coming to the school on parent-teacher night to meet with families and explain the SBIP verbally. This appeared to have some success, with a number of consents completed on the evening. However, other School Immunisation Coordinators felt they lacked the motivation to keep chasing consent cards: *"I probably don't do enough chasing up of [consent cards] which I know they like us to do. I probably don't do enough of that. If they don't come back, we are like - bad luck"* (Amy, school immunisation coordinator).

This subtheme reveals that parental consent for immunisation for young people with disability is very commonly difficult due to practical issues of family organisation. In this context of social disadvantage, it follows that despite this, immunisation at school is often the easiest option for families.

8.9.2 It's easier at school

A consequence of the impact of competing priorities was captured in the subtheme of *"it's easier at school."* This subtheme reflects beliefs expressed about the SBIP:

> *For the parents most of the time it is probably much, probably an easier or a better way for them to actually get the vaccinations done rather than having to get the child to the doctor. Some kids would be different but some kids I*

> *think if they weren't vaccinated here probably wouldn't be vaccinated at all.* (Lavinia, immunisation nurse)

This sentiment was expressed by Immunisation Nurses and Managers, School Immunisation Coordinators and parents. A number of Immunisation Nurses who worked in regions with low socioeconomic profiles linked this to the fact that *"probably about only 20% of them will probably get it outside of school if they've missed it here… if we don't do it then these kids potentially aren't going to have it"* (Jordana, immunisation nurse). Similarly, Philippa (immunisation nurse) said:

> *We are in a fairly low socioeconomic area and a lot of our parents, anything that the school can do is very quickly given to the school to do because it is just too hard. It's too difficult… Parents have learnt that if they do it, it is done. It is done here at school. There is no responsibility. We do all the work. It is done.*

While overall participants were empathetic to the challenges that families of young people in specialist schools were facing, the pressure on immunisation teams and schools to successfully immunise these students led to some frustration. Mandy (school immunisation coordinator) felt the SBIP *"crossed health over with education,"* but that school was nevertheless the best place to give adolescent immunisations because *"if you lived in an ideal world where everybody looked after their children… then I would say no, maybe they should all take them to the clinics themselves, but that is not the reality."* Sharon in Focus Group 1 was quick to state, *"I'm not judging [this] badly [but] it's a school and here they are, virtually doing what a parent should be doing technically."*

Logistically, the SBIP for adolescent immunisation was described as *"easier [for parents]"* (Focus Group 1, immunisation nurses; Niamh and Lavinia, immunisation nurses; Stephanie, parent), *"low hassle"* (Julie, parent) and *"something [parents] don't have to worry about"* (Peta and John, immunisation nurses). Yvonne (immunisation nurse) explained this further:

> *So if they are at school they are well enough to be immunised and it is one less thing for the parents because they no doubt have many appointments to attend as it is, so it is generally one less thing.*

Immunisation Manager Mary was blunter in her statement: *"This is an opportunity for parents to say, 'Oh, let them deal with it', you know, 'At least that way it gets* *done and I don't have to deal with it.'"*

However, a few participants suggested that the low coverage at specialist schools may be because a higher percentage of young people with disability were seeking immunisations at a community provider:

> *I also feel that they are probably in medical facilities or treatments or in regular contact with doctors, and the parents would probably use their GP or that treating physician as their source of information and treatment, and because you don't really know what happens in those clinics either, you just sort of wonder and hope that that is where they are seeking immunisation from.* (Jodie, immunisation manager)

Stephanie (parent) also suggested:

> *I mean also I don't know how well the immunisation register reflects it but there is also a possibility that a number of people are not missed at all, they just spend a lot of time seeing specialists and everything gets done there.*

However, interestingly Stephanie also reflected on the barriers to immunisation at a GP:

> *But is just easier to have it done at school because you know it kind of spoils the relationship with the GP if every time we go to the doctors it becomes about having a vaccination, so we try to avoid doing that as much as possible because we have other reasons we want to go there.*

Some participants expressed doubt that other health professionals were immunising young people with disability: *"I don't think their doctor is doing it"* (John, immunisation nurse). Fiona (immunisation nurse) also highlighted that if a child is difficult to immunise in the school setting they are likely to be difficult in the GP setting:

> *Sometimes parents maybe give up, so that is why we try the best we can because in our team it is probably a better option than maybe if they do go to the doctor, maybe the doctor just throws their hands up and says, "look we can't do it either." Or if the parent maybe can't get them in the car and maybe get them there once they sort of get a sense that that is where they are heading, maybe it is so difficult for the parents. So look there might be a number of factors why that is the case then.*

Sarah (school immunisation coordinator) suggested that in fact it is *"naïve"* to assume young people in specialist schools were linked in with health professionals at all. Although Julie (parent) and Shelley (parent) had discussions about immunisations with their health care providers when their children were young, there was little evidence from participants that health professionals practised opportunistic immunisation in adolescence. As Rose (immunisation nurse) observed: *"There are some children in those facilities that we know go and have routine care or they go and have a general anaesthetic, or they are seen by other clinics, but immunisation is never ever discussed by them seemingly."* Freya (parent) was well linked in with health care and named four paediatric specialists as well as a GP involved in her son's care. However, when asked if any of these health professionals had checked his immunisation status or discussed immunisation in the adolescent years, she replied:

> *It's never really discussed I guess no, never really discussed I don't think. Only if he has been admitted to hospital like as a standard admission question but yes, no I don't think it has ever really been brought up otherwise.*

8.9.3 Immunisation decisions are complex

While the overall sentiment was that for parents of young people with disability, immunisations were not a priority, there was still acknowledgement that immunisation decision-making, and the factors that influence this, are often not straightforward:

> *I think immunisation is one of those complex things. It's not just about actually the medicine and what it does. It's much broader than that. It is about the child, the family, the beliefs of the family and the stress of the child. Yes I think that there is multi layers to the issue of when and how and whether you even do immunise.* (Julie, parent)

Parents named their GP, paediatrician or council nurses as potential sources of information about immunisation, but only Shelley (parent) had actually questioned health professionals about the adolescent immunisations, after early advice not to immunise her daughter due to her underlying medical condition. Despite this, she felt most people made immunisation decisions by *"just talking to people… just randomly almost."* Other parents stated they had had no discussions about the adolescent immunisations, and in fact consented to them with very little information:

> *…there's not a lot of information comes home until after they have had it, you get a bit of paper to say that they have had it, but yes I don't think there was much come home before it. It was just a notice to say that they were having immunisations on that day but yes I don't think it was until after they had the immunisations that we got the information sheet about what it was.* (Freya, parent)

When Kathryn (parent) was asked what she thought about the amount of information she received about school immunisations, she responded:

> *I am happy because most of the time you can tell from what the needle is called, but some of it obviously I had to Google to find out what it was for, but yes I was, I just wanted her protected I guess, and so I didn't question it.*

The parents interviewed all freely offered the information that they supported immunisations, although in doing so recognised the potentially contentious nature of the topic. Andy stated: *"I certainly have no objections you know, I know there is a debate about immunisations but my personal opinion is that it is rubbish. So that's not in the picture."* Other parents described themselves as *"pro-immunisation… a strong believer"* (Lara, parent). Freya (parent) discussed the decision to immunise her children as a *"no-brainer,"* and Shelley (parent) that: *"I just think it's really important, and it upsets me sometimes that people don't see it as important and they don't immunise their children."* The main reason for parents choosing to consent to immunisation was to protect the individual health of their child, who in some cases they believed were more at risk of contracting disease than their peers, due to their disability. As Stephanie (parent) explained:

> *I think [my son] certainly needs to have all the vaccinations available really because he's not too great with his personal hygiene. He seems to touch everything and lick his hands and also you know, he currently goes to school where there are quite a number of immunosuppressed children so also it is very hard to tell when he is ill at any time until it is fairly serious, unless there are obvious symptoms.*

Other reasons for immunisation acceptance was to protect others. This referred to the local cohort, where *"being a lot more thorough and diligent [about immunisations], everybody would probably be helpful particularly and you know medically fragile school situations, it doesn't help for anyone to get the flu or anything"* (Stephanie, parent), as well as a wider sense of responsibility: *"what we do as part of our society for [our own] health and protection [is for] of all of our society"* (Julie, parent).

While the parents in the study acknowledged their child's feelings about immunisation, they viewed the decisions about immunisation as their responsibility:

> *There are some things as a parent that you do make non-negotiable. Sometimes that is tricky when they are in their adolescence and they have a mind of their own, but he probably understands more than most what happens when you get sick and how terrible that can be… I sort of explain to him and he says, "Oh do I have to" and as I say, "Well have one needle now or you can contract it and get a thousand needles. What would you prefer?" And of course he will always say, "I think I might just have the one," so yes.* (Lara, parent)

Despite the generally positive attitude towards immunisation, there was some reluctance among parents to discuss thoughts about specific vaccines, unless specifically questioned. During interviews, parents were vague about what the adolescent vaccines were, and for which diseases they offered protection.

However, one parent, with probing, differentiated the decision about consenting to the HPV vaccine based on her knowledge of HPV transmission. This parent, Stephanie, initially declared that her son was fully vaccinated, stating: *"We would really prefer to have him immunised against everything possible."* However, when the Researcher questioned Stephanie further, she corrected herself:

> *The HPV is the only one that he hasn't had… We didn't give him that simply because it is quite difficult to give him vaccinations and we thought with a severe intellectual disability there really wasn't anything particularly riskful… There would have to be an abusive situation, but it is pretty unlikely.*

Other parents consented to HPV simply because: *"it's another thing ticked off,"* although they expressed that they would *"hope that my daughter is never a sexually active person"* (Julie, parent). However, Julie felt that many parents of young people with disability would be reluctant to consent to HPV due to their belief that their child would be unlikely to be sexually active due to their disability:

> *I know the figures around abuse and I hope that it never happens, but again that is probably why I would just say yes, just let's tick that box anyway, but*

> *you know a lot of people cope with these by saying… I am putting that out of my mind, that is never going to happen. They couldn't bear to think about the possibility of abuse. It is easier just not to even put it on the radar and so therefore yes, maybe it is to them a non-event.*

School Immunisation Coordinators and Immunisation Nurses also discussed this view of the HPV vaccine:

> *Sometimes the parents might not see the, that they need it. They believe [these young people] are somehow protected because of their disability, that they won't be in contact with these viruses and these other things.* (Clare, immunisation nurse)

However, actual examples of HPV not being given to or consented for young people with disability due to concerns about this particular vaccine were described as small in number. Anna (school immunisation coordinator) stated: *"I would have had… two or three parents of girls who don't want them to have HPV because they believe that their children will never be sexually active I guess."* Athena (school immunisation coordinators) denied any widespread hesitancy about the relevance of the HPV: *"We might have one or two [who are hesitant] but that has been more isolated cases than a general trend."*

More concerning were personal views about the relevance of HPV for young people with disability from Immunisation Nurses. Kasey, a nurse from Focus Group 1, said:

> *I think, you know, if one of my children was that disabled you would think why? Why am I putting them through this? Yes I would do flu and Boostrix [dTPa] but I probably wouldn't do HPV either.*

Other participants in this Focus Group voiced general agreement to this statement. A similar thought process led Amy (school immunisation coordinators) to explain the rationale of prioritising dTPa over HPV:

> *With some of our really complex needs kids I really probably don't think the HPV is as important for those kids… With the tetanus it needs to be done. It is a good one to have done and we sort of encourage that if you are going to have one have that one done.*

Although less prevalent in interviews, some School Immunisation Coordinators and Immunisation Nurses commented about parental concerns about a connection between autism and immunisation. However, this was not specific. Jane (school immunisation coordinator) said:

> *There was all that negative press years ago about, you know, immunisation causing autism which is a bit of an interesting scenario because we work in a special school and obviously some of our students do have autism, so I don't know whether there's like that indirect link in people's minds about their either.*

However, when asked if she had any concerns or questions directly from parents about immunisations and autism, Jane stated she had none. Other school and health providers also reported very few, if any, questions or concerns of any type raised by parents. Caitlin (Focus Group 2, immunisation nurse) said: *"So I am the Acting Clinical Coordinator so no, I never get a phone call from a parent. No I have never had a phone call."* This was echoed by Yvonne and Mel (immunisation nurses), Sarah (school immunisation coordinator) and Fiona (immunisation nurse), who qualified this by saying: *"Look it's a bit hard to know because I suppose we haven't delved really and asked the parents if they've got concerns."*

There was agreement, however, about the powerful role of the media in immunisation decision-making. The examples raised in interviews were in regard to the influenza vaccine, which is offered at some specialist schools through the SBIP, and the Men ACWY vaccine, which has been available through the SBIP in Victoria since 2018. Mandy (school immunisation coordinator) discussed this immunisation:

> *We actually had the most ever consents for [flu] immunisations than we've ever had, so we immunised more people that day than we've ever done before, so it has been quite successful in getting some consents this year and I think that is part and parcel with the 60 Minutes program that came on, because where we the consents petered off and then all of a sudden that program went on and all of a sudden I had all these people saying, "I've lost my consent form but I'd like my child to be immunised."*

Amy (school immunisation coordinator) agreed: *"Usually you know most people take [the MenACYW vaccine] up because there have been a lot of things in the media and all that sort of stuff… I think that is probably the most uptake only because of the media."*

Therefore, there are a number of influences on immunisation decision-making. Nevertheless, there is very little evidence that parents of young people with disability are discussing adolescent immunisation with health professionals, although they identify these professionals as their trusted support. The role young people with disability have in decision-making about their immunisations is even less clear. At times, schools and immunisation providers may concentrate on administering vaccines at the expense of student autonomy. This is discussed in the next theme *"trust takes time."*

8.10 Trust Takes Time

The theme of "*trust takes time*" encapsulates the role of the student on immunisation day, the agency they have, and the ethical issues that arise in balancing the importance of immunisation with the autonomy of the child. This theme focuses on the interaction between four levels of the SEM – the community level of *immunisation teams*, the organisational level of *schools,* the interpersonal level of *parents* and the individual level of *students*. The success of the SBIP is optimised by trust between all these groups - immunisation and school staff and parents and school staff and immunisers. However the central finding in this theme is that enabling students with disability to have a voice in the process of immunisation requires the students' trust, which takes time and resources. Yvonne and Mel (immunisation nurses) explained how spending time gaining the student's trust is in the best interests of the child:

> *If the child is compliant or amiable and will let us sit and talk with them and you can gain their trust, then I don't think it is highly traumatic for them either because it's just like a small blip in their day and they can continue on going to swimming or whatever.*

However, not all students with disability can be immunised in the school setting, even with time and resources, without considerable distress to all involved.

There are four subthemes within this theme:

1. The key role of someone present who the student trusts to reduce anxiety and promote student agency in the immunisation process: *"A familiar face helps"*;
2. The difficulties of explaining the vaccination process and rationale to young people with disability: *"We can't prepare them properly"*;

3. The manifestations of anxiety in young people with disability on immunisation day, which can lead to unpredictable behaviour and significant safety considerations: *"Anything could happen"*; and
4. The ethical dilemma of immunising students with disability without their assent, and the lack of clarity about issues of holding and restraint: *"Crossing the line."*

8.10.1 A familiar face helps

School and immunisation team participants recognised how important it is to have someone known and trusted by the student with them during immunisations; that *"a familiar face helps"* (Focus Group 2, immunisation nurses). This was the most frequently mentioned factor discussed as helpful for students with disability on immunisation day. Jane (school immunisation coordinator) talked about the *"norm"* being *"the classroom teacher will actually go in with them as a support person [to] just alleviate their fears."* Similarly, Philippa (school immunisation coordinator) insisted on the student's aide being present, as they were the ones that have *"built up a little bit of a rapport."* School observations illustrated the supportive role of a known adult with the young person. This included sharing the student's individual likes and dislikes with the immunisation team, engaging in conversation about activities to distract the student, and providing constant encouraging and supportive comments to the student throughout the process. This was targeted at the student's cognitive level. In School 9, the School Immunisation Coordinator, Karen, illustrated this with student Macy in Box 2.

Box 2: School Observation from School 9

Karen brings Macy into the immunisation room, keeping up a steady stream of conversation about her recent birthday. Macy interrupts as she sits down.

Macy: "Does it sting?"

Karen: "Did it sting last time?"

Macy: "Yes really bad."

Karen: "Did it go away?"

Macy nods.

Karen: "So it may sting this time, but you know it goes away."

Students also provided support for each other, which was again apparent in school observations. Martha (immunisation nurse) reflected: *"One girl who was a bit anxious in the group of four and all the other girls were, you know, encouraging her and talking to her and trying to make her laugh."* Caitlin and Rylee (immunisation nurses) further discussed this support:

> *It is worth commenting, and it wasn't so obvious as some of the years, but you do see it that these kids are really supportive of each other… Incredibly supportive of each other. Will hug each other. Will cheer each other on and just, "You're alright Jack, you're alright." They're very supportive of one another, very, very supportive and it doesn't… it doesn't actually faze them if they see somebody not coping. It doesn't faze them at all. They are like that, very supportive.*

Immunisation Nurses were well aware of the level of student anxiety on immunisation day, and appreciated it when school staff known to the student were present. As Fiona (immunisation nurse) explained:

> *We don't know the background of these students and we don't really understand what triggers their behaviour and their response under stress. So of course what they are confronting is that they have got a stranger who they don't know, and suddenly they start to get panicky. And look, they have got their teachers there often with them but sometimes they stand back and we are, you know, trying to sort of talk to the student ourselves. But we often bring their carer in or somebody who is their support person to make sure that they are there and they can help us calm them or give them ideas you know, get ideas that may help them cooperate with us too.*

Student agency in the immunisation process was optimised with the assistance of staff familiar to the child, as well as giving students time and space:

> *Sometimes… they will say, "No, no, no" and you will say "Ok would like some time to think about it?" which we would never do to the mainstream kids… some of them [go] away, they process, they talk about it with their teacher and you sort of see them hovering and coming back and you go "Are you ready now?" and often they will come down quite calmly and do it, but like that could be half an hour later sometimes, which is they've got to do it in their own time.* (Jordana, immunisation nurse)

Rose (immunisation nurse) also emphasised the importance of giving students time and the importance of also trusting school staff to lead the way in terms of managing student anxiety:

> *We work with [school staff] to try and make sure that the students are in an area that they are most comfortable with, particularly with the senior students, and we take our time. We never rush them. If they need half an hour to talk someone down then half an hour it is.*

Knowledge of individual students also meant that school staff often took the lead in determining student assent, and when to keep trying to immunise and when to stop:

> *I suppose because we also know our kids you just know when it is too much, and it might probably to an outsider seem like, "Well they could have just been a bit more insistent" but it's like we know their no. You just know when it's like nope. You can't do this. This is going to be too distressing… Don't. Don't push him.* (Sarah, school immunisation coordinator)

Immunisation teams and School Immunisation Coordinators spoke of occasions when parents would elect, or were asked to come to the school for their child's immunisation. Opinions on parent presence varied. Amy (school immunisation coordinator) said, *"…if the parent is there it's far more successful."* Similarly, the Immunisation Nurses in Focus Group 1 discussed how *"…it would be nice for some children to have their parent there,"* but they weren't sure if the schools were open to this. However, Rose (immunisation nurse) was unsure about whether parental presence was always helpful:

> *Is it useful? If the child is happy to have their vaccine done and they want their mum there that is ok with us, but in the case with [today] where the kid just got more and more aggressive because dad was going to hold him… Sometimes they are helpful, sometimes they're not. It's really dependent on the situation and the child really, but I don't think on a whole, I don't really think it makes terribly much difference.*

Mandy (immunisation nurse) agreed the benefit of parental presence varied:

> *Frankie's mum had already organised with me the day before that could Frankie be done first up as she will sit with him at drop-off… And I said yes so he was done first up and that took lots of convincing and chocolate bribes and things from mum to get him to do it, so for him that worked. But I don't think, I think that is individual. I don't think that would work for every*

> *student. I think some parents wouldn't probably – I think they might upset them more than anything.*

Beth (immunisation nurse) was greatly concerned by the detrimental effects of too many people around the students trying to support them during immunisation. She had noted a calmer environment in the non-mainstream schools when the number of people in the immunisation room was kept to a minimum:

> *We have found that over the last two years, that the less nurses we send in the better. Because there is an issue with people, too many people around the child. That is my opinion personally and I think we get on a lot better when there is fewer people around the child. They just get overwhelmed with having a needle and then about five or six people around them trying to persuade them to have the needle.*

Clare (immunisation nurse) also mentioned the need to balance supportive talk with a calm environment:

> *I tend not to talk too much and just let one person talk if there is two of us there because they just find it confusing, whereas in a normal school you'd be both talking at the one time and it doesn't really matter.*

The negative effects of many people attempting to support students at once were evident in the school observations. At School 1, as described in Box 3, a situation unfolded when Mary was immunising students and another student, Ben, came in with two aides.

Box 3: Observation from School 1

Ben calls out "No! Not fair!" as he enters the room. Mary checks the student details with an aide.

The aide sits Ben on the chair, "Can you hold my hand? Squeeze hard!"

The second aide holds Ben's face. This agitates Ben more: "Stop holding my face, let go!" Ben pulls the aide's hand away. Ben slides down in the chair yelling and kicking.

There are several attempts by Mary and the other nurse Lisa to get close to Ben while the aides hold his arms. Both aides and both nurses are talking at once, trying to calm Ben down and encourage him.

Ben screams "No! Get off me!" He is distressed and ends up sitting on the ground.

> *Finally, the immunisation is given with Ben sitting on the ground squirming and yelling. Ben rips his Band-Aids off and runs out of the room.*
>
> *Mary is flustered and fanning herself as she stands up. She comments that she "hates doing it like that."*

Therefore, while there was general agreement that a support person known to the student is helpful, too many people offering support at the one time can overwhelm the student and add to their anxiety. Anxiety can be compounded by a lack of understanding of what is happening, but the need to lessen anxiety also emerged as one of the main reasons why students were frequently unprepared for immunisations.

8.10.2 We can't prepare them properly

The second subtheme is concerned with the challenges in adequately preparing students with disability with information about immunisations. There were two broad reasons expressed for this minimal preparation of students for immunisation day. The first was the complexity of explaining immunisations in the context of student difficulties with cognition and understanding. Although Fatima (school immunisation coordinator) had extensive experience in special education, she highlighted this as the most problematic aspect of the SBIP:

> *How do you tell a child who can't talk, is maybe working at a toddler level, like how do you tell a baby they're going to have a vaccination? You can't. But these kids are a lot bigger. So it was difficult that we couldn't prepare them properly.*

Fiona (immunisation nurse) disagreed with this sentiment:

> *I think even if they're non-verbal, if they are able to understand, even if it is with sign language, but maybe we do have somebody that is able to let the child know… if they are partially deaf or something and they do need to have something more visual supplied, maybe that might be helpful as well.*

There was general agreement that any preparation needed to be individualised for the student's cognitive level and communication method, and that the school was responsible for any immunisation education given. Certainly, immunisation teams were reliant on the preparation of students by the school. They met students first during the immunisation process, and were generally unsure about the information the students had received about what was happening:

> *I don't know whether they tell the kids that that's what they're having tomorrow. I don't know how much they give them warning. I think it is more like we turn up on the day and they say, "Come on kids it's time to have your immunisations today."* (Jordana, immunisation nurse)

A clear example of the difficulties of tailoring information to a range of cognitive levels was observed at School 10. An older student, Fred, came in for the Men ACWY vaccine and asked the nurse what the immunisation was for. She replied, *"It protects the lining of the brain."* Then realising perhaps that this was difficult for the student to comprehend, she said, *"It stops you getting headaches."* Fred looked even more confused and said, *"But I don't get any headaches."*

Parents also trusted that the school assisted with preparing their child. Freya (parent) said: *"I would assume that they would give the kids some sort of basic explanation of why they were having them done. You would hope so."* This is despite the fact that parents acknowledged the difficulty in preparing their children with cognitive difficulties for immunisation. Stephanie said: *"We are not really sure that he would understand if it was explained much further ahead about or might get distressed, misunderstanding what we are talking about."* Shelley (parent) summarised her experience of preparing her daughter for immunisations: *"I don't know how much she really took in. We couldn't really prepare her."*

The second reason for a lack of information and preparation for students was in order to minimise student distress. School Immunisation Coordinators reported that generally only basic information about immunisation was given to students, for fear of increasing anxiety:

> *I find with our kids the less they know on immunisation day the better. So the first they realise is they come up here and they kind of get a bit "Oh!" So because most of our students will have some form of anxiety, so the more time that they have to think about it, the worse it is.* (Jane, school immunisation coordinator)

Anna (school immunisation coordinator) gave an example of the typical information relayed to students: *"I will explain to them that they are going for a health thing. It's a needle and that it will hurt for a minute, and then it will be over."* Other explanations incorporated *"permission"* from the parent, such as were observed at School 7: *"Mum said, and your doctor said, you have to drink lots of water and you* *have to have your shots"* and "*Rosie, you're going to have a little needle for the flu, mummy said you had to have it. It will be very quick."* During observations, it was apparent that some schools gave no information to students, but rather focused on incentives or other encouragements, such as *"If you do this then you can have a jelly snake"* (Observation, School 1); or *"Come on Sarah, let's get it done, you're not going to let these boys think you're not a brave as them, are you?"* (Observation, School 9). There were a few incidents of school staff threatening withdrawal of activities, such as horse riding or swimming, if the student refused the vaccine, and a common warning used was *"We'll have to tell mum"* (Observation, School 1). At School 8, one teacher admonished noisy students, who were waiting for their immunisations, by inappropriately joking: *"You were going to get an injection, now you'll get the lethal injection!"*

In terms of resources, Amy (school immunisation coordinator) reported there were social stories about immunisation available at her specialist school, but she was unsure whether class teachers actually used them. Similarly, Philippa (school immunisation coordinator) considered it was the class teachers' responsibility to determine how and whether to tell students about immunisation:

> *They know the students. Sometimes it works in your favour to tell them and other times, oh no, it is a definite no-no. Because the kids just get too hyped and they get too agitated and everything else and we end up with, you know, having problems and we don't want to upset the kids and everything else.*

Andy (parent), whose son had extreme behavioural manifestations of anxiety, agreed that limiting information about approaching immunisations would be best for his son: *"I wouldn't pre-prepare him much. I would keep it very simple because I really don't want a big fury response before we even get there."* The reference to *"a big fury response"* illustrates the potential for difficult and dangerous behaviour from anxious students, and the concern that if anxiety levels were too high among students, *"anything could happen."*

8.10.3 Anything could happen

An aspect discussed by immunisation teams, which was unique to their experience in specialist schools, was the unpredictability of the students. This was particularly in reference to young people with intellectual disability who were put in this unfamiliar situation. Immunisation team participants described the need for increased vigilance concerning their surroundings in specialist schools, where *"anything could happen. You don't really know until the needle goes in, what they're capable of doing"* (Maree, immunisation nurse). Maree continued to describe how this affected her own level of anxiety:

> *I suppose I have been in the special schools, I have been uncomfortable in a couple of situations when it's a really large, strong-looking child, yes. And especially if [there] hasn't been a big, male teacher holding them down, then yes, I suppose I have felt a bit unsure, a bit uncertain, a bit concerned… those other couple of kids, they just look too scary to even really try to go near, particularly that girl. Gosh, you just see anything potentially happening to us nurses. I think it's just that defiance or just that lack of whatever, they're mentally not functioning as well as others.*

The physical size of secondary school students was a frequently mentioned concern in the Immunisation Nurse interviews. The Immunisation Nurses in Focus Group 1 explained that they were used to immunising very young children with limited capacity to understand what was happening, but the size, strength and unpredictability of the secondary students with disability made them particularly nervous. Beth (immunisation nurse) and Mel (immunisation nurse) also mentioned student size and strength as safety considerations.

Fiona (immunisation nurse) described the potential risks of immunising in specialist schools, and the need for a heightened awareness of staff safety:

> *We have to be very on the ball. We have to try and tune in and be very careful because if they suddenly do jump up or they decide to push their arm away then we will be right in the line of fire, so it will either cause a scratch on their arm if they have suddenly jerked or the needle can potentially go into us… I will see somebody who I can tell is going to be difficult and it does go through my mind – is this going to be too dangerous? And the potential of what could happen. If somebody does kick out, you could get injured and yes, they would be ready with their fists if they wanted to get away from you and they were scared. So yes, it's the unpredictable nature of it for sure.*

There were several references to actual harm being caused by students in specialist schools. Serena (immunisation nurse) talked of *"being quite hurt over the years"* and

Yvonne (immunisation nurse) said she had been *"headbutted at a specialist school."* Rowena (immunisation nurse) shared a particular incidence of violence that was a near miss in causing harm:

> *There is one kid I do recall clearly who grabbed the nearest thing after we'd injected him. I don't remember what it was but [it was] something like a stapler and hacked it at us. Now we were just really lucky that we can move. But he was only Year 7 at that stage, but he was a big strong boy who just didn't have the mental capacity [for us] to explain what we were going to do, and his response was violence.*

School Immunisation Co-ordinators were more matter-of-fact about the risk of injury. Although Philippa (school immunisation coordinators) said she had been *"pinched"* and *"hit"* during immunisations, she qualified this by describing those incidents as *"nothing substantial."* In one case the mismatch of risk assessment impacted on development of trust between immunisation nurses and the school to the point where the SBIP was ceased. Fatima was the School Immunisation Co-ordinator of this school that had recently recommenced participating in the SBIP after five years. When asked why the program was initially stopped, she explained how a nurse was hurt and suggested that Immunisation Nurses should be more prepared for students with disability:

> Fatima: *One of the nurses got kicked.*
>
> Researcher: *One of the nurses from the Council got kicked?*
>
> Fatima: *Yeah. So if you come to a special school, you've got to expect something different and I don't think they had even thought about what might… what might happen.*

Parent participants, who had children with a tendency to cause harm when stressed, had no such expectation that school staff or immunisation teams should put themselves at risk to immunise their child. Andy stated: *"I don't expect the local Council to be able to cope with, you know, someone who swings an arm out and smacks them in the head when they're trying to put a needle in someone."* In a similar discussion about immunising her son at her GP, after attempts to immunise through the SBIP were abandoned due to safety concerns, Stephanie (parent) explained:

> *The staff at the doctors are really not, when you are dealing with complicated kids, they are really not capable of doing it. They don't know how quickly he moves and what kind of way he tends to move and so on, so they end up getting kicked or hit or something.*

As happened with Stephanie's son, efforts to mitigate risk of harm to staff in the SBIP primarily involved deciding not to immunise at school. Alana (immunisation nurse) explained that if *"the nurses are going to be at risk doing the immunisations, we withdraw and just don't do it."* Similarly, Fiona (immunisation nurse) stated: *"[When] we do sense that the person is definitely not going to cooperate, then we decide not to do it."* The choice not to proceed due to safety concerns was described as a joint decision between the school and the immunisation team. Rose (immunisation nurse) explained: *"If the child is really throwing themselves around, we won't progress. We won't proceed. It is not something that sits well with us, and then usually we are guided by the school."*

Another safety consideration involved the set-up of the room. Most participants agreed that if a student was upset and attempted to leave the immunisation room, the safest option was to let them go, and participants spoke of having an easy exit route for students to avoid confrontation. Amelia (immunisation nurse, Focus Group 1) explained:

> *When you sort of talk about safety, I like staff rooms, there was always an exit as well, so if things were going, or they just needed some time out. Like you know, if you want to get out just for a little calm the child down so then they can walk out of the room. So it's always good to have I reckon exit points.*

This was also evident during school observations where typically the immunisation team set up the room with the chair where the students sat facing a door with the immunisation equipment behind. The nurses explained how this was a deliberate practice to ensure they were never between the child and an escape route. However, at odds with this practice was Alana's (immunisation nurse) description of the immunisation space in the specialist school in her region, which had *"a high lock, a high door handle… so the child can't leave the area."* She described this as students being *"appropriately carolled"* for their own safety, and explained that the set up was established after a student scaled a tree when faced with immunisation. This restriction on student's freedom in order to safely complete immunisations is discussed in the next subtheme *"crossing the line."*

8.10.4 Crossing the line

The challenges facing immunisation teams and specialist schools in immunising young people with disability, combined with the awareness that for many students school is the only place immunisation occurs, resulted in significant pressure to *"do what we have to do."*. This tension was described by Mary (immunisation manager): *"It's almost sometimes you feel like you're crossing that line."*

The weight placed on consent or assent from the student for the immunisation was varied. Anna (school immunisation coordinator) said:

> *My practice is I don't do it against their wish. If they are not looking like they are physically consenting to it, like some kids come in scared obviously, but you can coax them through with normal level of support I guess. I wouldn't come at a child that was saying "No!" and crying and I wouldn't let them immunise them.*

Similarly, Alana (immunisation nurse) explained: *"We have to respect their wishes. If they really don't want it, sorry that's it, we don't do it."*

The value of student assent in some schools is illustrated in the observation in Box 4.

Box 4: Observation from School 1

Anna comes in crying and pulling back at the door. Lisa (nurse) asks, "Do you want me to get mum?" Mum is in the car outside in case she is needed. Lisa guides Anna to the chair but Anna refuses, has her back against the wall. She says, "It's going to hurt."

Mum comes in, a small woman with a big smile. Anna runs to her for a hug saying, "I don't want it, it's going to hurt!" Mum tells her that her brother is also having a needle today and that he is going to be brave. She sits Anna on her knee, but Anna jumps up. Mum says, "Anna you have to have it done, do you want to sit on my knee?" Anna refuses, she is sobbing and incoherent.

Lisa: "Anna we need you to sit down, we can't chase you around the room."

Mum: "Mum just wants to give you a cuddle, calm down, take a few breaths."

Anna breathes in and out to mum's guidance and sits on her knee. "It's *going to be sharp."*

Lisa: "it will be so quick"

Anna stands up then sits down: "Is it only one arm?"

Lisa: "One in each at the same time."

Anna breathes slowly then faster and starts moaning. Lisa rolls her sleeve up and Anna starts sobbing. "It's going to hurt. I want to go home"

Lisa: "You are going home after this."

Anna: "OK."

Lisa: "Did you say OK?"

Anna: "Yes."

Lisa: "Good girl."

Anna: "Is it going to bleed?

Lisa: "Not always, sometimes. Can we get it done?"

Anna: "Yes."

In Box 5, another observation in the same school illustrates clear student refusal, which was accepted by the immunisation team.

Box 5: Observation from School 1

Jasmine enters with three aides.

Jasmine: "Do I have to have this done?"

Jasmine sits down and the nurse, Lisa, offers a snake. Jasmine shakes her head.

An aide holds Jasmine's hands: "It doesn't hurt."

Jasmine: "It will hurt!!"

The aide takes a breath: "Only for three seconds then a snake."

Jasmine: "I don't like snakes!!" Jasmine pulls her arm away and sits forward crouching in her chair. "No," she says, shaking her head.

All the staff wait, one aide squats beside her, the other two stand with their arms folded. Jasmine: "No! Forget it!"

Lisa is standing back: "What were you doing this morning Jasmine, I heard you were baking Anzac biscuits?"

Jasmine nods and then with some prompting talks a little about baking.

Lisa chats with Jasmine for a few minutes then says, "Ok we need to make a decision Jasmine, we either need to do the needle or it's someone else's turn."

Jasmine shakes her head vigorously "No! It's not happening."

Lisa says "OK" and allows Jasmine to leave.

In contrast, Philippa (school immunisation coordinator) was clear that it was parent consent, not student assent, that mattered, and if a parent had given consent, then it was quite appropriate to give an immunisation to a student with a disability who was protesting. She said: *"And most of the parents who will then say… well ok, we will do what we need to do. I want them to have the injection. You and I will do what we need to do. That's fine with me."* This was also illustrated in an observation at School 5, where parent consent, not student assent, was the focus. Nurse immunisers and school staff decided *"a sneak up approach"* in the classroom would be best for Gareth, a student who refused immunisation clearly in the immunisation room.

"Doing what we need to do" in many school immunisation sessions also included some level of restraint of the student. This varied between schools. Some had a strict *"hands-off"* policy (Trish, school immunisation coordinator) that was enforced in all situations, including immunisations. Sarah (school immunisation coordinator) explained:

> *No we don't hold any of our children. Our policy is no. So you can guide kids, so you know, just like with gentle touch to say ok, you need to sit down here. So you might gesture first and then you might place a hand on their back so that they know that they have got to actually sit on this chair, and those sorts of things. But yes we wouldn't ever like restrain a child.*

In contrast, at School 6, immunisation nurses commonly asked aides accompanying the student to sit them on their knee to keep the young person still. Although there was hesitation from some, all the aides did as requested. Halfway through the immunisations, the Immunisation Nurse, Jan, turned to the Researcher and mused: *"I wonder what their restrictions are? Are they allowed to sit kids on their knee?"* However, at no point was this clarified with the school staff.

At School 5, sitting students on a school staff member's knee to *"cuddle"* them during immunisation was also common practice. In this case, it was the school immunisation coordinator who remarked to the Researcher: *"You have to be careful when sitting students on your lap, as it's not politically correct… but how do you do it otherwise?"*

Fiona (immunisation nurse) described a variety of other restraining techniques used in schools where she immunised:

> *The level of holding? It's just the sometimes we might stand up and lean in to them so that they are a little bit less likely to have the room to move. So we put one arm behind that person's back as they are standing and so that's one arm out of the way, and then the other hand is around the lower part of where the elbow is securing that area there. And somebody hopefully is holding their hand as well.*

Fiona continued to describe a clear line that should not be crossed:

> *We have to be very careful that we don't overstep the line, that we are not attacking or restraining beyond what would be seen as a reasonable firm hold, because then it goes on to being a pull or more of a forceful technique. So I think you've just got to get that fine line, that you don't overstep that line.*

Restraint, in the guise of *"procedural holding,"* was justified by Immunisation Nurses Yvonne and Mel with reference to the potential cognitive age of the students: *"We use procedural holding on one-year olds, eighteen-month olds. They have no choice because they don't understand. It's almost the same thing."*

Rita, an Immunisation Nurse in Focus Group 1, reflected that restraining young people for immunisation was happening less, and that it had *"changed over the twenty years… because we would chase them around. We were told you have to… But now we don't."* However, another nurse in Focus Group 1, Lee, negated this somewhat when she interjected:

> *And it's not as many luckily, and that does feel more traumatic, and they will get quite a monkey grip on them if they think they are going to… We have had them lying on the ground …but luckily it's not as often because it is distressing for us and it is distressing for the child.*

Although not common, observation of school sessions revealed several incidents of a student being held on the ground. Generally, this was a result of the student struggling and ending up on the ground, where they would then be immunised. This was observed in the case of Luke at School 5, as described in Box 6.

Box 6: Observation from School 5

Luke comes in and stands at the doorway. He doesn't speak or make eye contact with anyone and looks at the floor. He has headphones over his ears.

As the nurses come towards him, he starts crying then yelling and starts backing towards the door. Belinda closes it. "Come on Luke, sit down."

Luke starts thrashing, his back is against the wall and three nurses and Belinda, the School Immunisation Coordinator, surround him. Nurse Di starts taking his jumper off: "I have to take his headphones off I think." Luke's headphones are taken off and he screams louder, a high pitched scream that echoes in the room. The nurses are trying to reassure him, talking over one another: "It's ok"; "Cuddle me"; "Sit down."

Two of the nurses hold Luke's arms and he drops to the floor and ends up on his back kicking and screaming. He is held steady as the immunisation is done on the floor.

After Luke is escorted out, one of the nurses comments: "In the end, we could give it because he was nice and still. He succumbed."

However, the most distressing incident was the immunisation of Flynn, a 13-year-old boy with severe intellectual disability, which was achieved through the use of planned restraint between school staff, immunisation nurses and Flynn's parents. This is described in Box 7.

Box 7: Observation from School 7

Flynn is a tall boy who is non-verbal. He comes in with both parents and a male aide, and towers above his mother who is a slight woman. He comes halfway into the room and sees the nurses and refuses to come towards the immunisation area. The two nurses then move towards him. He yells and thrashes and kicks out. His parents, the aide and Rhonda, the School Immunisation Coordinator, surround him and are trying to calm him. "Do we need to take him down?" asks Rhonda. There is general agreement. "Ok let's take his legs. Flynn we are just going to lie you on the floor."

Flynn's legs are lifted and yelling, kicking and hitting out he is laid on the floor amongst the desks with his arms and legs held down. Flynn's mother is lying on top of his body and Flynn jerks his head up and bites mum's shoulder, "Ow" she yells, "It's ok. Just do it."

The immunisations are given, one at a time with Flynn on the ground. Mum is crying, "I'm sorry Flynn, it has to happen, it's important."

When the immunisations are done, Flynn is helped to his feet and mum gives him a cuddle "I'm so sorry Flynn."

Mandy (school immunisation coordinator) explained the thought process that enables those involved to fit this type of practice into allowable restraint according to the DET policy[239]:

> *[DET] write a blanket policy in terms of schooling and saying well, in school and for education you don't restrain a student and I agree with that, but I don't think they take into account immunisation as being part of that …I actually think that there is always exceptions and I think that that is one of them, and I think, you know, there is certainly restraining having to go on when we have a student abscond and race out onto the road. We are not going to say, "Oh we have a no restraint policy so go for your life." So I think that health, which would be if they abscond and they put themselves at risk, would be an exception. And I would think that immunisation, I don't know whether they would see it as an exception, but I think it should be. Our students are very vulnerable in terms of flu, especially kids with cerebral palsy and chronic lung conditions. I think if they make it a no restraint policy for immunisation, and if they saw what we do and say that that is restraint, my inkling would be to say to [the principal], "Let's abandon the project then because there will be no point."*

Description of who was, or would be, responsible for restraining a student also varied. Mary (immunisation manager) suggested she was *"more comfortable with a teacher involved."* Maree (immunisation nurse) agreed if a student needed to be held, it would be by a school staff member: *"Look, to be honest, I really would prefer not to have to restrain them, but it's never actually come to that because there's always a teacher that would do it."*

Schools Immunisation Coordinators and Immunisation Nurses were generally more comfortable with holding a student if the parents were present, and certainly if parents were providing the restraint, to the point where at times, parental permission to restrain a student appeared to absolve staff of responsibility:

> *I feel that if they need more restraint than that, we would never ever sit on anybody or provide extreme pressure, only because they are not with their parent and we will do and hold as the parent guides us when the parent is present there. Because if they really want us to get it done, then they may get further staff in to maybe secure that person, but with the parent's permission.* (Fiona, immunisation nurse)

Interestingly, Stephanie and Andy, the two parents who had children difficult to immunise because of their behaviour, expected and accepted restraint would be used. Stephanie assisted with restraint when she took her son to the GP for immunisations. She explained: *"We sit with him and hold an arm each and sometimes someone has to sit on his legs as well."*

Andy (parent) did not advocate restraining his son for immunisations, but because of the futility of it rather than the any moral issues:

> *Why bother doing that? It's not going to get a result. He will thrash and be traumatised by it, but he will never go near that process again, so it's just, it's really just throwing into the wind really. It's a waste of time to my mind. You know what I mean? I'm not horrified by the morals of it. I think if it's necessary it's necessary, you know, you've got to do what you've got to do. But I just don't see any positive outcome there, doing that to [him].*

It was clear that incidences of resistance and consequently possible restraint were common, and that individual nurses used their own judgement as to what was acceptable in regard to the management of students who resist. This was decided with consideration of the difficulty of immunising anxious young people with disability.

8.11 Identifying Barriers and Facilitators

Barriers and facilitators to immunisation in specialist schools can be identified within the themes and subthemes described, and are illustrated in Figure 8-1.

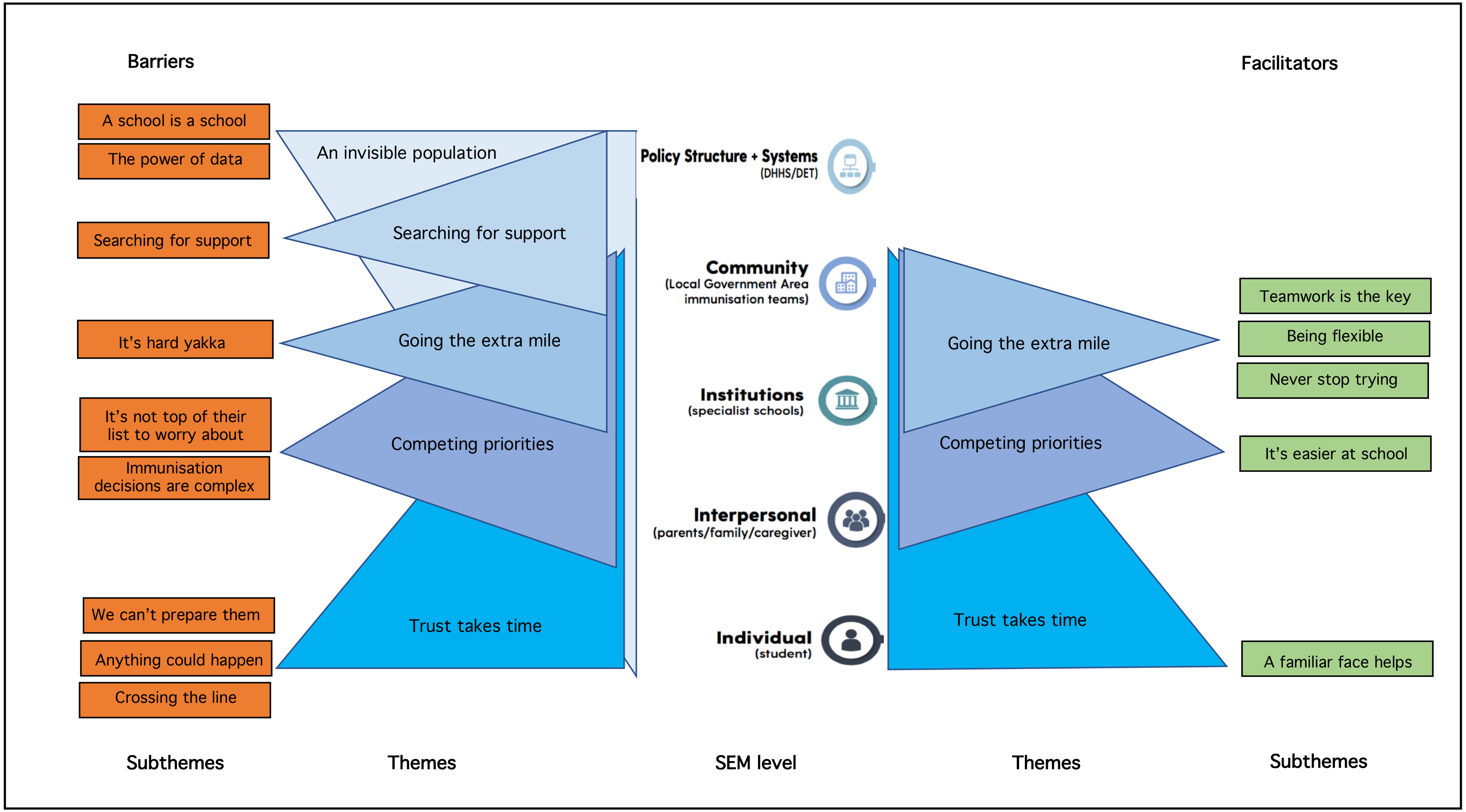

Figure 8-1 Summary of the Findings of Phase Two with respect to the Barriers and Facilitators of the SBIP in Specialist Schools

Figure 8-1 shows subtheme barriers in red and subtheme facilitators in green, linking to each theme and the relevant interactions this encompasses on the SEM model. Importantly, some of the themes have both barriers and facilitators within their subthemes, and are therefore represented by triangles on both the left and right sides. As this illustration shows, according to the data there are more barriers than facilitators with respect to the SBIP in specialist schools, with barriers identified at every level of the SEM. In contrast, facilitators are largely concentrated at the Community (immunisation team) and Institutional (school) levels of the SEM. Although there are some facilitators evident at the Interpersonal (parent) and Individual (student) levels, the interventions that promote school immunisation in this population are driven by immunisation teams and schools, and their knowledge and expertise should therefore be central to further interventions and policy recommendations. The next chapter will summarise these findings with respect to Phase One data and the literature, in order to develop recommendations moving forward for the SBIP in specialist schools, with the aim of minimising these barriers and maximising the facilitators.

9 DISCUSSION, RECOMMENDATIONS AND CONCLUSION

9.1 Introduction

This chapter discusses the overall findings of the research, and synthesises the evidence to draw conclusions and propose recommendations to improve the uptake and experience of immunisation through the SBIP for young people with disability. The research questions and choice of methodology and framework are reviewed, as is the literature on the topic published during the course of the thesis. This establishes the ongoing importance and significant of the research. Phase One and Phase Two data are integrated, with inferences drawn from the combination of the phases presented in a joint display table. These inferences are discussed with respect to the literature to propose realistic recommendations that can be implemented in policy and practice. The chapter concludes by discussing the strengths and limitations of the thesis, and presenting suggestions for further research.

9.2 Research Questions Revisited

The aim of this thesis was to explore and describe acceptance and delivery of immunisation in specialist schools for young people with disability in Victoria, Australia. The questions that the thesis sought to answer were prompted by the paucity of research and the importance of the enquiry. These questions, which were outlined in the literature review in Chapter 3 and further detailed in the methods sections for Phase One, in Chapter 4, and Phase Two, in Chapter 7, were:

> *What is the uptake of school-based, government-funded vaccinations in young people with disabilities attending specialist schools in Victoria, Australia, as compared to the general Victorian population, and what are the reasons for non-vaccination in this group?*
>
> *What are the socio-ecological determinants that prevent or enable immunisation for young people with disability in specialist schools in Australia?*

Central to both health care in disability, and analysis of any immunisation program in minority populations, is the concept of health equity. This, in part, directed the research design.

9.3 Health Equity and Mixed Methods

As outlined in Chapter 2, equity is intrinsically linked with human rights frameworks. Equity is a notion of social justice and fairness, where to achieve equality among individuals or groups, there may need to be a different, or individualised, distribution of resources. Whitehead and Dahlgren (2007) explained the concept of health equity as a situation in which *"everyone [can] attain their full health potential and… no one [is] disadvantaged from achieving this potential because of their social position or other socially determined circumstance."*[240]

Thus, health equity is dependent on individual and cultural values and norms.[241] In the context of immunisation, while accurate objective coverage data are vital in informing health policies to achieve equity, this is not enough to fully understand issues with immunisation in sub-populations. As health equity is measured and valued subjectively, any research about immunisation in people with disability requires qualitative data in order to contextualise the social structures and determinants that maintain inequity. This is essential in order to explain the quantitative information.

Despite this, as discussed in Chapter 3, all research on immunisation in children and young people with disability prior to this thesis was exclusively quantitative, with the predominant focus on immunisation coverage rates. Interestingly, published studies since the thesis literature review, outlined in Table 9-1, have continued this trend.

9.4 Recent Literature

Of the eight studies on immunisation in children and young people with disability published since February 2017 (the end date of publications cited in the literature review in Chapter 3), seven are retrospective audits or cross-sectional studies that have examined uptake of one or more vaccines in a population of people with a disability (see Table 9-1). The exception to this is the study arising from Phase One of this thesis, which is a prospective cohort study (see Chapter 4), although it is still a quantitative enquiry measuring immunisation uptake.

Some of these recent studies utilise data sets in order to calculate immunisation rates. While the increasing availability of data sets is invaluable in research, they should not be the only source utilised when considering complex health equity issues. While accurate ongoing coverage data are essential, this is not enough. As argued in Chapter 5, qualitative and mixed methods are needed in order to contextualise the coverage rates, and this is especially important in understanding the barriers and facilitators of an immunisation program when coverage rates in a population are low.

The recent studies published since February 2017 support the literature reviewed in Chapter 3 of this thesis, which concludes that coverage of childhood and adolescent immunisations across a range of vaccines in high-income countries is likely to be lower in children and young people with disability than coverage in typically developing children. These studies, like those previously found, need to be appreciated in terms of the disability definition used. For example, Chandrupatla, Khlid and Tavares (2019) found no significant difference in HPV vaccine coverage of young people with SHCN,[242] and McRee, Maslow and Reiter (2017) also found similar rates of adolescent vaccinations between youth with SHCN and those without.[243] However, the applicability of these two North American studies is limited by the very broad definition of SHCN, as discussed in Chapter 3. The third recent North American study, and the four studies from Australia and the UK, all used narrower and more specific disability definitions and did find that immunisation coverage was lower in the group with disability than the general population.[244–248]

This topic remains under-researched. In particular, there is an absence of literature on immunisation in people with disability in LMICs, and apart from studies with the writer of this thesis as primary author, there is a paucity of Australian literature. The

Phase One Study in this thesis remains the only source of data on adolescent immunisation coverage in specialist schools in Australia, and the Phase Two Study remains the only qualitative study on immunisation in young people with disability internationally.

Table 9-1 A Summary of Literature on Immunisation in Children and Young People with Disability published since February 2017

Study, Year, Location	Study Design/Data Collection Method	Research Aim	Participants	Disability or Definition of Disability	Immunisation	Relevant Results	Limitations
2019 **Chandrupatla, Khlid & Tavares** **USA**	Cross-sectional study Secondary analysis of data from the National Health and Nutrition Examination Survey dataset 2013-14, which included a sexual health questionnaire and oral HPV samples	To assess the prevalence of oral HPV in adults with SHCN, and compare the prevalence of HPV vaccination in individuals to the general population	665 adults with SHCN Females between 9-26yrs and males between 9-21yrs with SHCN were analysed as to their HPV vaccine status (numbers are not reported)	SHCN	HPV	Those with SHCN are significantly more likely to have oral HPV than the general population. Women with SHCN were significantly more likely to have high-risk oral HPV than the general population HPV vaccination rates are lower amongst those with SHCN 9-26 yrs than the general population, but this is not statistically significant	'People with SHCN' is a broad definition, including, but not limited to those with disability Numbers of females and males analysed as to their HPV vaccine status were not reported
2019 **Emerson, Robertson, Baines & Hatton** **UK**	Cross-sectional study Secondary analysis of parental report of child	To determine if children with ID are at risk of missing immunisation, and to determine the	18,552 children of which 672 (3.6%) had ID Four waves – at aged 9 mnths, 3 yrs, 5	ID as determined by abbreviated scales of cognitive testing Where not	DTP Hib Polio Men C MMR HPV	Overall coverage was high, but immunisation coverage was lower for children with ID than those without, except for the MMR	ID not determined by full scale IQ Receipt of immunisation by parent report Age of ID diagnosis not clear

Study, Year, Location	Study Design/Data Collection Method	Research Aim	Participants	Disability or Definition of Disability	Immunisation	Relevant Results	Limitations
	vaccination in the UK's Millennium Cohort Study	extent to which known at-risk factors affect immunisation coverage rates in children with ID	yrs and 14 yrs	available determined by parent report		vaccine at 5 years Adjustment for known variables of immunisation coverage cancelled out the significance of this at 9 mnths but not 3 and 5 yrs More parents of children with ID gave the reason for non-vaccination as parental choice at 9 mnths and 3 yrs, however this was small in number	or how this was incorporated
2019 **O'Neill et al.** **Australia**	Prospective cohort study	To determine the uptake of dTPa and HPV in young people with disability in specialist schools in Victoria	374 students aged 12-13 yrs in 28 specialist schools for young people with disability	Students attending specialist schools for young people with physical and/or intellectual disability	HPV dTPa	dTPa was received by 63% of students in specialist schools compared to 89% in mainstream schools, and first dose of HPV was received by 66% of females and 67% of males compared with 75% for mainstream	Reliance on schools accuracy in reporting data Only 1/3 special schools in region participated Significant attrition of data for 2nd and 3rd doses of HPV

Study, Year, Location	Study Design/Data Collection Method	Research Aim	Participants	Disability or Definition of Disability	Immunisation	Relevant Results	Limitations
						schools Main reasons for non-immunisation were absence from school, lack of consent and inability to immunise due to anxiety/behaviour	
2019 **O'Neill, Elia, & Perrett** **Australia**	Retrospective audit	To determine the uptake of HPV in a cohort of adolescents with developmental disabilities as compared to the general population	72 adolescents aged 14 yrs who attended a paediatric outpatient clinic for developmental disabilities in the last year	Adolescents attending a developmental medicine clinic at a tertiary centre Diagnoses included CP, ASD, ID and epilepsy	HPV	44.1% of females and 39.5% of males in this population were fully vaccinated for HPV compared to 77.4% females and 66.4% males of 15 year olds in general population More likely to miss HPV vaccination if they had intellectual impairment, irrespective of motor function	Small sample size, all linked with developmental medicine tertiary clinic so may not be representative of health care encounters of population of adolescents with disability

Study, Year, Location	Study Design/Data Collection Method	Research Aim	Participants	Disability or Definition of Disability	Immunisation	Relevant Results	Limitations
2019 **Tiley et al.** **UK**	Cross-sectional ecological study	To determine school-level factors that influence HPV and Men ACWY uptake amongst adolescents	41/152 (26.3%) local areas in the UK submitted data for HPV uptake for 1,407 schools, including 179 special schools and 48/152 (31.6%) local areas submitted data for Men ACWY uptake for 1,432 schools, including 208 special schools	Students attending specialist schools for those with special education needs in UK	HPV Men ACWY	HPV vaccine coverage was >80% in 33.5% of special schools compared to 67.1% of state-funded secondary schools Men ACWY vaccine coverage was >80% in 26.9% of special schools compared with 68% of state-funded secondary schools	Relied on accuracy of data submitted from local areas
2018 **Dinleyici et al.** **Turkey**	Retrospective audit	To evaluate immunisation coverage for children with neurological disease, identify serological	366 children and adolescents 6 mnths to 18 yrs with chronic neurological disorders	Chronic neurological disorder as diagnosed by a paediatric neurologist. Includes children with	MMR Varicella Hep A and B DTP Influenza Pneumococcal	350 (95.6%) children were up-to-date with vaccines, similar to typically developing children 12 (4%) children were unvaccinated, 2 with true	Most vaccines were included in the childhood schedule within the last 10 years with no catch-up program funded

Study, Year, Location	Study Design/Data Collection Method	Research Aim	Participants	Disability or Definition of Disability	Immunisation	Relevant Results	Limitations
		status for vaccine-preventable diseases	presenting to a paediatric neurology unit in Turkey	epilepsy, CP, congenital muscular disorders, ASD and ID. Excludes those with febrile convulsions and acute meningitis	Meningococcal	contradictions 86.6% had no history of influenza vaccine Serological assessment confirmed vaccination status in most cases Under-immunisation was most often due to the absence of a catch-up program	
2017 **McRee, Maslow & Reiter** **USA**	Cross sectional study Secondary analysis of data from the Child Health Assessment and Monitoring Program	To compare adolescent vaccine coverage in youth with special health care needs as compared to youth without special health care needs	2156 young people 11-17 yrs, 604 (28%) with special health care needs	Youth with SHCN	DTP Meningococcal HPV	Overall rates low with 12% of all youth receiving all vaccines, although 90% received tetanus Immunisation rates for each vaccine were similar between the groups except more	Broad descriptor of special health care needs includes chronic health issues and emotional disorders Reliance on parent recall of vaccination status

Study, Year, Location	Study Design/Data Collection Method	Research Aim	Participants	Disability or Definition of Disability	Immunisation	Relevant Results	Limitations
						YSHCN received HPV (33%) vs those without SHCN (23%). In particular YSHCN who had elevated services had greater odds of receiving HPV Fewer youth with SCHN received meningococcal (22%) vs (33%) although this lost significance when disaggregated for number of SHCN	
2017 **Rowe, Pritt, Stratton & Yoost** **USA**	Retrospective audit and cross sectional survey Immunisation record and phone survey with sample	To evaluate if HPV vaccination rates are different between female adolescents with mental	1673 females presenting to paediatric or gynaecology clinics in 2012, 72 (4%) with mental or physical limitations	Mental and physical limitations as determined by medical notes and diagnostic codes	HPV	Of those with mental or physical limitation 43% initiated HPV schedule, compared with 57% of control group The most common reasons for non-	Only females included as the study was undertaken in 2012 and males had only been eligible for HPV for one year Small sample size

Study, Year, Location	Study Design/Data Collection Method	Research Aim	Participants	Disability or Definition of Disability	Immunisation	Relevant Results	Limitations
	of parents	and physical limitations and those without	44 parents of control group and 21 parents of affected group			vaccination in the affected group was a belief the immunisation was not needed and lack of recommendation by medical provider. The most common reasons for non-vaccination in the control group was safety concerns and lack of recommendation by medical provider	of those in affected group Not adjusted for demographic factors

Key:

ASD – Autism spectrum disorder
CP – Cerebral palsy
CSHCN – children with special health care needs
DTP – diphtheria, tetanus, pertussis vaccine
dTPa – diphtheria, tetanus, pertussis booster
Hep A – Hepatitis A vaccine
Hep B – Hepatitis B vaccine
Hib – Haemophilus influenzae type B vaccine
HPV – Human papillomavirus vaccine
ID – intellectual disability
IPV – invasive pneumococcal vaccine
Men C – meningococcal C vaccine
Men ACWY – meningococcal ACWY vaccine
MMR – measles, mumps, rubella vaccine
Polio – poliomyelitis vaccine
SHCN – special health care needs
YSHCN – youth with special health care needs

9.5 Justification of the Framework

Mixed methods design allows appreciation of both the need for numerical data, as well as subjective perspectives and experiences. Through the integration of the phases in mixed methods, complexity is embraced rather than negated, and this is vital in the assessment of a public health program with many layers of influence. The importance of acknowledging and allowing for complexity is further highlighted in this thesis by the use of the SEM as a framework, which ensures many voices are represented.

The need for in-depth qualitative data and the value of using an ecological model in immunisation research has recently been recognised by Dubé et al. (2011), who adopted the SEM as a framework to explore HPV acceptance in Canada.[249] The focus in this study was mainstream schools, and the age of the HPV program implementation in Canada is Grade 4 students, so significantly younger than in Australia. Despite this, there were several similarities in the findings of this study and the data from Phase Two in this thesis. For example, Dubé et al. (2011) reported issues with parental consent, issues with the lack of resources to follow-up and catch-up students, and the importance of a trusting relationship between the school and immunisation providers. However, when comparing this study to the qualitative phase of this thesis, what is most confirming is that the use of the SEM in both studies allowed for in-depth exploration of the experiences and perception of stakeholders at interpersonal, organisational, community and policy levels, which was therefore inclusive of all those with a role within the SBIP. Therefore, the findings of both studies incorporate rich description of the barriers and facilitators of immunisation particular to context, and clear identification of the impact of the SDH on acceptance and delivery of vaccines.

While Dubé et al. (2011)[49] also used the SEM as a framework to structure the thematic analysis, in this thesis there was a deliberate emphasis to iteratively analyse themes in Phase Two independent to the SEM, and then to outline how the themes fit across layers within the model. This was done to portray the true complexity of a multi-level, intersectoral public health program, in which barriers and facilitators were experienced across stakeholder groups, and to enable future discussion of targeted interventions to be clearly defined and justified as the responsibility of all stakeholders across SEM levels. What also differentiates the methodology in this thesis is the mixed methods design, which allows for another level of data analysis through integration of the quantitative and qualitative data.

9.6 Integration of Phase One and Phase Two Findings

When the quantitative and qualitative findings in mixed methods studies are combined to draw conclusions, the aim is that the integrated inferences are more than the findings from each phase. Table 9-3 illustrates this by considering the qualitative findings alongside the quantitative results in a joint display table,[220,250] to describe three overall inferences. These inferences act to:

1. Explain the primary Phase One quantitative outcome of lower immunisation uptake rates in specialist schools as compared to mainstream schools
2. Relate to stakeholders and systems across all levels of the SEM, as described in the thesis
3. Provide the basis for recommendations to optimise the acceptance and delivery of the SBIP for young people with disability in specialist schools going forward

Table 9-2 Joint Display Table Integrating Phase One and Phase Two

Phase One (Quantitative) Result	Phase Two (Qualitative) Finding	Integrated Inference
Coverage of immunisations given in specialist schools through the SBIP not included in the Victoria coverage figures	*An invisible population* The power of data	***Young people with disability are currently invisible in immunisation data reports and policy considerations***
Significantly lower uptake of adolescent immunisations through the SBIP in specialist schools as compared to mainstream schools The attrition in uptake between doses for the HPV vaccine was greater in specialist schools than reported on the Victorian HPV register Main reasons for missing immunisation were absence from school, lack of parental consent and difficulty immunising due to the level of anxiety or behaviour of the students	*The invisible population* A school is a school *Searching for support* *Going the extra mile* Never stop trying Teamwork is the key Being flexible *Parental priorities* Not top of their list to worry about Immunisation decisions are complex *Trust takes time:* A familiar face helps	***There are barriers to immunisation specific to the specialist school setting, which need targeted support***
A quarter of the number of students who were immunised required extra support or were very distressed	*Searching for support* *Going the extra mile* It's hard yakka *Parental priorities* It's easier at school *Trust takes time* Anything could happen We can't prepare them properly Trust takes time	***Negotiating the ethical tensions in immunising in specialist schools results in physical and emotional harm, and moral distress***

The three inferences represent the key aspects arising from the integration of Phase One and Phase Two, and involve multiple levels of the SEM framework. These statements, which are discussed further below, are the essence of the outcomes of this thesis and should provide the basis for interventions, further research and policy decisions on this topic.

9.7 Integrated Inference One: *Young People with Disability are Currently Invisible in Immunisation Data Reports and Policy Considerations*

9.7.1 Invisibility

Health equity begins with accurate information about the health intervention in the target population,[119] and in this case, immunisation coverage data for young people with disability is fundamental. Phase One of this research provides the first data on coverage of immunisations through the SBIP in specialist schools in Australia. It was a necessary phase of the research because immunisation coverage in ungraded specialist schools is not centrally recorded in aggregate reports. Despite the fact the adolescent immunisations are officially recommended and funded according to age, uptake is measured using year level enrolment. The use of year levels to structure the SBIP extends to the information and consent forms. Year levels are also used in the media and in general conversation. Thus, the HPV and dTPa vaccines are referred to as the *"Year 7 Immunisations,"* Men ACWY is the *"Year 10 Immunisation,"* and centrally-distributed parental consent forms for these immunisations have the allocated year level printed on the top of the form. This acts to reinforce the exclusion of students who do not fit into year levels, and the message of the lesser importance of the SBIP in young people with disability, and indeed the lesser importance of people with disability themselves. This exclusion of people with disability is echoed throughout disability literature.[251–254]

The invisibility of immunisation data in specialist schools, which was the impetus for Phase One and a theme in Phase Two, has carried over to become the first of the three inferences from the mixed methods integration, due to the far-reaching consequences of this lack of data. The low coverage of adolescent immunisation uptake in specialist schools in Victoria in Phase One is concerning in its own right, and highlights the complex interplay between the SDH and preventive health of people with disability. The fact that adolescent immunisation coverage in this population was unknown has even more significant implications.

The impact of the invisibility of this group in immunisation policy considerations was evidenced through all SEM stakeholder groups, and therefore, it can be understood to underpin the issues raised throughout this thesis. Policy participants in Phase Two, who were individuals in state government, had *"no idea"* (Mallory) of the coverage, nor any means to find out. The consequences of the absence of data extended also to stakeholders in immunisation teams, who not only confirmed an invisibility of specialist schools in system level considerations, but by proxy, an invisibility and lack of appreciation for the work and the extra effort required to immunise young people with disability. Specialist staff in schools, who have day-to-day experience of supporting young people with disability, spoke of the invisibility of this population of students. The related sentiment from parents is about 'not fitting into the box,' or as Andy explained, it is about being more than different – it is about being altogether *"the kind of sausage you can't sell at a shop."*

Therefore, the issue of invisibility can be understood to be broader than the issue of the SBIP in specialist schools, or health programs in general. Essentially, the lack of data and ensuing invisibility reflect inequity in social inclusion and acceptance of people with disability. Understanding the historical context of inequities in the lives of people with a disability, as outlined in Chapter 2, is crucial in appreciating the significance of the need for the Phase One Study.

9.7.2 The importance of reliable ongoing disaggregate coverage data

The coverage data presented in Phase One of this thesis established the scope of under-immunisation and provided an evidence foundation for further in-depth research in Phase Two. However, going forward, it is not enough to rely on the work in this thesis in establishing that students in specialist schools are at risk of under-immunisation. Without reliable ongoing disaggregate immunisation coverage data of young people in specialist schools, and young people with disability more broadly, there is no method of evaluating ongoing issues, or the impact of any interventions. As Georgie from the policy participants emphasised, reinforced by the related subtheme in Phase Two, *"data is just so powerful."* This is echoed in the literature on immunisation inequities in other sub-populations. In the context of immunisation inequities in LMICs, Brearley (2013) observed, *"what gets measured, gets done,"*[10] and in literature on Aboriginal and Torres Strait Islander immunisation: *"what isn't measured, isn't done."*[255]

The significance in ensuring accurate and adequate data in disability health surveillance extends beyond immunisation to other preventive health care, and identifying other health disparities.[256] Internationally, health surveillance in people with intellectual and developmental disabilities is recognised as challenging.[257] This includes, as discovered in this thesis, the difficulties with the terminology defining disability, which determines who is included and excluded from data.[257,258] Krahn, Walker and Correa-De-Araujo (2015) call for standard disability identifiers across surveys in order to routinely collect and compare disaggregate health outcomes for those with disability, in order to inform health policy.[259] Ideally, these should be internationally recognised identifiers.

One way that has been utilised to record and examine prevalence of disease, health and wellbeing, and health inequity issues in disability in Australia, is the use of databases specific to disability diagnoses. Examples of these are the national Cerebral Palsy Registry[260] and the Western Australian Intellectual Disability Exploring Answers (IDEA)[261] database. However, while providing important information on a range of factors, there remains the issue of those not included, whether due to a rare or undiagnosed condition, or social or demographic factors that act as barriers to individuals' inclusion in these databases.

In the same way that the issue of invisibility in the data is not unique to immunisation policy, it is also not unique to those with disability. For example, the convention of organising the SBIP according to year levels is not inclusive of ungraded schools. Although ungraded schools are primarily for students with intellectual and physical disabilities, there are other types of ungraded schools in Australia, including English Language Schools and schools for youth at-risk of disengaging from the schooling system due to social stressors, mental health or behavioural challenges. Consequently, immunisation uptake in these schools is also unmeasured and undocumented. More broadly, the impact of lack of health indicators has been reported in other minority groups at risk of health inequities, such as Indigenous Australians,[262,263] ethnically diverse[264] and sexually diverse populations.[26–28] Therefore, this inference extends beyond the subject of this thesis to the broader issue of health in minority populations, and the way in which lack of data may compound existing inequities.[6]

9.8 Integrated Inference Two: *There are Barriers to the SBIP that are Specific to the Specialist School Setting and which need Targeted Support*

9.8.1 Policy and structural level: Funding and resources

The findings from both Phase One and Phase Two reveal many differences in immunising in specialist schools as compared to mainstream schools. Barriers arise due to the absence of systemic acknowledgement of these differences, and the ensuing lack of flexibility to provide more or alternative supports to enable the impact of differences to be minimised. The main support that immunisation providers, and to some extent schools, were searching for included funding and resources, which is a direct result of the specifics of the specialist school environment.

The need for extra funding and resources for specialist schools reflects a system that is structured around the logistics of a service for young people with typical receptive understanding, who can verbally communicate and to some degree rationalise any anxiety about immunisation. Funding is not flexible to allow for students who require more time to communicate or build trust with, such as students with disability. Resources in terms of staffing do not allow for multiple catch-up visits to specialist schools, which would be optimal given the high student absentee rate. This results in frustration, and inability for immunisation staff to follow-up and catch-up students with disability thoroughly, or indeed, provide a comprehensive childhood catch-up immunisation service within the SBIP, such as Beth (immunisation nurse) attempted. Such projects, while beyond the scope of the SBIP, clearly fit with the role local government has been assigned by the WHO in working towards health equity,[267] and which is a legislated part of local government's role through the *Public Health and Wellbeing Act 2008*.[78]

There are no easy solutions to increasing available funding and resources. In Victoria in particular, the complex vaccine funding structure would require review to change the current payment-per-dose arrangement. The in-depth funding analysis required to determine other vaccine funding possibilities is beyond the scope of this thesis, but must be a key consideration henceforth. With the overall high immunisation coverage in Victoria, there is now scope to focus on optimising support for under-immunised sub-populations, including young people with disability. This requires the flexibility in systems to allow targeting funding and resources to be allocated.

In qualitative interviews with local government providers about the ability of local government in Victoria to impact the SDH, participants spoke of *"upstream determinants of health"* compared to *"downstream behaviour change programs."*[268] While there was a strong message from participants in this study that the way to drive change was to *"push upstream"* rather than just provide service delivery, this was limited by funding, and support for long-term health and wellbeing plans based on the SDH.[268] This reflects the complexity of public health programs, which require intersectoral collaboration across levels of government and other domains.

9.8.2 Community and institutional level: Intersectoral collaboration

The unique intersection between health and education sectors and local government necessary to undertake the SBIP requires a skilled level of intersectoral collaboration. Intersectoral collaboration is vital in many public and preventive health programs, particularly when the SDH need to be considered. Engaging industries outside health in implementing health interventions is recognised by WHO as a way to achieve health outcomes that are *"more effective, efficient or sustainable than might be achieved by the health sector acting alone."*[72]

Health and wellbeing interventions have long been embedded in schools in Australia. Apart from the SBIP, other health programs that are actioned in schools include dental services, interventions for mental health issues, and drug and alcohol and sexuality education.[79] In a qualitative analysis of school-based intersectoral collaborations in Australia, Tooher et al. (2017) found the main driver of effective collaboration was clear communication at organisational and interpersonal levels, including developing strong personal relationships and identifying *"champions."*[79] Reviews of SBIPs also consistently report the central role that the relationship between the school and the immunisation providers has on the success of the immunisation day, and uptake of the adolescent immunisations.[73,269,270] This was also reflected in the data from Phase Two interviews, focus groups and observations, with an emphasis on consistency of both school and immunisation staff. This generates trust between staff and students, resulting in a smoother session and better immunisation experience for all.

Therefore, while the idea of 'champions' was not mentioned in the data in this thesis, it is an interesting concept to consider in the context of the importance of consistency, when turnover of both immunisation and school staff may be unpredictable. The idea is that 'school immunisation champions' in the immunisation team in the specialist school system foster consistency of routine, policies, logistics and communication, in order that despite any changes in staff, trust is maintained. As Tooher et al. explains, in this way *"practices become embedded rather than vulnerable to change."*[79]

Champions could also have a role in communication across SEM levels beyond the immunisation provider-school collaboration. This would allow community and institutional level input into higher level policy discussions and decision-making about the SBIP, where it is currently clear that there is a perception that the program is deemed *"not an important service"* (Rose, immunisation nurse). Although policy participants spoke of many aspects of logistical and practical assistance provided to local governments to administer the SBIP, this appears to be at odds with the support that immunisation teams perceive they receive. While immunisation teams were not clear about the specific support they were searching for, Rose's comment, *"If you've got a school that is identified as really low coverage nobody rings you and says is there something we can do?"* suggested that an acknowledgement of difficulties and offers of assistance with problem-solving by the Victoria State Government would be appreciated. However, as Ming (policy) stated, state government *"rarely hear"* about any immunisation issues at the local level. This suggests that assumptions about roles and responsibilities are made by both groups of stakeholders. The Victoria State Government is unaware of the support local government wants and needs, in part at least because that conversation is not happening. This tension reveals a fine line between allowing local governments to run an autonomous immunisation service and still provide adequate central support.

Part of this tension is the different outcomes that key stakeholders aim for in the SBIP. This is illustrated throughout this thesis by the variety of definitions of a successful immunisation session and the idea that it goes beyond coverage rates. This includes *"reduction of disease"* (Georgie, policy); *"public confidence in the program"* (Ming, policy); that *"everyone is safe, they are safe and we are safe"* (Clare, immunisation nurse); *"if all consent cards are back"* (Peta and John, immunisation nurses); how *"efficient"* the day is (Phuong, LGA Manager); *"the general mood in the school… how we feel about things"* (Kate, immunisation nurse); ensuring that you don't *"close that door"* forever (Andy, parent).

The vast array of aims and measures of successful outcomes highlights that perhaps the intersectoral collaboration between immunisation teams and schools needs to extend beyond these middle layers of the SEM to encompass state government and the policy level upstream, as well as parents and young people downstream. An example of strategies to do this is illustrated through the Health Bridges Study, which explored intersectoral collaboration between immunisation providers and schools with regards to the HPV program in South Australia.[113] The use of citizens' juries for adolescents and parents of young people to discuss the program, and a key stakeholder roundtable to bring stakeholders from all levels of the SEM together, were examples of extended intersectoral collaboration.[113,174] Although this was undertaken in a research context, the shared understanding of facilitators and challenges of the SBIP implementation is impressive, and the process is one that could be trialled in non-mainstream schools. Key to this success was the role of the researchers as neutral *"knowledge-brokers."*[113] Understanding and respecting the different priorities in the SBIP are vital for shared success. This is especially the case in specialist schools where priorities are often not straightforward.

9.8.3 Interpersonal level: Parental priorities and multiple disadvantage

Within Phase Two, both immunisation teams and specialist school staff discussed the disproportionate prevalence of social and economic disadvantage in families of children with disability. This was attributed by some participants to *"intergenerational disability"*, but the overall profile was one of families under significant stress, including financial, personal, substance abuse issues and families where English was a second language. This layered disadvantage intensifies the risk of health disparities, as discussed by Havercamp and Krahn (2019) in relation to disability, race and ethnicity.[257] The association between low socioeconomic status (SES) and low immunisation uptake is well established.[6,42,271,272] With 55 of the 73

(75%) specialist schools in Victoria examined in Phase One enrolling students from families with low or low-middle SES status, any immunisation intervention for this population must consider the SES context of the families.

Echoing findings in this thesis, a qualitative study of barriers to HPV uptake in the UK by Batista Ferrera et al. (2016) found that school nurses reported *"chaotic family environments"* rather than objection to the vaccine as the primary reason for missed immunisation.[64] Similarly in Hunter New England, NSW, an analysis of low immunisation coverage of pre-school children found that family factors associated with missed immunisation were most commonly *"parents' conflicting priorities, chaotic lives and significant access barriers to primary care."*[273], As such, barriers on the interpersonal level were logistical rather than due to specific immunisation beliefs or vaccine hesitancy.[273] Therefore, the widespread assumption that the majority of under-vaccination of children is attributable to anti-vaccination beliefs must be challenged to understand the many other barriers to immunisation that exist.[271,274] This is a particularly important message to communicate to health care providers of families of children with disability, where the default may be to assume missed vaccination is due to vaccine refusal. This assumption may mask the many social and logistical barriers that affect immunisation coverage, but are modifiable with targeted intervention.

While working to reorientate family demands to prioritise their child's immunisation may seem optimal, more effective strategies may accept the many competing demands for families with children with disability. In practice, such strategies would ensure signing and returning the consent form for SBIP is as easy for parents as possible. The issue of return of consent forms for school immunisations is not unique to families with disability,[64,275,276] but the evidence for multiple disadvantage in this group compounds the need to consider the consent process.

Although online or e-consent for school events is widespread, it is not yet available in Australia for vaccine delivery, although has been trialled in schools in the UK.[277] This would be valuable for families who already face large amounts of paperwork and would reduce workload for nurses and school staff. In addition, Kolff, Stock and Stockwell (2018) discuss the potential of technology to assist in providing immunisation reminders and notifications.[211] Examples from these authors are structured across SEM levels, from individual mobile phone text reminders that a vaccine is due, to social media reminders, to the use of personal health records and electronic medical records that can be accessed by multiple providers.[211] Specific to adolescent vaccinations, mobile phone reminders have been shown to increase HPV completion rates, and as mobile phone use now commonly extends across socioeconomic groups, these mobile phone text and voice vaccine reminders have the potential to cross socioeconomic divides.[211]

A more targeted approach of personalised calendars including immunisation dates, artwork and a photo of the child was successful in increasing timeliness of immunisation for preschool children in a population of Aboriginal and Torres Strait Islander families.[39] It is possible that a similar community-driven intervention would help families with children with disability remember immunisations and consent forms. To date, there are no published studies reporting trials of vaccine reminder systems in families with children or young people with disability.

Interviews with stakeholders in Phase Two of this thesis provided evidence of a variety of flexible and innovative strategies immunisation teams and schools implement in order to optimise immunisation uptake. This included individualising how the sessions are run and where the students are immunised, and flexibility about whether two immunisations are given concurrently or sequentially. In terms of consent return, strategies specific to certain schools included immunisation nurses attending parent information nights at schools to consent families face-to-face and school staff personally delivering signed immunisation cards to the LGA offices. The knowledge and experience of school nurses in the SBIP in the UK has been described by Boyce et al. (2019) as *“an untapped resources to address health inequalities… to identify and vaccinate difficult-to-reach [students].”*[275] This expertise and skill were also evident in immunisation nurses and school staff in Phase Two of this thesis. Co-design with these stakeholders who intimately know the students and families should be part of any intervention to improve the SBIP in specialist schools.

9.8.4 Individual level: Student anxiety

The individuality of each student in the specialist schools associated with their disability, such as level of receptive and expressive understanding, behavioural challenges and expression of anxiety, is the central driver of the need for the SBIP to be flexible. Within this thesis, both Phase One and Phase Two found that the level of student anxiety was a significant barrier to immunisation in specialist schools, which either resulted in missed immunisation or immunisation with significant distress for the student and the staff. While student anxiety in mainstream schools is acknowledged, it is not a major reason for missed immunisation. The significance of this issue for young people with disability was alluded to in an audit of immunisations performed under sedation at a paediatric tertiary centre in Melbourne, in which 40/139 (31%) of patients who presented had a developmental disability.[278]

While anxiety about immunisations is recognised in the literature,[279–282] and there are studies pertaining to needle-related distress children with a disability in acute care,[283–285] there are no studies on managing anxiety in young people with disability receiving immunisations through the SBIP. Consequently, there are no guidelines or best practice evidence available for immunisation providers and schools to refer to in managing this challenge. During school observations in Phase Two, there were students for whom immunisation was abandoned due to their severe distress, and occasionally due to their violent reaction to presenting for immunisation. Few stakeholders interviewed in Phase Two were aware of the option for families to obtain a referral to a tertiary paediatric hospital for immunisation under sedation through their GP.[278] This is available in Melbourne for all children and young people with significant procedural anxiety or needle phobia, allowing immunisation to be performed with no or minimal distress for the child.[278] In the context of families with multiple disadvantage and many priorities, it is likely that for this service to be used to its full potential for young people with disability, like the consent process, it would need to be easy to access, organise and complete. Arranging this option is not currently in the remit of the local government immunisation teams, and the referral pathway is not widely known outside the hospital system. This is certainly a resource that should be optimised as it could prove to be the only option for some young people with disability to safely and appropriately receive their immunisations.

The data in this thesis illustrate a range of other strategies implemented in specialist schools to lessen student anxiety. Certainly, all the schools that were observed in Phase Two minimised waiting times and reduced the number of students presenting for immunisation at one time. Most schools gave limited information to students prior to immunisation, although it was not clear if this was entirely to prevent escalation of anxiety, or due to confusion about whose responsibility (parents, schools, immunisation providers) it was to inform and educate students with disability about the immunisation. However, beyond those similarities schools differed in the length of time spent building rapport with the students, the consistency of immunisation and school staff attending with students, the consideration as to whether parents should be present during the immunisations, the verbal reassurances given, and the level of holding or restraint during immunisation. Uncertainty about these decisions was expressed by a number of immunisation and school staff, and it was clear that there are a number of unspoken and undocumented ethical tensions in immunising young people with disability in the school setting. These ethical issues must be addressed to ensure the rights of the student are balanced with the benefits of immunisation.

9.9 Integrated Inference Three: *Negotiating the Ethical Tensions in Immunising in Specialist Schools results in Physical and Emotional Harm, and Moral Distress*

9.9.1 Ethics of immunisation

Ethical aspects of immunisation have been discussed in the literature, including the role of immunisation in reduction of health inequity,[6,286] factors affecting public trust in immunisation,[287–289] introduction of mandatory immunisations and financial penalties for failure to immunise,[20,21,286] and the factors with informed consent.[276] There are very few studies exploring the ethics of immunisation in schools. Specific ethical tensions in immunising young people with disability, and particularly in the context of immunisations given at school, have not been recognised in the literature prior to this thesis.

Braunack-Mayer et al. (2015) undertook a qualitative study of immunisation nurses, teachers, parents and female students in mainstream schools in South Australia.[290] This study found the three main ethical issues included (1) informed consent, including the provision (or lack of) adequate information to student and parents and the student role in making a decision to be immunised; (2) acknowledgement of anxiety and fear of pain; and (3) concerns students had about lack of privacy during the immunisation.[290] Interestingly issues of consent and the management of anxiety in students mirrored findings in this thesis, however privacy was not raised by any of the stakeholders with regards to students in specialist schools. Whether this is related to lesser emphasis on the importance of privacy for students with disability is unknown. Other differences in the ethical issues raised were subtler. Although informed consent was discussed by stakeholders in Phase Two of this thesis, it was in the context of parental consent rather than informed student assent, which reflects a different emphasis on agency in decision-making for young people with disability. Anxiety was also discussed in Phase Two, but with an emphasis on anxiety related to a lack of understanding rather than fear of pain. The combination of anxiety and lack of assent in specialist schools raised the specific ethical issue of the use of restraint to immunise in schools. This is an ethical tension in the SBIP unique to the specialist school setting.

9.9.2 Parental consent and student assent

In paediatric health care, parental consent must be sought for any intervention, including immunisations. Informed consent involves ethical concepts of individual choice and autonomy and respect, and is enshrined legally.[291] It involves full disclosure to the individual before the intervention, and assessment of the capacity of the individual to understand the information and make a voluntary decision weighing up the risks and benefits.[291]

In terms of a young child, the historical assumption is that he or she does not have the capacity to fully understand the benefits and risks of the interventions in order to provide consent for him or herself. Therefore, a parent or primary caregiver applies the ‘best interest’ standard in making a decision on behalf of the child.[291] The exception is when the ‘mature minor’ principle may be applied, where a young person is deemed able to make a truly informed decision independent of a parent.

However, it is now recognised as optimal in paediatric practice for a health professional to gain a child or adolescent’s informed assent before any procedure, to a level that is appropriate to age, maturity and cognitive ability. Wasserman, Navin and Verclur (2019) argue that there is, in fact, an obligation to solicit a child’s preferences.[292] While acknowledging that the best interests of the child may supersede the child preferences, which inevitably cause *“moral harm”*, the authors in this commentary suggest that seeking paediatric assent demonstrates respect and acknowledges the value of the child's voice.[292] This includes very young children and those with cognitive impairment.[292]

Assent does not have to be verbal, but can be determined by soliciting *"an expression of the [young person's] willingness to accept the proposed care."*[291] With respect to students with disability, the need for an expression of assent was recognised in the data in Phase Two by some participants such as Anna (school): *"I don't do it against their wish. If they are not looking like they are physically consenting to it."* Yet the alternative view, dismissing the importance of assent from students in special schools, was just as strong, as evidenced by Philippa (school): *"Ok we will do what we need to do. I want them to have the injection. You and I will do what we need to do."*

Anna puts more emphasis on the student's right to refuse than beneficence, and Philippa is prioritising the benefits of immunisation over the autonomy of the student. The question of which value should hold more weight in the context of a student with intellectual disability in a specialist school not demonstrating assent to immunisations offered through the SBIP has not yet been debated in the literature. This discussion is long overdue, as failure to acknowledge this ethical tension leads to a wide variety of practice in the use of restraint and how forcefully immunisations are given in this setting.

9.9.3 Beneficence vs student autonomy: The use of restraint

While there are many examples and commentaries about use and misuse of restraint of students with disability in the Australian school system,[107] the dialogue is largely in the context of behaviour management rather than health care. Debate about use of restraint to give immunisations to students in specialist schools is absent in the health, education and ethical literature. This thesis provides the first data to evidence that restraint is being used in Victorian specialist schools for this purpose, that there are no clear guidelines to inform decision-making in this area, and that it causes moral distress to those making this decision, as well as potential harm to students.

The use of restraint for school immunisations in young people with a disability is complex logistically, ethically and legally. There are no adequate policies or guidelines that cover this issue, and it is somewhat hidden – not documented and not spoken about. The Royal Commission into Violence, Abuse, Neglect and

Exploitation of People with a Disability, launched by the Australian Federal Government in April 2019,[103] serves to reinforce the importance and urgency in ethical discussion, agreed best practice and transparency with regards to any restrictions on an individual's autonomy and freedom.

In Victoria, the guideline for the use of restraint and seclusion in schools was comprehensively revised in 2018, and provides guidance for the use of physical restraint, defined as *"the use of physical force to prevent, restrict or subdue the movement of a person's body or part of their body."*[239] This policy allows for the use of restraint only where the student's behaviour poses an imminent threat of physical harm and danger to self or others and where there is no more conservative option.[239] Specifically, prone and supine restraint on the ground is prohibited and any use of restraint must be reported to DET. If this is strictly adhered to, students should not be held at all for immunisations.[239] Yet there is no specific mention of restraint for health or wellbeing interventions in this policy; it is written primarily as a behaviour management policy. This has led to a wide variety of interpretations, to the extent that, as some school participants verbalised in Phase Two, they do not see the applicability of this policy for immunisations.

More broadly, there are no national guidelines that address the use of restraint in schools in Australia. There are relevant international conventions, such as the *Convention on the Rights of the Child*,[293] and the *Convention on the Rights of Persons with Disabilities*,[88,294] which are the two most applicable ones to which Australia is a signatory. Both these Conventions seek to protect children's liberty and security, protect them from physical violence and ensure their equal access to education and health. The committees for each have stated that restraint in schools should be a last resort, subject to safeguards and only for protective purposes.[295] However, what is clear from the school observations and interviews is that despite these Conventions, there is a wide variety of practice in specialist schools with regards to restraint for immunisations.

This variety of practice included schools where students were not held, even by the hand, during immunisations. Observations suggested these schools had fewer students who presented for immunisation who successfully received the vaccine during the session. In other specialist schools where students were held or restrained, nurses referred to this as *"procedural holding"*; as Yvonne suggested, this is done with younger children in the health care setting and it's *"almost the same thing."* However, some significant differences between immunising young children and adolescents cannot be ignored. Younger children usually have their parents present and are sat on their parents' lap to be cuddled as the procedural holding strategy. In Phase Two, many schools did sit students on a staff member's lap to be held still for immunisations, despite this not being appropriate in a specialist education context, or indeed any context where there is a professional/student relationship. Other ways of holding or restraining a student that were observed in Phase Two included more forceful practices, such as where several staff members surrounded the student sitting in a chair, holding each arm and each shoulder and sometimes also the legs. As in the case of Flynn, there was also evidence of students with disability being held on the ground for their immunisation.

Harm resulting from the restraint of any person, but particularly in the context of persons with disability in institutional settings, is well described in terms of human rights violations as a form of violence and abuse. This includes associated emotional and mental distress and fear, and physical injury, including death.[294] Restraint during immunisations of students with disability was justified by Phase Two participants through implied consent for restraint in the parental consent for immunisation, or the belief that the importance of immunisation, which may not be done if not at school, outweighed student autonomy. Immunisation nurses agreed that restraint would not occur during the SBIP in mainstream schools, and therefore it is a direct consequence of a different interpretation of individual rights in the context of disability. Another justification for restraint used by participants was in order to ensure staff and student safety: *"...if [there] hasn't been a big, male teacher holding them down, then yes, I suppose I have felt a bit unsure, a bit uncertain, a bit concerned"* (Maree, immunisation nurse). This rationale is echoed in the literature on the use of restraint, both for people with disability and challenging behaviours, and people in mental health settings.[296,297]

This discrepancy illustrates the lack of state-wide recommendations about best practice, including safety of staff, when immunising in specialist schools. The absence of such guidelines also results in a grey area with respect to holding or restraining a young person with disability to administer immunisations in the school setting. These guidelines are urgently needed to ensure consistency and transparency of practice, safety of all and working towards eliminating any lasting trauma due to the experience of immunisations for young people with disability.

9.10 Recommendations

Recommendations arising out of the integrated findings of this thesis are as follows:

1. Guidelines and policies relating to the SBIP are inclusive of ungraded schools, both in terminology and in clearly outlining how to determine cohort by age where there is no year level.
2. Ongoing accurate coverage data for ungraded schools should be implemented and coverage data for ungraded school should be included in the aggregate reports of school immunisation data.
3. State government support to local government immunisation teams should be strengthened, initially by increasing formal and informal communication. Ideally, there should be an individual in state government responsible for the SBIP who could act as a direct contact for all schools and immunisation providers.
4. A comprehensive review of the funding model for the SBIP should be initiated, with reforms implemented to adequately adjust for schools that need more time/resources to achieve successful immunisation of all students, and to potentially allow for increased immunisation visits to non-mainstream schools to improve catch-up and follow-up.
5. The process for consent for the SBIP should be made as easy as possible for parents. This urgently requires investment in online consent forms and working with specialist school communities to consider and trial reminder systems, face-to-face information sessions or other interventions as deemed through co-design.
6. The development of clear guidelines about appropriate use of restraint for immunisation of young people with disability in special schools, with input from ethicists, paediatricians, immunisation providers, school staff, parents and young people.
7. The development of a pathway for students who are difficult to immunise at school, which may include assessment of individual circumstance and

initiation of immunisation by community providers through home visits, in outpatients or under sedation in hospital. Schools and parents need to be made aware of these alternate pathways.

9.11 Implementation of Recommendations in Policy and Practice

This thesis has significant implications for immunisation practice for young people with disability, but also potentially for other disadvantaged sub-populations. Most importantly, this thesis illustrates the need for policies to consider whose needs are being met, and who is invisible. Invisibility of a population, such as those with disability, in public health policy implies that current policies and practices are not truly inclusive. This thesis has outlined the need for targeted resources, funding and support for immunisation policies for young people with disability, as well as the urgent development of ethically informed guidelines about best practice for immunisation in specialist schools, including the ethical and legal use of restraint. The recommendations outlined in this chapter can be reflected in policy and implemented in practice in a sustainable and impactful way by using the WHO Tailoring Immunisation Program (TIP) process.

9.11.1 Tailoring support

The concept of individualising immunisation programs to overcome specific barriers in disadvantaged groups is the basis for the WHO Tailoring Immunisation Program (TIP). This program was developed by the WHO European Regional Office in 2013, reviewed in 2017 and revised in 2019.[298] In those six years, projects in sub-populations vulnerable to under-immunisation in twelve countries were undertaken utilising the TIP approach. This has included immunisations in migrant and transient populations, orthodox Jewish communities and pregnant women.[299] The three pillars within TIP aim to use a framework to assess the context, identify barriers and targeted interventions to improve immunisation uptake, which are tailored to the setting and population. This is a useful strategy in LMICs and has also been applied to immunisation efforts in sub-populations in high income countries like Australia.[273]

There are many parallels between the formative phases within the TIP process and the research within this thesis. In formal evaluation, the strengths of TIP are noted to be inclusion of in-depth qualitative research, and identifying, listening to and developing relationships with stakeholders central to the sub-populations and specific environment.[299] These are aspects that are also of key importance in this thesis. In addition, there is a focus in the TIP, not only on the behavioural factors that impact immunisation uptake, but also the *"contextual, social and societal mechanisms which support the behaviour."*[298] This mirrors the framework of the SEM in this thesis, with an appreciation that immunisation uptake is affected by factors beyond the individual. However, interestingly the TIP utilises a broad behaviour change framework that focuses on Capability, Opportunity and Motivation for Behaviour to occur (COM-B), rather than an ecological model. This enables structural and societal supports, which are commonly the outer layers of an ecological model, to be comprehensively considered in this behavioural model, and in doing so, emphasises the need for a broad understanding of barriers and facilitators to immunisation. Therefore, the modification to COM-B in this established international program to support immunisation in sub-populations supports the appropriateness of a broad ecological framework to structure this thesis.

The parallels between the work of this thesis and the first phases of the TIP process allows for guidance in order to translate the findings into interventions which can be incorporated into policy and practice. The work in this thesis covers Phase One and Two of the TIP process, as illustrated in Figure 9-1. Therefore, continuing work arising from this thesis could follow the TIP format from Phase Three – intervention design.

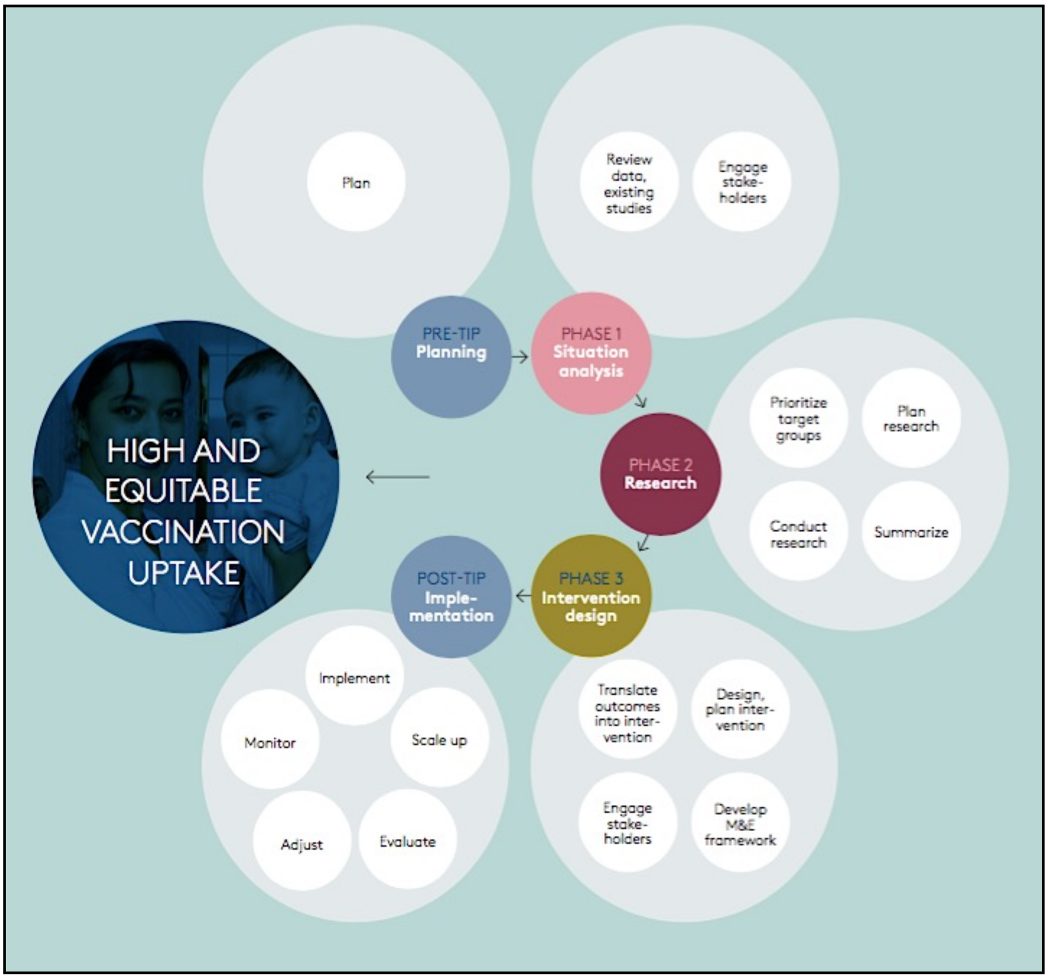

Figure 9-1 The TIP Process

Source: WHO Regional Office for Europe, Tailoring Immunizations Programmes, 2019

The process sets out a structure to work through stages of planning of the intervention/s, including key interventions, budget and ongoing evaluation. Similar to the recommendations arising out of Integrated Inference 2 of this thesis, the TIP intervention design phase suggests it should occur by co-design, in conjunction with the community for which the intervention is aimed. All seven recommendations outlined in this chapter could be assessed using this structure, by defining the intervention and determining how policy could support that intervention, and then prioritising each according to affordability, feasibility, equitability and potential effectiveness. Utilising the TIP resources in this way would be a natural progression of this work and has been previously tested in terms of translating research findings and community consultation into policy and practice change.

9.12 Strengths, Limitations and Further Research

9.12.1 Strengths of the research

True to mixed methods methodology, the qualitative and quantitative phases of this thesis were integrated.[220] These points of integration included in the design and methods phases, as discussed in Chapter 6, and the interpretation and reporting phase presented in a joint display table and narrative weaving, as illustrated in this chapter.[223] This allowed for analysis and reporting of complexity. Complexity was also encouraged through the use of the SEM as a framework, which appreciated and included the perspectives of stakeholders from policy, community, institutional, interpersonal contexts and the use of observations for proxy individual perspectives.

There was triangulation within data collection methods and participant perspective. This provided the ability to confirm findings from multiple perspectives but also resulted in rich thick description, which is necessary for in-depth understanding of an issue. Other elements of rigour were maintained throughout the study, including a continuous reflexivity, which allowed for acknowledgement of the Researcher's clinical background as a nurse and how this influenced her stance on immunisation, disability and health care equity, and her responses to information from data and from the participants. A multidisciplinary team of supervisors also ensured a number of perspectives of the data were considered.

9.12.2 Limitations of the research

In addition to the limitations of the research in Phase One, as outlined in Chapter 3, there were other limitations pertaining to Phase Two and the integration of the thesis overall. It must be acknowledged that these data apply to the sub-section of young people with disability who attend specialist schools, not those with disability in mainstream schools. The difficulty in identifying those with disability in Australian mainstream schools is the reason for this. Havercamp and Krahn (2019) report this as the *"denominator issue"* in disability research, where data are only based on those receiving services or that are known from enrolment in programs.[257] During the time period of this research, the Nationally Consistent Collection of Data on Students with Disabilities,[§§§] has been established in an attempt to maintain an accurate database of

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[§§§] The Nationally Consistent Collection of Data on Students with Disabilities has been established by students with disability in all schools for funding purposes. This marks the first such aggregate information on students with disability collected. However, the ability for this information to be used for research is not established.

While the number of students and schools involved in this research was small, this was the inherent nature of exploring immunisation in a minority population and is part of the reason for the invisibility of this group. Thus, it is paradoxical to name participant number as a limitation of the research. While the specificity of focus on specialist schools in Victoria, Australia, does limit generalisability, situating the findings of the research, as is described in this chapter, does reflect the experiences and realities of health interventions and health equity issues for other minority populations. Thus, while the data may not be broadly generalisable, the concepts and application of methodology could have wide applicability.

In retrospect there were limitations in identifying key stakeholders for interview. Data in Chapter 8 illustrates the importance of teachers and aides and the role of GPs for young people during immunisation, however these groups were not specifically recruited to be interviewed. School immunisation coordinators were identified as the key stakeholders in the institutional level, as they are the staff involved in all school aspects of the SBIP. Some of these positions are held by teachers, but certainly the importance of the voice of classroom teachers and aides was underestimated and exclusion of these is a limitation of this research.

General Practitioners were not included in this research as they are not included in organisation or administration of the SBIP. However their role as default immunisers for those young people who cannot be immunised in the schools has now been described in the thesis. Future planned work is inclusive of GPs in discussions about adolescent vaccination in young people with disabilities.

It must be acknowledged that it was particularly difficult to recruit parents and disappointingly, no young people were able to be interviewed. There was an assumption made that parents may be able to be recruited through specialist schools. However, in reality there were restrictions on this in relation to the majority of schools involved that had policies preventing advertising to families for research recruitment through school channels. Although multiple other recruitment methods

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the Australian Federal Government. For more information see: https://www.nccd.edu.au were attempted, there was very little uptake by parents of recruitment requests. The reasons for this are not clear and need to be explored in future research.

Young people could be interviewed with their parent's permission if they were able to verbally participate. Unfortunately, none of the children of parents engaged in this project met this criterion. Best practice in qualitative research, particularly with youth and people with disability, is direct participation by those individuals in the research. While observations allowed a proxy understanding of the young person's experience during immunisation, the absence of the young person's voice was a limitation of this research. This emphasises the vital role of co-design in any subsequent interventions arising from this thesis.

As this thesis focused on the adolescent immunisations received at schools, it did not explore adolescent immunisations provided to young people with disability in the community and hospital settings. There were some assumptions expressed by participants that young people with disability would be linked in with GPs and paediatricians and therefore would be receiving their immunisations outside the school setting, and indeed, this possibility was not excluded in this thesis. However, also expressed was a very strong belief from immunisation nurses and schools that if the young person did not receive their adolescent immunisations at school, they would not receive them at all, as well as statements about lack of regular health care input for many of the young people with disability. The role of health care providers in recommending and administering vaccines to young people with disability is a topic which needs further research, including eliciting the views and beliefs of the health providers about adolescent immunisation in young people with disability. Meanwhile, there is no evidence to date that significant numbers of these young people are receiving adolescent immunisations outside the school system. In addition, there are suggestions that rather than assume this is the default, there is an opportunity to promote opportunistic immunisation at every health care encounter for young people with disability. Many studies support the important role of health provider recommendation in immunisation uptake, and this specifically includes children with chronic medical conditions.[167,300–302] Despite this, none of the parents in this thesis had discussions about immunisations initiated by their GP, or the (sometimes many) specialists involved in their child's care. This illustrates missed opportunities to follow-up and catch-up vaccines for an under-immunised and medically vulnerable population.

9.12.3 Further research

As well as the suggested continuation of this work in terms of co-design and implementation and evaluation of interventions based on the recommendations in this chapter, this thesis gives rise to other further research. There remains a paucity of qualitative research on immunisation of young people with a disability, and in particular, the voice of the young people themselves would be invaluable to elicit. As also mentioned, research is needed on community provider opinions and practices about immunising young people with a disability. This will allow for provider influences on immunisation for this population to be explored and optimised. In addition, gaps have been identified in understanding the experience of immunisation for people with disability in LMICs.

More broadly, ethical tensions in immunisation practice require open discussion in academic and clinical arenas. This is in relation to people with disability, but also for other populations where the concepts of health equity, informed consent, informed assent, autonomy and fear, distress and anxiety are unspoken and undocumented. Acknowledging the moral dilemmas in the everyday practice of immunising ensures transparency and allows practical support in the form of informed debate, best practice guidelines and ongoing discussion in the context of changing values.

9.13 Conclusions

This thesis has made important contributions to the research on immunisation of young people with disability. Most significantly, this work has identified the absent data on coverage in specialist schools and has provided the first Victorian figures on coverage of adolescent vaccinations given through the SBIP in specialist schools. The second phase of the thesis is the first qualitative research internationally on immunisation in children or young people with disability, and the use of the SEM as a framework has allowed the complexity of multiple layers of influence to be captured. The results from Phase One and Phase Two, as well as the integrated inferences from the combined phases, have resulted in new data that have critical policy and practice implications. This includes evidence about significant under-immunisation of young people with disability in specialist schools through the SBIP, and the absence of data from ungraded schools in aggregate data reports in Victoria. Other novel findings include the identification of unique barriers to immunising in this population, such as the need for targeted funding and resources, an understanding of the priorities of the population and the challenges of managing anxiety in young people with disability. An unanticipated aspect of this study was lack of guidelines, discussion and support for ethical decision-making in the SBIP in specialist schools, particularly with regards to the use of restraint.

The outcome of this thesis includes seven recommendations that could be implemented during a third phase of research using the WHO TIP process, which provides guidelines to develop, implement and evaluate interventions to increase equity in immunisation coverage in sub-populations. These interventions could not only improve coverage of adolescent immunisations for young people with a disability, and therefore reduce preventable disease, but could improve the SBIP process for immunisation teams, school staff and parents, as well as students. The population of young people with disability would become visible in immunisation policies, and this would be an example of working towards health equity that could be applied to other preventative health measures in minority populations.

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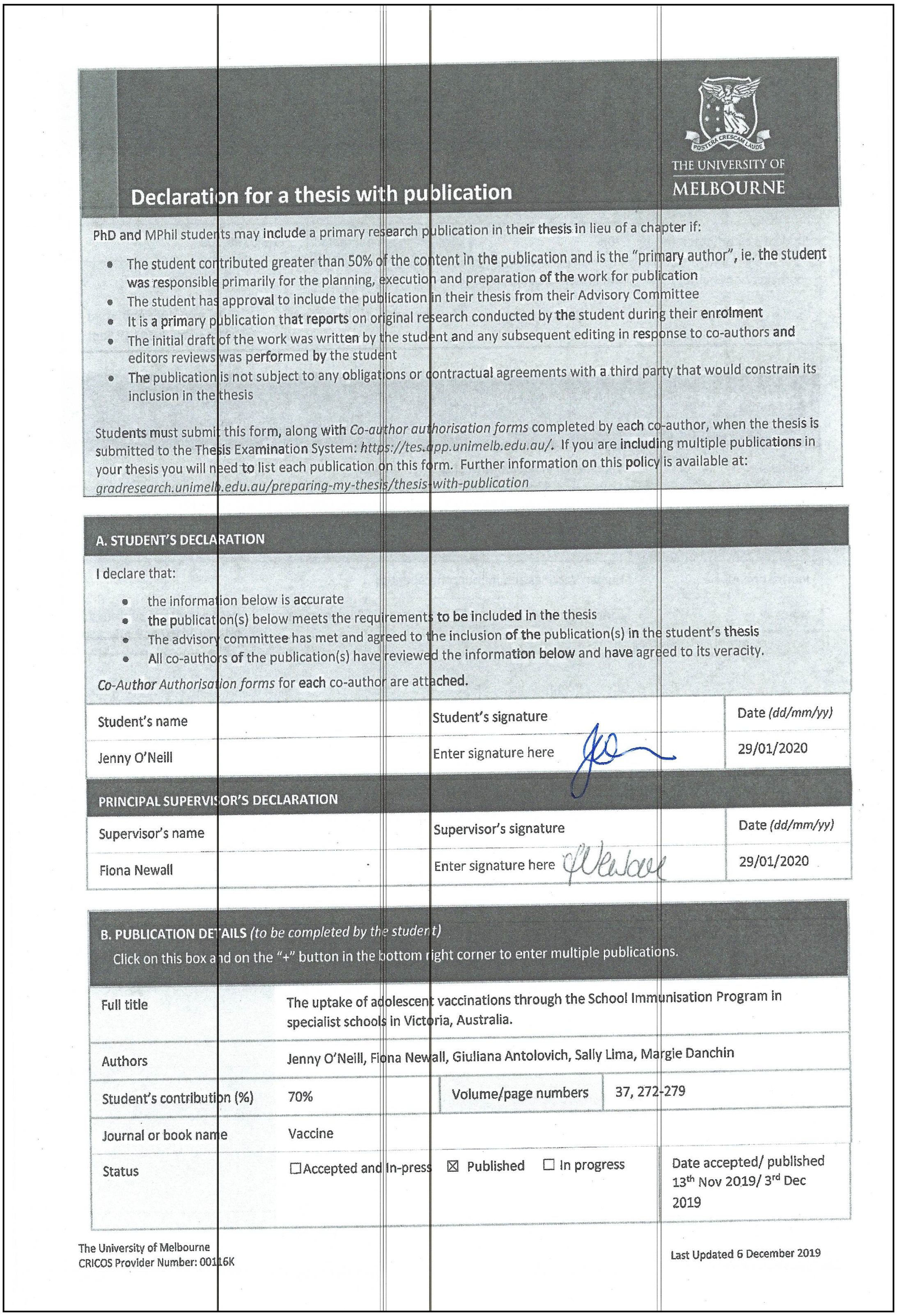
APPENDICES

APPENDIX A: DECLARATION OF THESIS WITH PUBLICATION



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Declaration for a thesis with publication

PhD and MPhil students may include a primary research publication in their thesis in lieu of a chapter if:

- The student contributed greater than 50% of the content in the publication and is the "primary author", ie. the student was responsible primarily for the planning, execution and preparation of the work for publication
- The student has approval to include the publication in their thesis from their Advisory Committee
- It is a primary publication that reports on original research conducted by the student during their enrolment
- The initial draft of the work was written by the student and any subsequent editing in response to co-authors and editors reviews was performed by the student
- The publication is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in the thesis

Students must submit this form, along with *Co-author authorisation forms* completed by each co-author, when the thesis is submitted to the Thesis Examination System: *https://tes.app.unimelb.edu.au/*. If you are including multiple publications in your thesis you will need to list each publication on this form. Further information on this policy is available at: *gradresearch.unimelb.edu.au/preparing-my-thesis/thesis-with-publication*

A. STUDENT'S DECLARATION

I declare that:

- the information below is accurate
- the publication(s) below meets the requirements to be included in the thesis
- The advisory committee has met and agreed to the inclusion of the publication(s) in the student's thesis
- All co-authors of the publication(s) have reviewed the information below and have agreed to its veracity.

Co-Author Authorisation forms for each co-author are attached.

Student's name	Student's signature	Date *(dd/mm/yy)*
Jenny O'Neill	Enter signature here	29/01/2020

PRINCIPAL SUPERVISOR'S DECLARATION

Supervisor's name	Supervisor's signature	Date *(dd/mm/yy)*
Fiona Newall	Enter signature here	29/01/2020

B. PUBLICATION DETAILS *(to be completed by the student)*

Click on this box and on the "+" button in the bottom right corner to enter multiple publications.

Full title	The uptake of adolescent vaccinations through the School Immunisation Program in specialist schools in Victoria, Australia.		
Authors	Jenny O'Neill, Fiona Newall, Giuliana Antolovich, Sally Lima, Margie Danchin		
Student's contribution (%)	70%	Volume/page numbers	37, 272-279
Journal or book name	Vaccine		
Status	☐Accepted and In-press ☒ Published ☐ In progress		Date accepted/ published 13th Nov 2019/ 3rd Dec 2019

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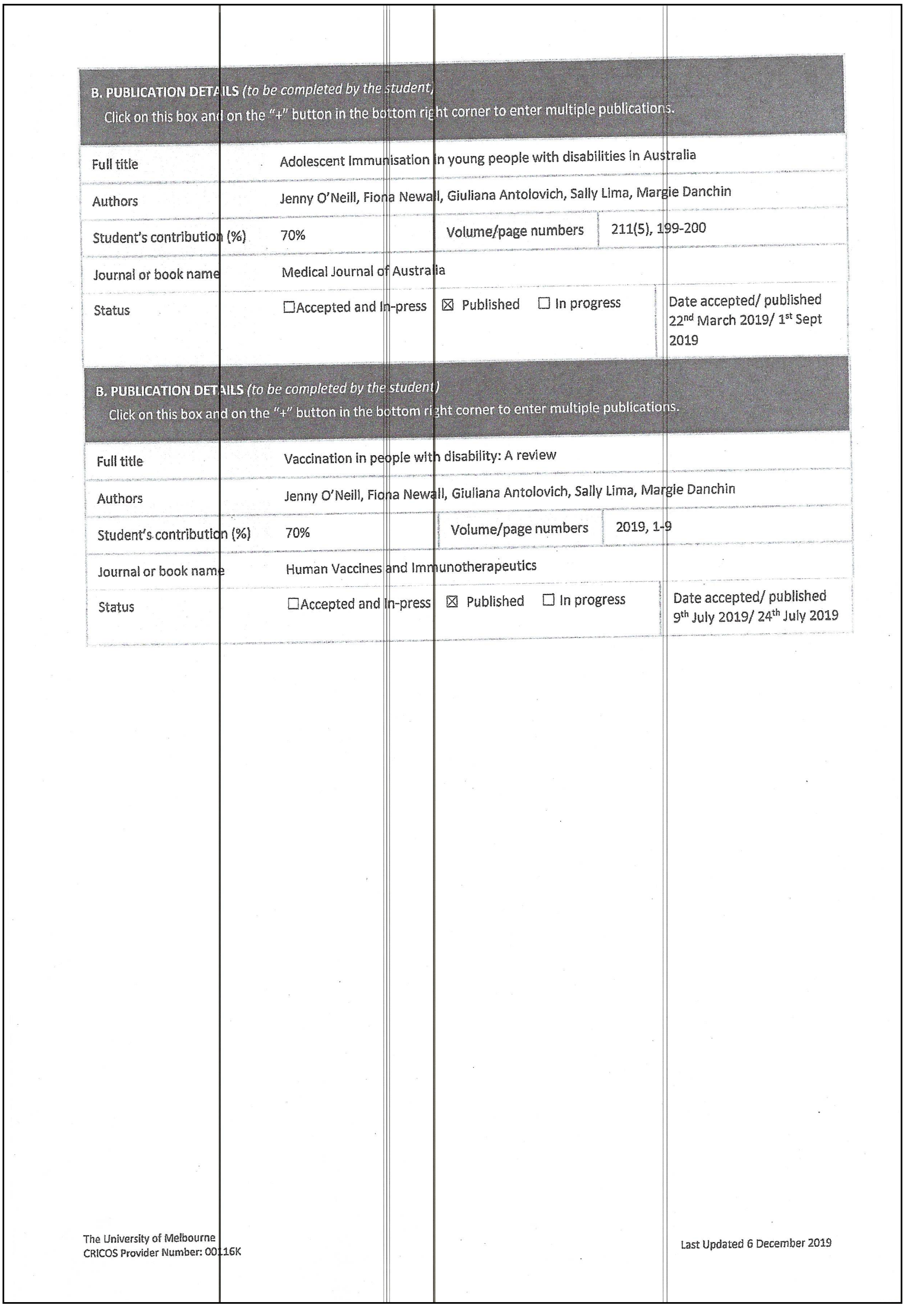
Last Updated 6 December 2019



B. PUBLICATION DETAILS *(to be completed by the student)*

Click on this box and on the "+" button in the bottom right corner to enter multiple publications.

Full title	Adolescent Immunisation in young people with disabilities in Australia		
Authors	Jenny O'Neill, Fiona Newall, Giuliana Antolovich, Sally Lima, Margie Danchin		
Student's contribution (%)	70%	Volume/page numbers	211(5), 199-200
Journal or book name	Medical Journal of Australia		
Status	☐Accepted and In-press ☒ Published ☐ In progress		Date accepted/ published 22nd March 2019/ 1st Sept 2019

B. PUBLICATION DETAILS *(to be completed by the student)*

Click on this box and on the "+" button in the bottom right corner to enter multiple publications.

Full title	Vaccination in people with disability: A review		
Authors	Jenny O'Neill, Fiona Newall, Giuliana Antolovich, Sally Lima, Margie Danchin		
Student's contribution (%)	70%	Volume/page numbers	2019, 1-9
Journal or book name	Human Vaccines and Immunotherapeutics		
Status	☐Accepted and In-press ☒ Published ☐ In progress		Date accepted/ published 9th July 2019/ 24th July 2019

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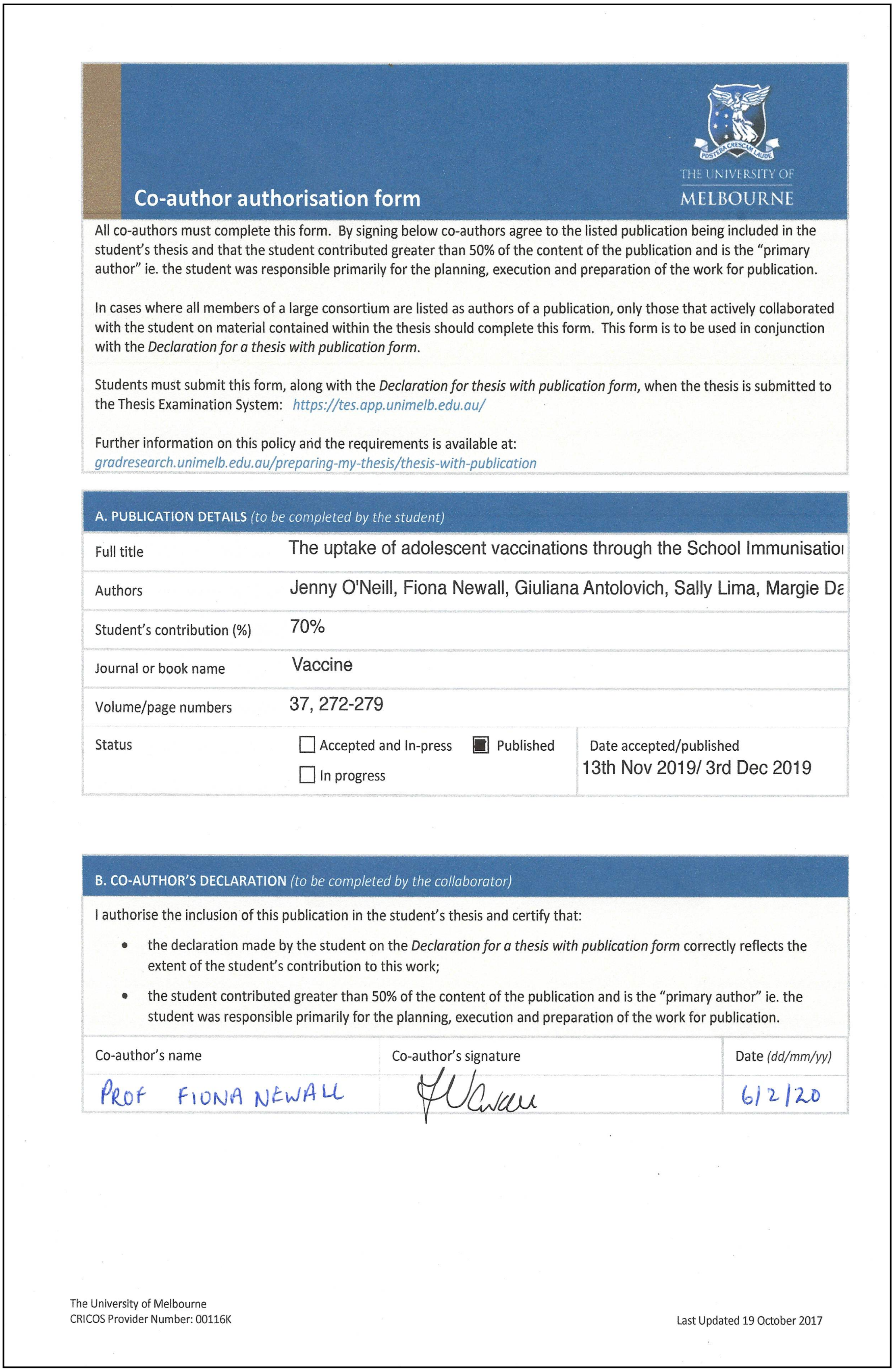
APPENDIX B: CONTRIBUTION OF AUTHORS



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Co-author authorisation form

All co-authors must complete this form. By signing below co-authors agree to the listed publication being included in the student's thesis and that the student contributed greater than 50% of the content of the publication and is the "primary author" ie. the student was responsible primarily for the planning, execution and preparation of the work for publication.

In cases where all members of a large consortium are listed as authors of a publication, only those that actively collaborated with the student on material contained within the thesis should complete this form. This form is to be used in conjunction with the *Declaration for a thesis with publication form*.

Students must submit this form, along with the *Declaration for thesis with publication form*, when the thesis is submitted to the Thesis Examination System: *https://tes.app.unimelb.edu.au/*

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gradresearch.unimelb.edu.au/preparing-my-thesis/thesis-with-publication

A. PUBLICATION DETAILS *(to be completed by the student)*

Full title	The uptake of adolescent vaccinations through the School Immunisatio	
Authors	Jenny O'Neill, Fiona Newall, Giuliana Antolovich, Sally Lima, Margie Da	
Student's contribution (%)	70%	
Journal or book name	Vaccine	
Volume/page numbers	37, 272-279	
Status	☐ Accepted and In-press ☒ Published ☐ In progress	Date accepted/published 13th Nov 2019/ 3rd Dec 2019

B. CO-AUTHOR'S DECLARATION *(to be completed by the collaborator)*

I authorise the inclusion of this publication in the student's thesis and certify that:

- the declaration made by the student on the *Declaration for a thesis with publication form* correctly reflects the extent of the student's contribution to this work;
- the student contributed greater than 50% of the content of the publication and is the "primary author" ie. the student was responsible primarily for the planning, execution and preparation of the work for publication.

Co-author's name	Co-author's signature	Date *(dd/mm/yy)*
PROF FIONA NEWALL		6/2/20

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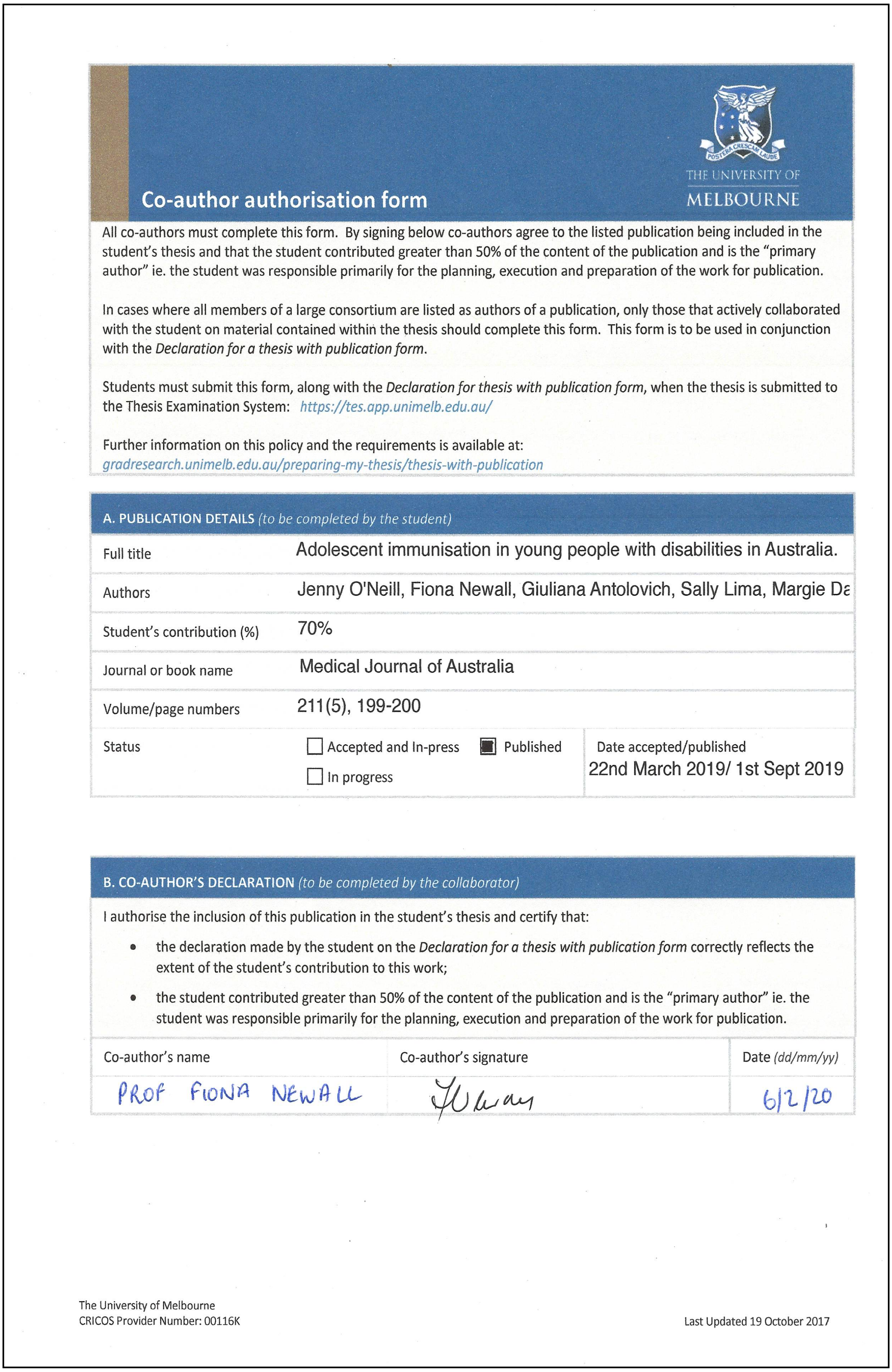

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All co-authors must complete this form. By signing below co-authors agree to the listed publication being included in the student's thesis and that the student contributed greater than 50% of the content of the publication and is the "primary author" ie. the student was responsible primarily for the planning, execution and preparation of the work for publication.

In cases where all members of a large consortium are listed as authors of a publication, only those that actively collaborated with the student on material contained within the thesis should complete this form. This form is to be used in conjunction with the *Declaration for a thesis with publication form*.

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Journal or book name	Medical Journal of Australia	
Volume/page numbers	211(5), 199-200	
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PROF FIONA NEWALL		6/2/20

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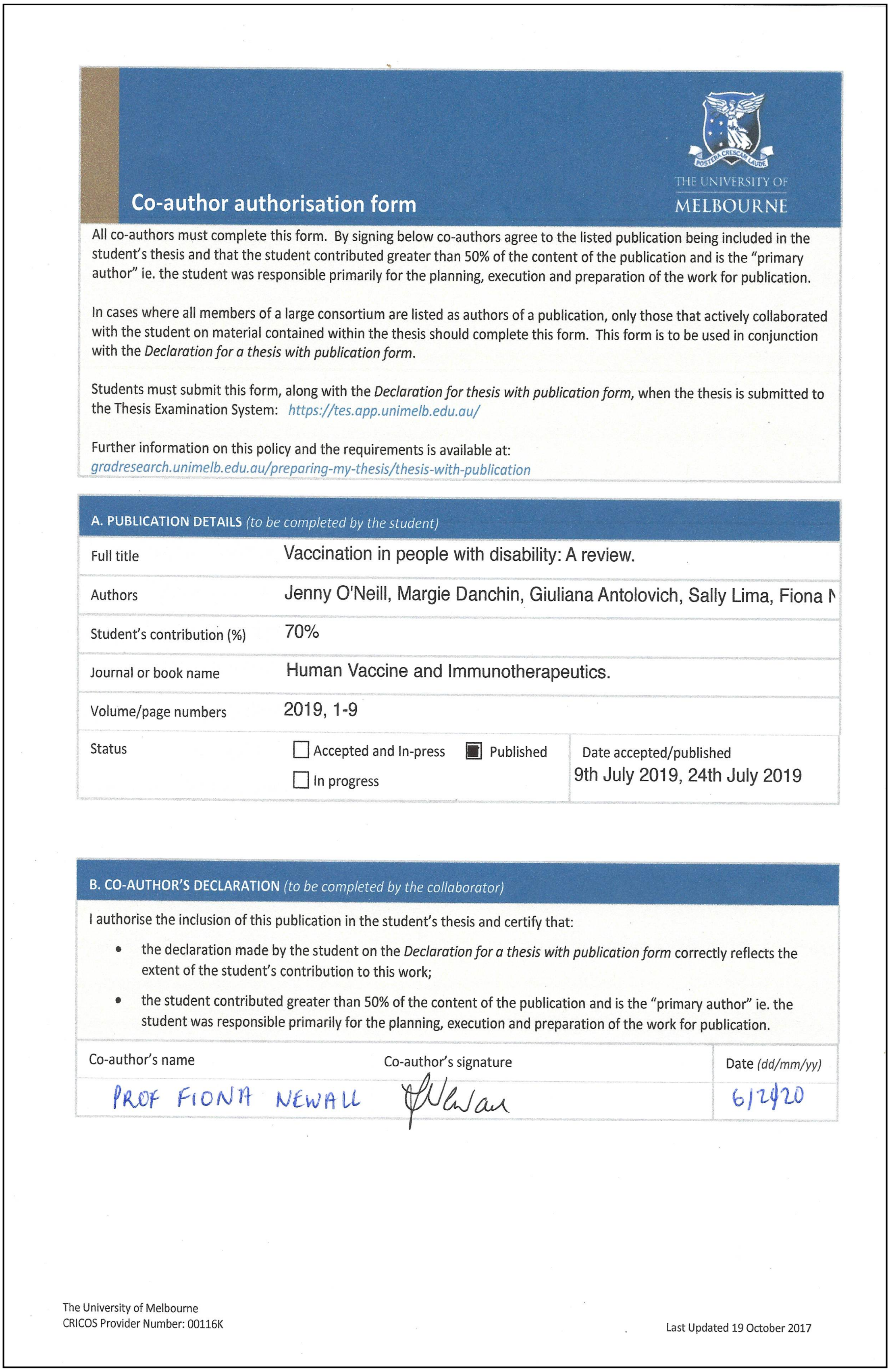

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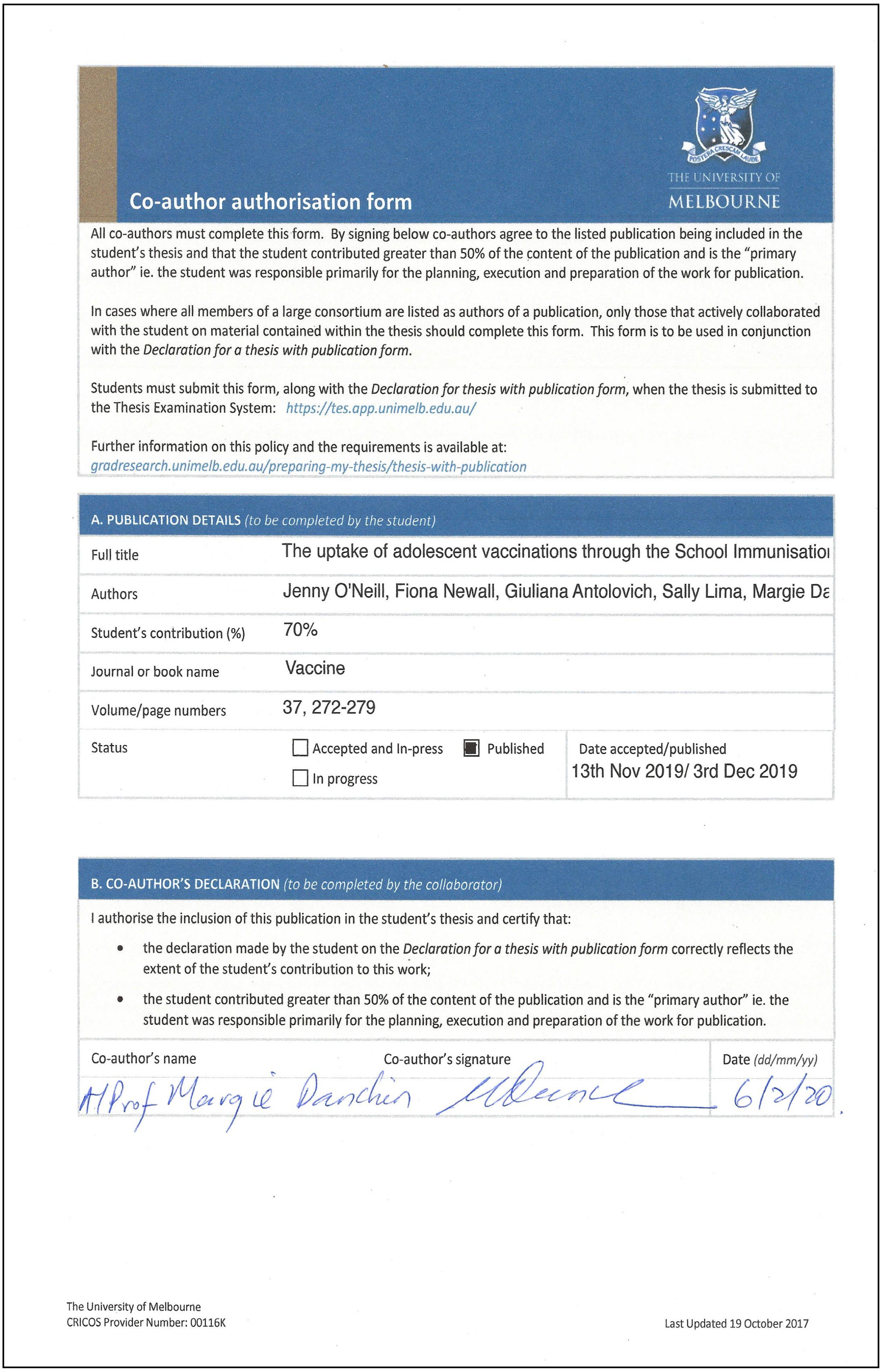

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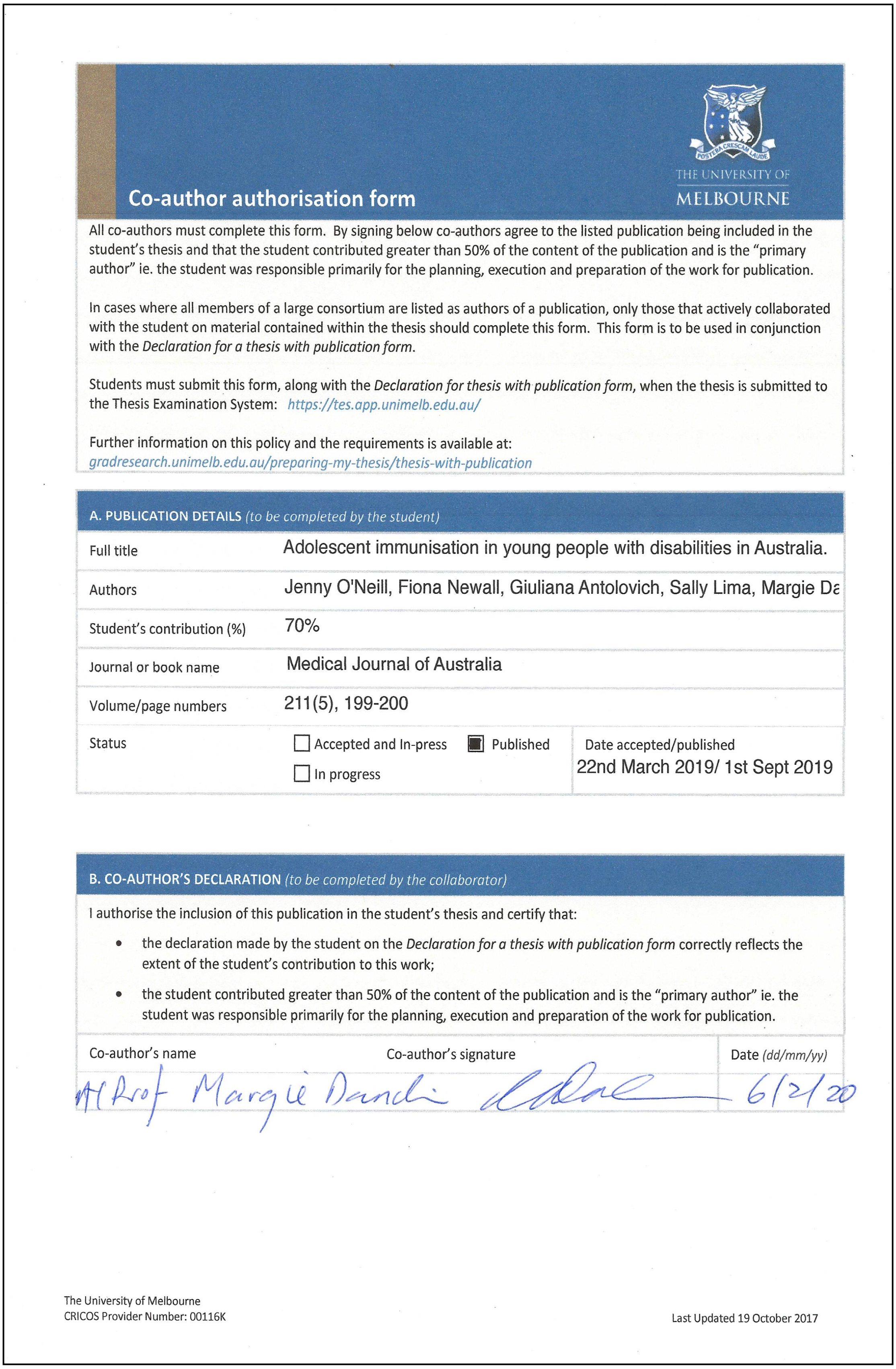

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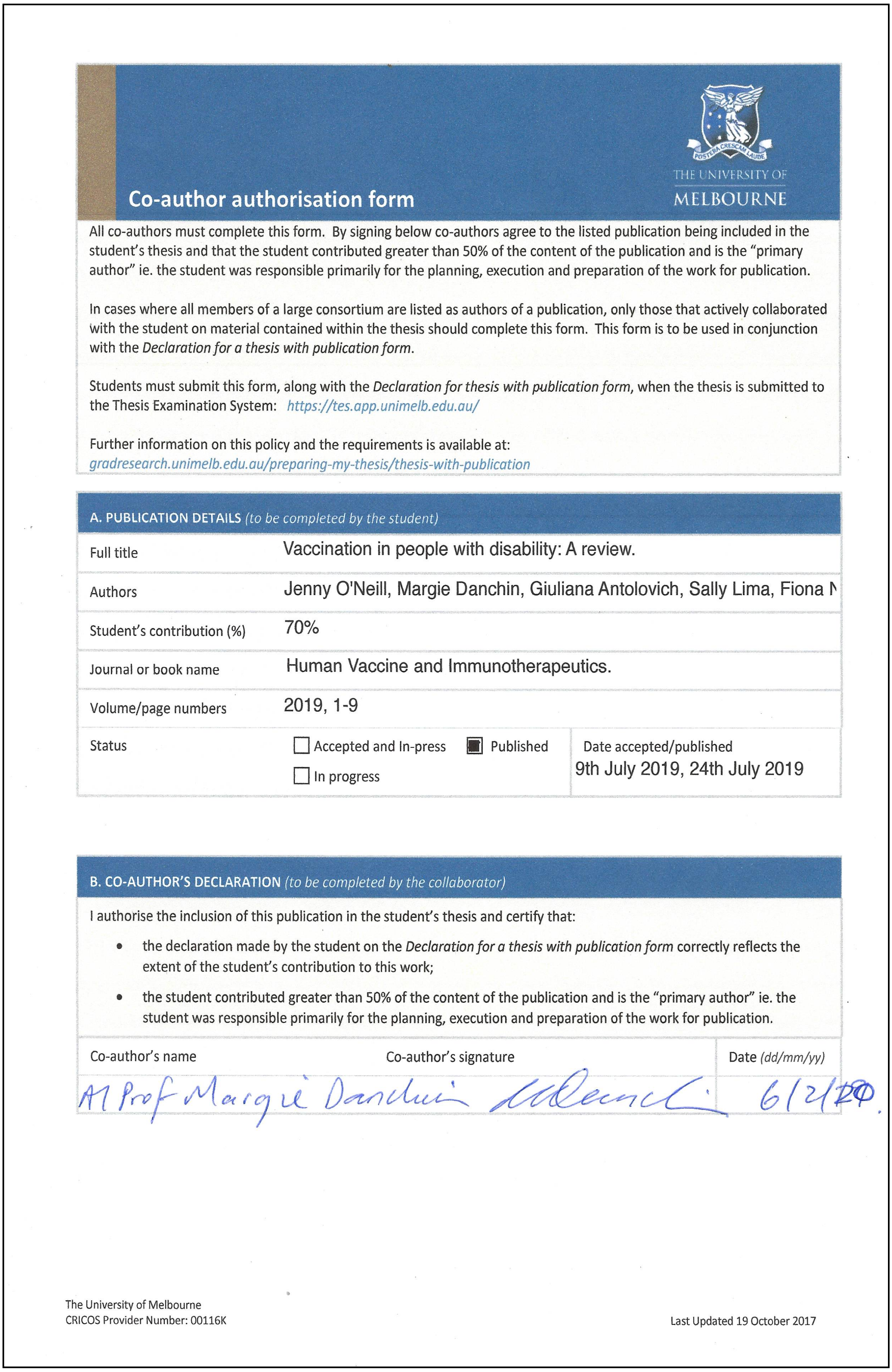

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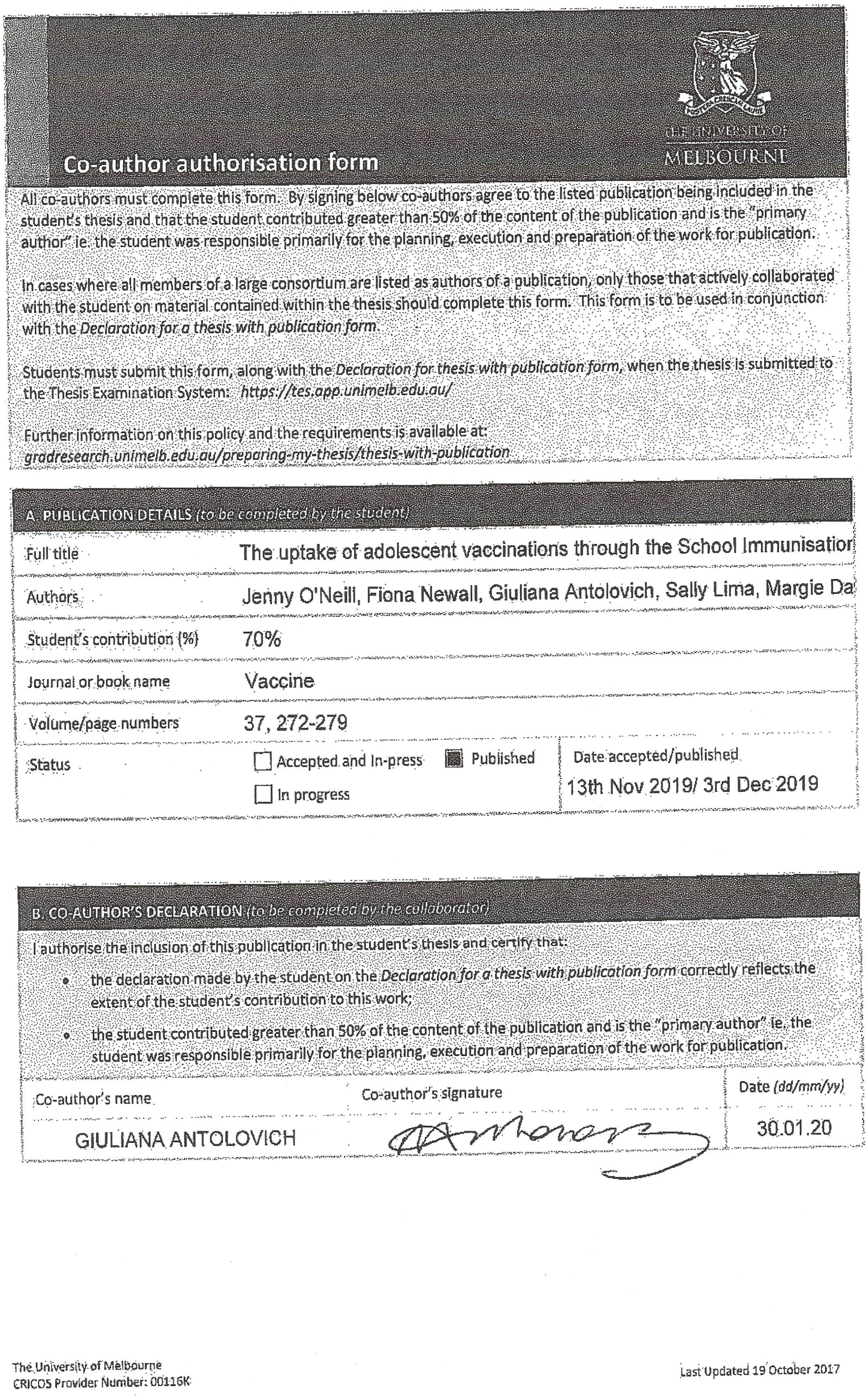

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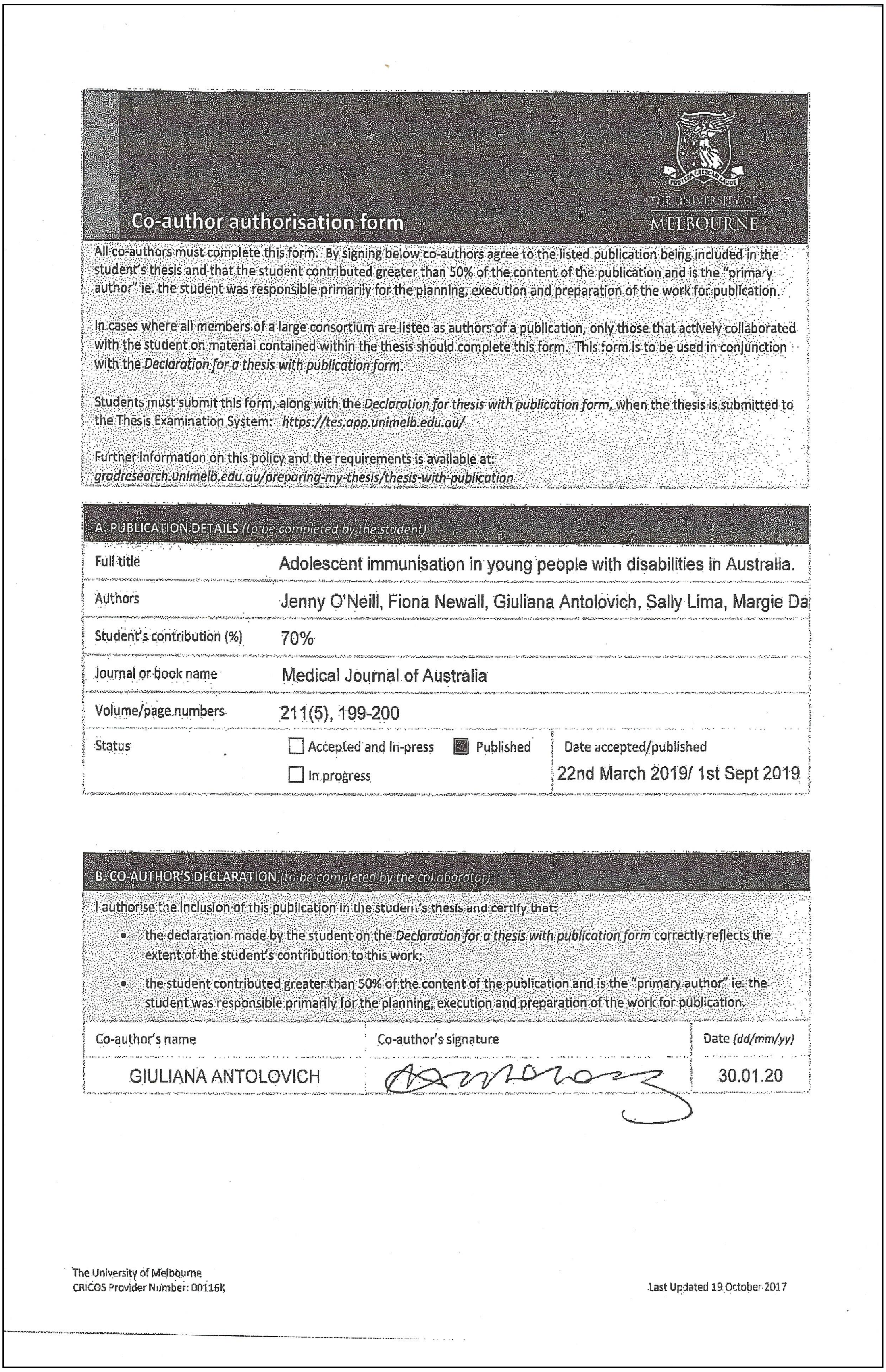

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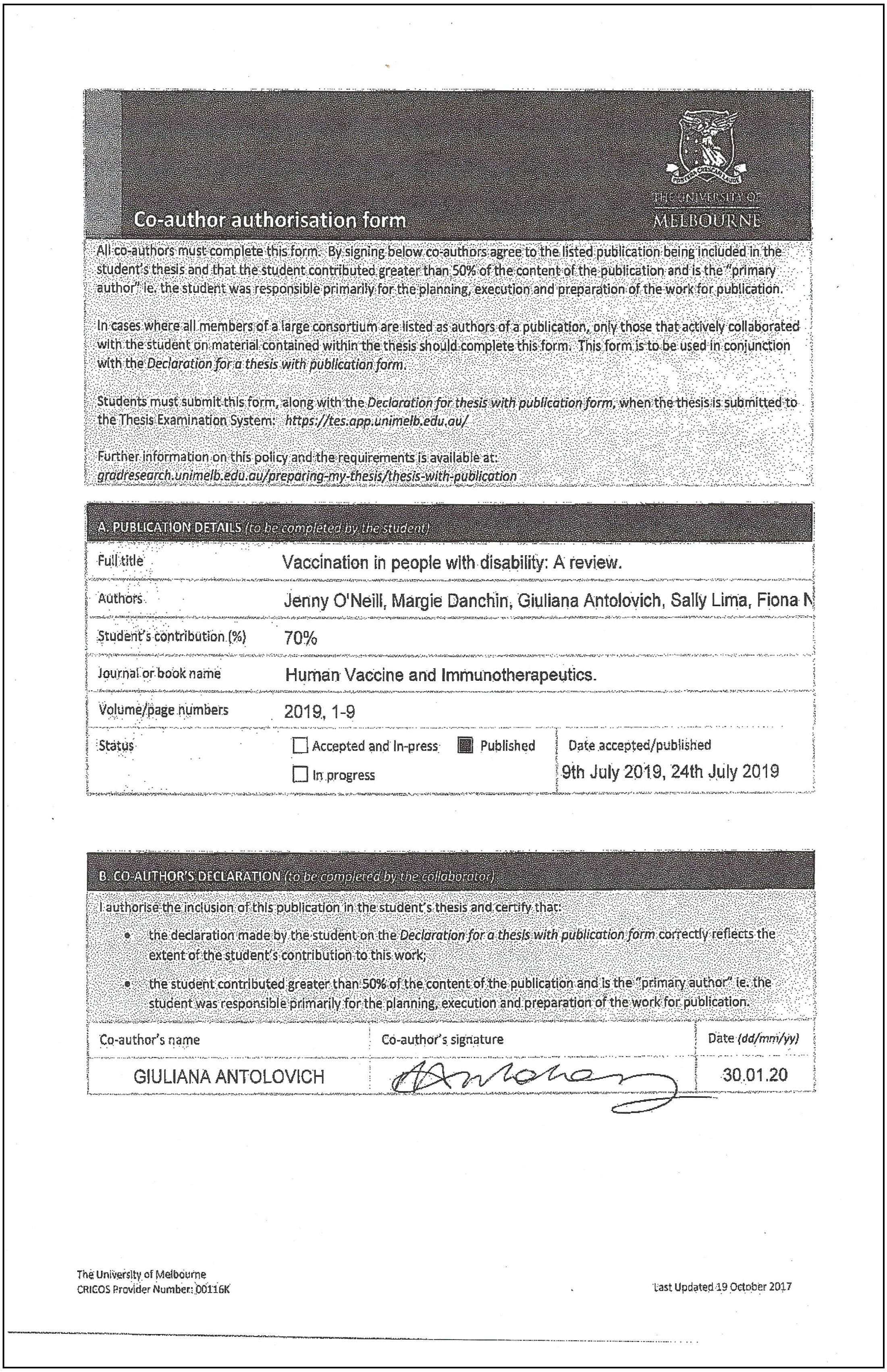

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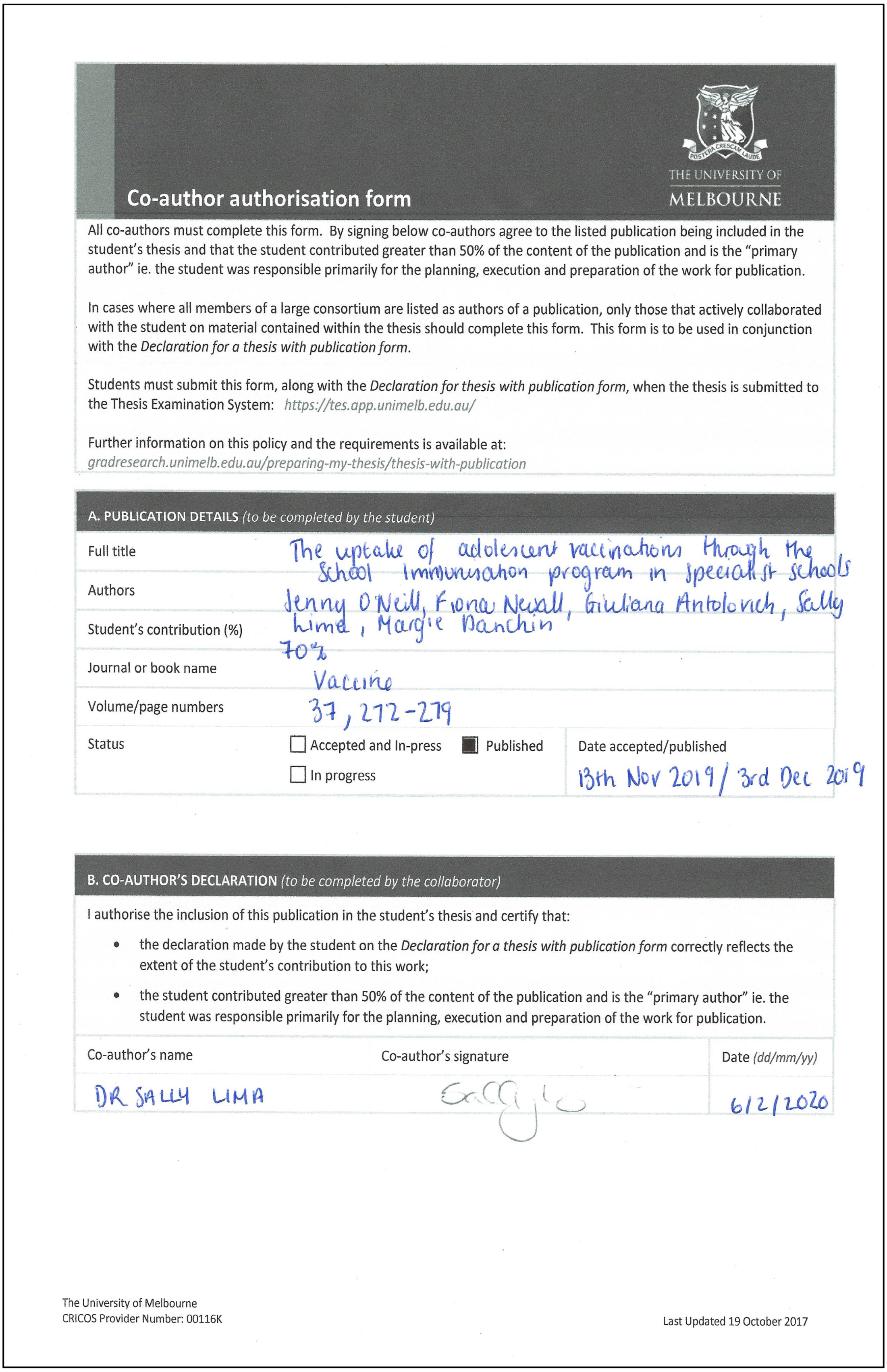

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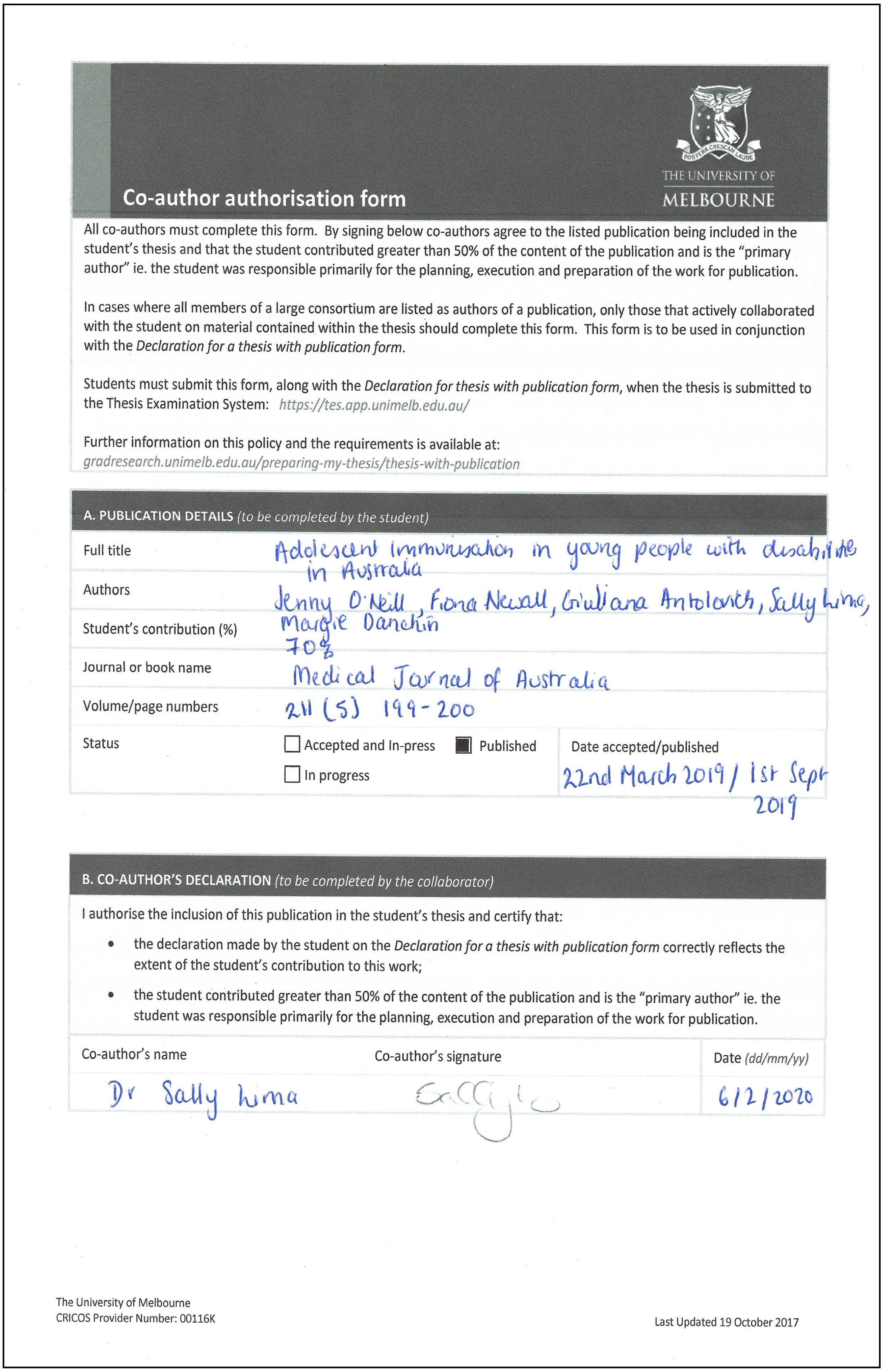

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Dr Sally Lima		6/2/2020

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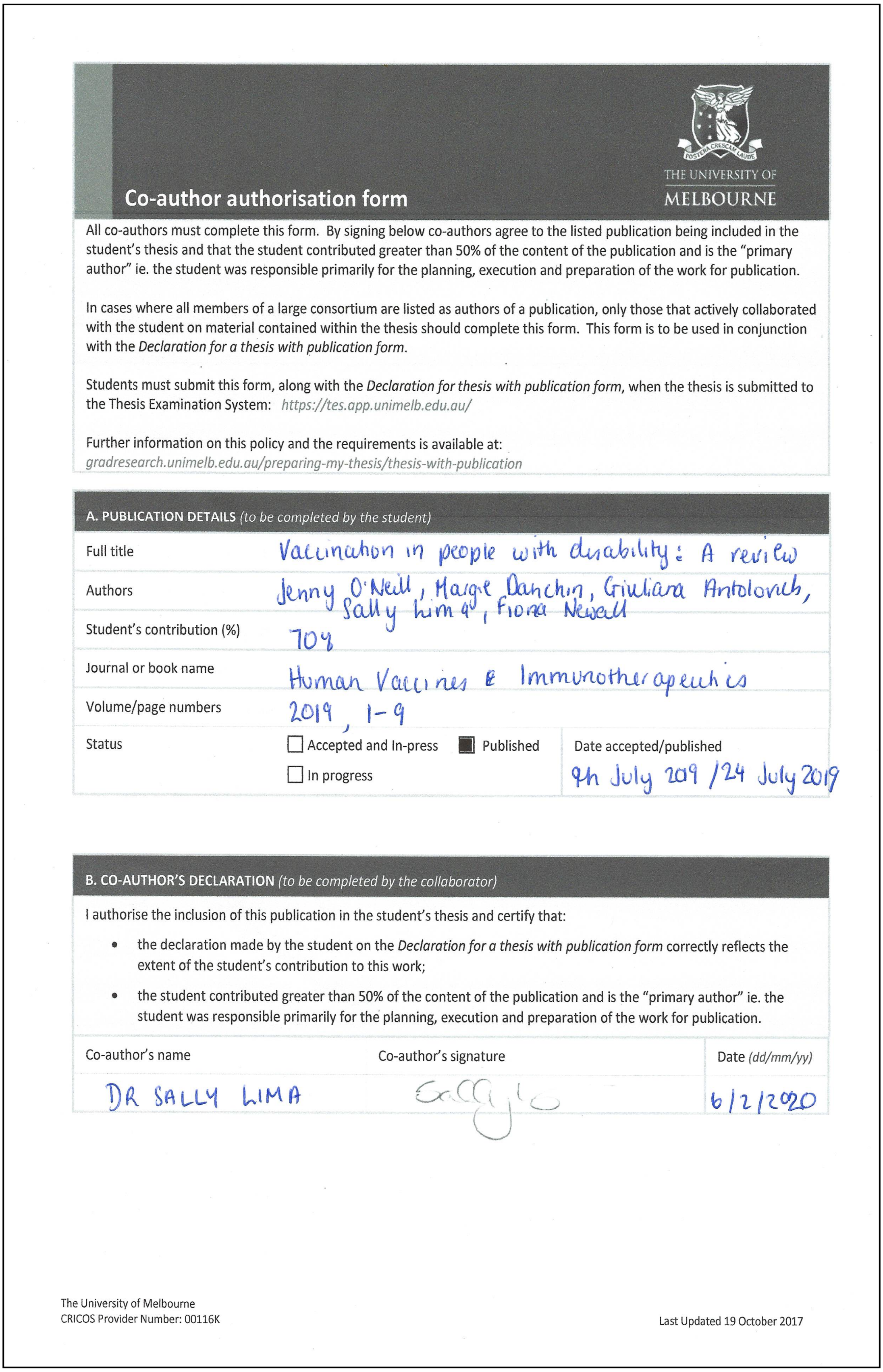

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DR SALLY LIMA		6/2/2020

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APPENDIX C: LITERATURE REVIEW PUBLICATION

Author submitted version of published article:

O'Neill, J, Newall, F, Antolovich, G, Lima, S, Danchin, M. Vaccination in people with disability: a review. Hum Vaccin Immunother. 2020;16(1):7-15. DOI: 10.1080/21645515.2019.1640556

Final published version available online at the Taylor & Francis Ltd web site: www.tandfonline.com. Link: https://tandfonline.com/doi/full/10.1080/21645515.2019.1640556

Vaccination of people with disabilities: a review

Abstract: People with disabilities are vulnerable to complications from vaccine-preventable diseases, and every effort should be made to ensure equitable access to immunization for this population. This paper aims to summarize the research on immunizations in people with disabilities, in order to ensure a comprehensive understanding of knowledge in this area and direct further research. The literature is weighted towards coverage data that is difficult to synthesize because of the different definitions of disability, and the variety of settings, vaccinations and age groups across the studies. In depth qualitative data and data from a variety of health care providers and people with disability is notably lacking. This is vital to redress in order to develop effective immunisation interventions in this population.

Keywords: immunization, disability, health, equity

Immunization is arguably the most successful public health initiative of all time,[1] through prevention of death and reduction in disease severity, complications and disability. Effective immunization programs also improve health equity for vulnerable groups in society who have a higher burden of vaccine preventable diseases (VPDs).[2,3] However, there appears to be a disconnect in identifying the need for the prevention of disability by immunization against VPDs and efforts to ensure optimal protection in those with existing disability. Underlying disability, particularly physical disability or disability related to prematurity, predisposes an individual to respiratory illness and more severe respiratory compromise from viral and bacterial infections.[4] Disability is as a factor in a disproportionate number of hospitalizations and complications, including death, from varicella[5] and influenza.[6–11]

The Tailoring Immunization Program (TIP) framework, developed by the World Health Organization (WHO), identifies barriers to immunization in under-vaccinated populations. [12,13] This approach has been used in migrant and transient populations, orthodox Jewish communities, and pregnant women, leading to targeted interventions to improve uptake for these groups. However, unlike other vulnerable and medically at-risk groups, strategies to improve vaccine uptake in people with physical and/or intellectual disabilities, who face considerable access and acceptance barriers, have not been explored. This literature review aims to summarize the state of knowledge about vaccination in people with disability, in order to establish this group as a population vulnerable to under-immunization and to identify areas for further research and intervention.

Definitions of disability

The International Classification of Functioning, Disability and Health (ICF) is a broad measure of disability based on impairments of body function, activity limitations and participation restrictions.[14] Data from WHO suggests that 15% of the world's population has some impairment in function, with 2-4% having significant difficulties with activities of daily living.[15] This includes those with disability due to aging, mental illness, trauma and chronic illness as well as those with physical and intellectual disabilities diagnosed early in life.

The ICF classification incorporates environmental factors that impacts on an individual's ability to participate. This definition of disability therefore goes beyond the medical and biophysical aspects to allow for the recognition that disability is a social and cultural construct. This highlights that without special attention to ensure there are no social, logistical, communication or education barriers to provision of good and equitable health care for people with disabilities, they are at risk of poor health outcomes.

UNICEF clearly articulates the intersect between disability rights, health, and immunization, and highlights the inequity in access to immunization for children, young people and adults with disabilities and the subsequent impact on their health and well-being.[16] Identifiable factors include inequitable access to health services, exclusion from health care initiatives and a lack of understanding of the safety of immunization for those with underlying disability. [16] UNICEF highlights the need to better understand the factors that influence immunization practices for this population and to advocate for further research in this area.

Search strategy

The literature search aimed to identify any primary research on immunization in children, adolescents or adults with physical and/or intellectual disability with any underlying etiology present from early in life.

A list of search terms was compiled in discussion with a developmental pediatrician, accounting for the number of terms used to describe disability, and incorporating both broad descriptors and specific diagnoses, to ensure a comprehensive search of the disability literature (see Table 1). These terms were paired with immunization search terms in order to find relevant articles through five databases: PubMed, CINAHL, ERIC, Embase and Scopus. Reference lists of identified articles were searched for other relevant studies. Excluded were studies focusing on disability occurring post immunization, and immunization in adults with disabilities primarily due to aging. In total 28 studies were found (see Table 2).

Results

The studies on immunization in people with a disability are characterized by the diverse settings, study design, disability type and vaccinations included.

Disability type

Information was difficult to synthesize largely due to the variety of disability types. Some studies used specific diagnostic groups such as: those with inborn errors of metabolism,[32] ASD,[38] intellectual disability, [20,21,30] cerebral palsy, [4] and spina bifida.[24] Other studies used broad definitions of disability such as: children with special health care needs (CSHCN), [31,33,39] women with physical disabilities, [40] youth attending specialist schools,[19,26] children with neurological diseases, neurodevelopmental disorders, chronic neurological deficits or developmental disabilities, [18,22,23,27,29] and females with mental and physical limitations.[28]

The issue with broad definitions is illustrated by two American studies which found no difference between immunization uptake for people with disabilities as compared to their typically developing peers. The first study measured uptake in a cohort of children with special health care needs[17] and the second explored whether a medical model of care for children with special health care needs improved immunization rates. [39] The definition of “children with special health care needs” is commonly used in America, and includes children who require health or medical input above what would be typical, or any child on prescription medication or with emotional or behavioral disorders or chronic illness, as well including those with a disability.[45] Therefore “children with special health care needs” is too broad a definition to measure difference in immunization uptake in the sub-population of those with disability. Other studies from America have not replicated this finding with more specific populations for children with spina bifida,[24] autism,[42] and neurodevelopmental disorders.[29]

Immunization coverage

The majority of the studies measured immunization uptake, with 18/28 (64%) calculating the uptake of one or more vaccinations in a population of people with disability.[4,17–33] The recognition of inequities in immunization services for vulnerable populations relies on the existence of disaggregate data.[34] Aggregate immunization uptake figures do not generally identify small populations at risk for under-immunization[34] and therefore lower immunization coverage in people with disabilities can be missed. The studies suggested a likelihood of missed immunizations in people with disabilities, with 14/18 (78%) of the coverage studies finding that people with disabilities have lower rates of immunization uptake across a range of different vaccines then their typically developing peers. [4,18–21,23,24,26–28,30–33]

Some studies measured immunization coverage indirectly. Three studies did not specifically explore a cohort of people with disabilities but instead found that disability predicted incomplete vaccination, including in girls in non-mainstream schools,[35] children with congenital malformations,[36] and Trisomy 21 and Autism Spectrum Disorders (ASD).[37] One study did not specifically investigate immunization coverage, but explored overall health service use among youth with ASD and found that they were less likely to receive immunisations.[38] Another assessed whether enhanced primary care in the form of a dedicated nurse practitioner to coordinate the child's care improved immunization rates for children with special needs[39] and found that it did not. Although immunization uptake for children with disability in these practices was already above the national average prior to the intervention.[39]

In addition to vaccine uptake, other studies aimed to explore acceptability of HPV vaccine among women with physical disabilities[40] and provider recommendation for vaccines in a cohort of children with disability.[41] Two studies examined parental decision making about vaccines after a diagnosis of ASD in their child.[42,43] Both these studies concluded that parents were more likely to miss or delay immunizations after their child's diagnosis of ASD, highlighting persisting concerns about the disproved link between vaccinations and autism.[42,43] One study used grounded theory to explore the satisfaction of adults with ID with an immunization program.[44]

Qualitative data

Although there were a few studies that aimed to determine barriers to immunization in people with a disability,[23,25,26] there was only one primary qualitative study to date.[44] This study explored the satisfaction of adults with ID with a program to immunize against Hepatitis B, with data collected directly from the individual with the disability rather than parents and/or care providers. This study used qualitative interviews from adult clients with intellectual disability and questionnaires with care staff to describe information in regards to the logistics of Hepatitis B delivery, use of restraint and information needed about immunization for this population. This level of analysis, not present in the other studies, allows an understanding of the experience of immunization and barriers to immunization that may inform meaningful, effective and equitable policies. Both in-depth qualitative research and the perspective of people with a disability is largely missing from research. This information is pivotal to understanding the barriers to uptake and the experience of immunization in this population.

Location of the research

The location also influences definition and cultural understandings of disability and immunization policy and practice. The majority of studies were from the USA,[17,24,29,31,33,38,39,42,43] with other high income countries represented, including Australia,[4,26,27,36] Taiwan,[20,21,30,40],UK,[19,35] Italy,[22,23] France,[32] Ireland,[44] Canada,[37] Japan[41] and Switzerland.[18] Two studies were from low and middle income countries (LMICs). The first was a small study from Ecuador,[25] and the second was a cross sectional study of families with children with chronic neurological conditions in Nigeria.[46]

The Ecuadorian study was one of the four studies which found that children with disabilities did not have lower immunization rates than their typically developing peers. The authors suggested that the culture of the local society in valuing children with disabilities influenced immunization practices despite the poverty, isolated locations and difficulty accessing healthcare. This contrasts with the Nigerian study,[46] in which children with more obvious neurological deficits were less likely to be immunized. The environmental and cultural context is important in attitudes towards disability. More research in LMICs may improve our understanding of how different contexts impacts health care decision making and act as a barrier to delivering equitable preventive health care for people with disability.

Age and types of vaccination

Only two studies include adults with disability,[40,44] reflecting the weight of immunization research concentrating on childhood and adolescent funded vaccinations. The majority of research on childhood immunization focuses on a number of vaccines or the concept of being "up-to-date" with the current schedule. This contrasts with the studies on adolescent immunisation, where five studies focus specifically on HPV immunization. These studies were divided between Australia,[26,27] which offer a school-based immunization program for adolescent immunization, and the USA,[28,31,33] which offers adolescent vaccinations through local health care providers. This is reflected in the lower rates of HPV uptake in the USA, but relative to their peers, adolescents with disabilities in all these studies had lower rates of initiating and completing the HPV course.

Acknowledging the need to optimize uptake of the HPV vaccine for young people with disabilities requires recognition that sexual health is important and relevant for this population. Indeed one of the barriers that is reported by parents is that the HPV vaccination is “not needed”.[28] Other barriers to HPV acceptance are the lack of recommendation by a medical provider, and safety concerns. O’Neill et al.[26] also list reasons for non-vaccination for HPV, with the main reasons being absence from school, lack of consent and anxiety of the student. This study found no significant difference between dTPa and HPV uptake, suggesting that concerns about individual vaccines may be less of a barrier than logistical issues, which is a finding not previous explored for this population. The differences in barriers reported between these two studies may reflect the parent perspective as compared to the school perspective, establishing the value of multiple viewpoints.

Three studies specifically examine influenza immunization uptake for children and adolescents with disabilities. [20,22,29] Influenza is an annual immunization which is funded and recommended for at-risk groups in many countries. This includes people with impaired respiratory health, which is often present in children with cerebral palsy, epilepsy and other neurological conditions. Nevertheless immunization rates in those with disabilities in all three studies are lower than, or similar to, the general population.[20,22,29]

Provider recommendation

Several studies found that predictors of immunization in children with disabilities are were regular health checks,[20,31] or recommendation to immunize by a health care provider.[22,28,41] The importance of health care provider recommendation is mirrored in the literature regarding interventions to improve confidence and uptake in immunizations in the general population.[47] Given this, the paucity of research exploring opinion and behavior of health professionals giving advice about immunizations to families with children with disabilities highlights the need for further exploration. Two studies included pediatrician perspectives on immunization as to whether they recommended vaccination in children with epilepsy or severe handicap.[41] It is unknown what beliefs and concerns other health professionals, such as GPs and immunization nurses, have about recommending vaccination to people with disability. This limits the current level of understanding of the many factors that may influence immunization decision making, as well as the interventions that may be needed on a health professional level.

Conclusion

Drawing clear conclusions from the currently available research on immunization in people with disabilities is challenging, due to the different contexts, methodologies, definitions, age groups and vaccines studied. Published studies are limited primarily to exploring immunization coverage in high income settings. These knowledge gaps do not allow the development of strategies to ensure improved immunizations rates in this vulnerable population. Research is needed to develop a greater understanding of the barriers to immunization for people with disabilities and their families, including the perspective of people with disability and the advice and attitudes of health professionals and immunization providers. Immunization in people with disabilities is an important issue of both health and equity and deserves further research and discussion. Future research will provide opportunities to impact on provider and parental attitudes and policy recommendations with a view to improving immunization rates in this population.

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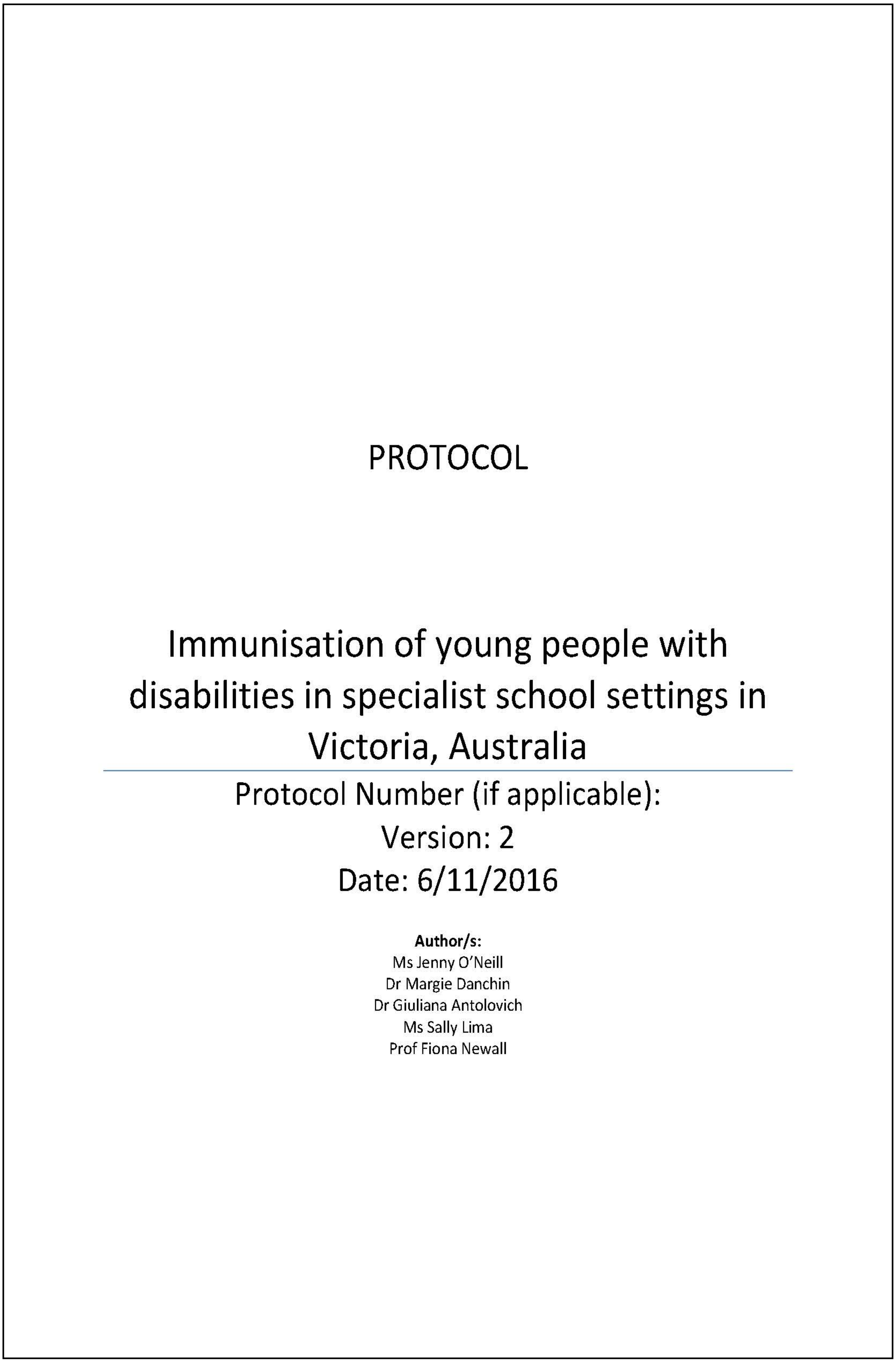
APPENDIX D: PHASE ONE HREC PROTOCOL



PROTOCOL

Immunisation of young people with disabilities in specialist school settings in Victoria, Australia

Protocol Number (if applicable):
Version: 2
Date: 6/11/2016

Author/s:
Ms Jenny O'Neill
Dr Margie Danchin
Dr Giuliana Antolovich
Ms Sally Lima
Prof Fiona Newall

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Statement of Compliance

This document is a protocol for a research project. This study will be conducted in compliance with all stipulation of this protocol, the conditions of the ethics committee approval, the NHMRC National Statement on ethical Conduct in Human Research (2007) and the Note for Guidance on Good Clinical Practice (CPMP/ICH-135/95).

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1. GLOSSARY OF ABBREVIATIONS & TERMS

Abbreviation	Description (using lay language)
DTP	Diphtheria/tetanus/pertussis
HPV	Human papillomavirus
DHHS	Department of Health and Human Services

2. STUDY SITES

2.1 STUDY LOCATION/S

While ethics approval is only required from the single site at the Royal Children's Hospital, data will be collected from a number public specialist schools in Victoria who enroll students with physical and/or intellectual disabilities. Seventy-eight schools will be invited to participate. There is no data on prior engagement rates with schools for this type of study, therefore it is difficult to anticipate how many schools will consent to take part. It is hoped that over half will choose to participate to ensure a range of specialist school types and locations.

3. FUNDING AND RESOURCES

3.1 SOURCE/S OF FUNDING

The principal investigator is supported with an Australian Postgraduate Award and any expenses will be covered by this funding.

4. INTRODUCTION/BACKGROUND INFORMATION

4.1 LAY SUMMARY

Victoria has a program of scheduled vaccinations, which are included in the National Immunisation Program (NIP) schedule and are paid for by the Australian government. Included in the NIP schedule is the school-based immunisation program, which offers all young people aged 12 to 13 years the Diphtheria/tetanus/pertussis (DTP) vaccine, the varicella (chickenpox) vaccine if they have not already received one dose (<= 14 years old) or have a clear history of prior varicella infection, and the Human Papillomavirus (HPV) vaccine, which is currently given as three doses within 6 months. In Victoria these vaccinations are given in Year 7, administered in schools by immunisation nurses arranged by the local government areas.

In Victoria, this school-based program is successful with high rates of young people being vaccinated. However, it is not clear if this is different for young people with disabilities in specialist school settings. There is very little information worldwide about vaccination in children with disabilities, but the limited studies that have been conducted suggest vaccination rates are lower in children with disabilities than for children in mainstream schools. Young people with disabilities in special schools may have specific factors which put them at greater risk of missing out on vaccinations, including missing more days at school, difficulty understanding the vaccination process, difficult behavior on immunisation day due to anxiety, and specific concerns from their parents that prevent them giving consent for their child to be vaccinated. There is a clear gap in the literature and we need to collect information about young people's vaccination status in specialist schools in Victoria, in order to understand the size of the problem, and what factors are contributing to these young people remaining un-vaccinated. With this information, we can inform tailored interventions to ensure that young people with disabilities are able to achieve the same rate of vaccination as young people in mainstream schools. This is essential to ensure that young people with disabilities are protected against infectious diseases that can be prevented by immunisation.

Participants in this study will be attending specialist schools in Victoria and have a range of physical and/or intellectual disabilities. The specialist schools will be asked to collect information on immunisation days in 2017 about each student who is eligible to be vaccinated, whether they were vaccinated and what vaccines they received, their physical and intellectual ability, and the reason they were not vaccinated, if they weren't. The young people in the school will not be able to be identified from the information collected. This study will require a teacher or nurse at the school to fill in a short online data form for every student eligible for the school vaccinations on each immunisation day. Each form will take approximately two minutes to fill in.

4.2 INTRODUCTION

As part of the government-funded immunisation program in Australia, all young people aged 12 and 13 years are eligible to receive DTP, HPV and varicella immunisations through the school-based immunisation program. In Victoria this is given in the first year of secondary school (Year 7), with DTP and varicella given as one dose each, and HPV given as three doses within six months (0, 1 and 6 months). Uptake of these vaccinations is recorded by the Department of Health and Human Services (DHHS) Immunisation in Victoria and through the HPV register. In 2015, 89.6% of eligible students received the adolescent dose of DTP and 77.4% of girls and 66.4% of boys received all three doses of HPV. Varicella is only necessary if the young person has not received one dose in childhood (<= 14 years) or does not have natural immunity or a strong clinical history of infection. Therefore the uptake of varicella in the school-based program is not representative of varicella vaccination coverage and therefore not included in the focus of this study.

Each Local Government Area in Victoria is responsible for coordinating and implementing the school-based immunisation program. Data on the number of vaccinations given is recorded through the

Immunisation Programme System (ImPS) software. Using Year 7 enrolment data from the Department of Education and Training (DET), the uptake for all mainstream schools can be calculated. However, there is no denominator data (enrolment in Year 7) for specialist schools, as these schools do not stream students according to mainstream grade levels. Therefore, there are no available immunisation uptake figures for specialist schools.

The importance of understanding immunisation uptake, the barriers and enablers to immunisation delivery in the specialist school setting cannot be underestimated. In 2008, Australia ratified the United Nation Convention on the Rights of Persons with Disabilities, which recognises the need to provide health care for those with disabilities "in the same range, quality and standard of free or affordable health care and programs as provided to other persons" (United Nations, 2006, sec. 25). Without having accurate data to assess the delivery of the school-based vaccination program in non-mainstream schools, nor understanding the potential reasons for missed immunisations, it is difficult to be certain that young people with disabilities are receiving equitable preventative health care.

Therefore, the main purpose of the study is to measure the uptake of school-based immunisations for young people with disabilities in the specialist school setting in Victoria. Collecting information on motor and intellectual function and reasons for non or under-vaccination as secondary outcomes will provide data to enable a more complete understanding of whether the type of disability influences immunisation receipt, and what the barriers and enablers are to immunisation delivery in this minority group. This study represents the crucial first phase of a larger study aiming to explore the issues relating to school based vaccination uptake for young people with disabilities in specialist schools using a socio-ecological framework.

4.3 BACKGROUND INFORMATION

There is very little research internationally and in Australia on immunisation in children and adolescents with a disability. When considering children of all ages, most studies suggest children with disabilities are at risk for under or non-immunisation. Lower rates of immunisation are recorded for children with disabilities in early childhood (Greenwood, Crawford, Walstab & Reddihough, 2013; Raddish, Goldmann, Lawrence, Kaplan & Perrin, 1993; Tillmann, Tillmann, Heininger, Lutschg & Weber, 2005), and for the seasonal influenza vaccine (Pandolfi et al., 2012; Yen et al., 2012). Of these studies only Greenwood et al. (2013) is Australian, with the focus on children with cerebral palsy under 7 years. Only one study in the USA (O'Connor & Bramlett, 2008) found that children with special health care needs, broadly defined to include children with developmental issues, emotional issues or needing any specialist care or medication, had immunisation rates similar to typically developing children. This was a data linkage study in the USA, which relied on parent report of vaccination coverage as opposed to data obtained from an immunisation register.

In terms of adolescent immunisation specifically, two studies from the USA and Canada found that only 17% of children with special health care needs were immunised against HPV, and that having Down syndrome or ASD was significantly associated with missing HPV immunisation (Cody & Lerand, 2013; Remes et al., 2014). Tuffrey and Finlay (2001) reported that only 59% of children from special schools in Bath, United Kingdom were fully immunised compared to 83% of matched controls. There is no published data on adolescent immunisation for children in special schools in Australia.

Therefore, there is a significant gap in the literature with respect to understanding school-based adolescent immunization for young people with disabilities in Australia. If indeed the bulk of the international data regarding immunisation uptake rates for this group is similar in Australia, there is much work to be done to ensure that this already vulnerable group has increased access to and promotion around the importance of immunisation. This research has the potential for considerable impact on immunisation policy. Most importantly interventions, which could be developed as a result of this research, have the potential to affect the morbidity and mortality of children with disabilities and are congruent with the principles of equity in health care and the rights of persons with disabilities.

5. STUDY OBJECTIVES

5.1 RESEARCH QUESTION

What is the uptake of school-based, government-funded vaccinations in young people with disabilities attending specialist schools in Victoria, Australia as compared to the general Victorian population and what are the reasons for non-vaccination in this group?

5.2 PRIMARY OBJECTIVES

The primary objective of the study is to measure the uptake of school-based government-funded immunisations, specifically DTP and HPV in young people with disabilities attending specialist schools in Victoria Australia, and compare to the uptake of school-based, government-funded immunisations in the general population in Victoria, Australia.

5.3 SECONDARY OBJECTIVES

Secondary objectives of this study are:

1. To describe the uptake of school-based, government-funded vaccinations in specialist school settings according to the degree of motor and intellectual impairment of the child
2. To collect information on reasons for non or under-vaccination.

5.4 OUTCOME MEASURES

The primary outcome measure is the uptake of school-based immunisation (HPV and DTP) in specialist school settings, as expressed as a percentage of the eligible population of 12-13 year old children.

Secondary outcome measures include:

1. Immunisation uptake by the degree of motor and intellectual impairment:
    a. Categorisation of motor function as:
    - ambulant without aides
    - ambulant with aides
    - non ambulant
    b. Categorisation of intellectual impairment as:
    - no impairment
    - probably no impairment
    - probably impaired, severity unknown
    - mild/moderate impairment

2. Reason for non-vaccination if applicable
    a. Up to date with vaccination
    b. Vaccine not available
    c. No consent form returned
    d. Consent form returned with consent for immunisation not given
    e. Not able to immunise due to student behavior
    f. Immunisation not offered
    g. Other

Study Design

5.5 STUDY TYPE & DESIGN & SCHEDULE

This study is a prospective cohort study, collecting immunisation information at up to five time points for each special school identified in Victoria (n=78) in 2017. This is the first phase of a larger study aiming to explore issues relating to school based vaccination uptake for young people with disabilities in specialist schools using a socio-ecological framework.

The principal of all eligible schools will be sent an introductory letter and information statement mid-December 2016 or late January 2017 outlining the aims of the study. If they agree to their school participating, they will be asked to return the participation form using a stamped self-addressed envelope or via email to the principal investigator. On this form they will be asked to nominate a teacher or school nurse who can be the school contact for the purposes of the study. If no form is returned the principal investigator will follow up with a telephone call to the school two to four weeks after this paperwork is sent (depending on whether this falls in school holidays). There will be a maximum of two follow up calls made.

For schools that agree to participate, the principal will make contact with the nominated immunisation contact for each school and explain the process of collecting data, which will also be outlined in the information statement. The nominated contact will be responsible for collecting data on immunisation days via a link to the data collection form on Redcap (See Appendix A: Data collection form). This will occur on each scheduled immunisation day, the dates of which are organised between the local government immunisation providers and each school. There are three immunisation days scheduled over six months for each school, to enable the full course of HPV vaccine to be given. The nominated immunisation contact will also be asked to fill in forms for up to two immunisation catch up days, which may be offered at the school by the local council, in addition to the three scheduled days.

The data collected will include all young people enrolled at the school who are aged 12 or 13 on the first immunisation day of the year, whether or not they are offered vaccination, and any other young person outside this age range who is offered the adolescent DTP or the HPV vaccination. Young people outside this age range may be offered these vaccinations opportunistically, if the school is aware that they have previously missed a vaccination. Information collected will include limited demographic data, the motor and intellectual function of the young person and receipt of, or reasons for non-receipt of the DTP and the HPV vaccine. As not all adolescents are eligible for the varicella vaccine, the comparison of uptake is not meaningful, and therefore information for this vaccine will not be collected. There will be no identifiable data collected.

This data on Redcap will only be accessible to the study investigators through a secure password protected system. The nominated immmunisation contact at each school will only be able to access, view and enter information for students in their own school. Data collection will continue for the 2017 school year or until all the 2017 immunisation days have been completed.

Analysis will be undertaken by the principal study investigator as part of a PhD study in the Department of Paediatrics at The University of Melbourne. Analysis will compare the difference in proportions and relative assessment measures between uptake of school immunisations in specialist school settings with the overall school immunisation uptake for that local government area. The school immunisation uptake for each local government area in Victoria can be calculated from information from DHHS on the number of vaccinations provided to schools, and the Year 7 enrolment data for local government areas provided by DET as denominator data. This data is kept by DHHS and DET and for the 2017 school year will be publically available in 2018.

STUDY TABLE

Data collection	Late January/Early Feb 2017	Immunisation Day 1	Immunisation Day 2	Immunisation Day 3	Catch up Immunisation Day/s
Informed Consent by the Principal of the School	X				
Contact with the nominated immunisation contact	X	X	X	X	X
Demographic data for each eligible child		X	X	X	X
Motor and intellectual function data for each eligible child		X	X	X	X
Information about immunisation/reason for non-		X	X	X	

immunisation for DTP and HPV for each eligible child					X

6. STUDY POPULATION

6.1 RECRUITMENT PROCEDURE

Eligible specialist schools will be identified from a list of all schools in Victoria provided by DHHS in Victoria. The principal investigator will check the enrolment criteria of each school to ensure inclusion criteria are met. An application to DET is currently in process for approval to approach eligible schools for research purposes. Once approved by DET, each principal will be sent an information statement outlining the study aims, methodology and input required from the school. If the principal agrees to the school taking part they will be asked to sign the consent and nominate a nurse or teacher responsible for coordinating the immunisation days. The nominated immunisation contact in each school will be responsible for identifying eligible students according to the inclusion criteria, which will be set out in writing and also discussed by telephone by the study coordinator. This nominated contact will also be required to sign the consent.

6.2 INCLUSION CRITERIA

All specialist schools in Victoria which enrol young people in early adolescence with physical and/or intellectual disability will be invited to participate. This includes Special Schools, Special Developmental Schools, Dual Mode Schools (sometimes also called Special Developmental Schools), Autism Specific Schools and schools for young people with significant Physical Disability/Chronic Health Needs. Within this details of immunisation in 2017 for any student who is aged 12 or 13 on the first immunisation day of the year will be included, whether or not they are offered vaccination. In addition, any student who is outside this age range and is offered vaccination will be included.

6.3 EXCLUSION CRITERIA

Exclusion criteria include young people attending mainstream schools. Also excluded will be satellite units for young people with special needs attached to mainstream schools, schools for hearing impaired students and specialist schools for students with emotional and behavioral issues.

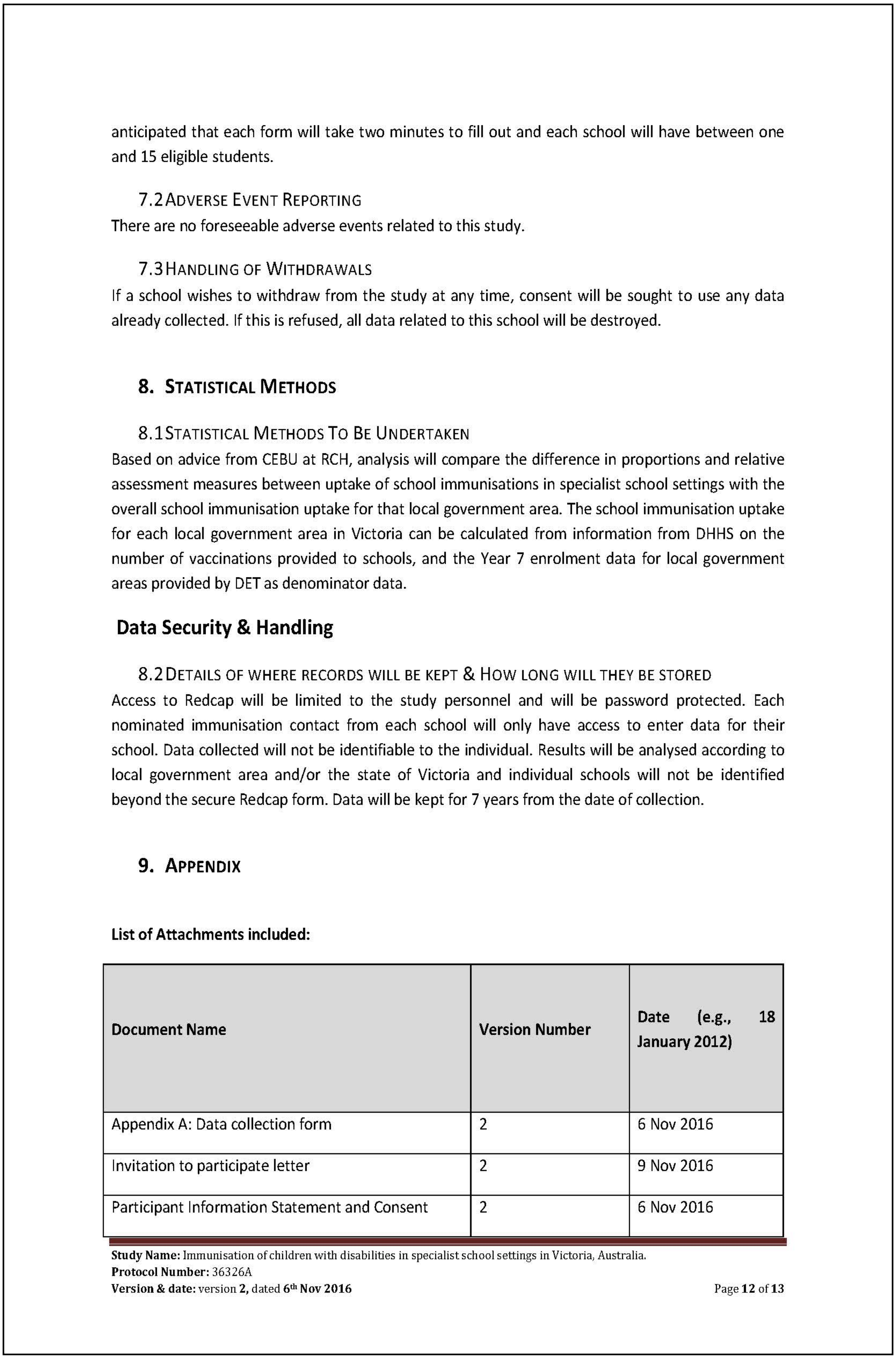
6.4 CONSENT

No individual consent is required. Schools will receive the information statement and will assent to participate as evidenced by return of the form indicating this.

7. PARTICIPANT SAFETY AND WITHDRAWAL

7.1 RISK MANAGEMENT AND SAFETY

There are no risks to the school or individuals, apart from inconvenience and time for the nominated immunisation contact to fill out the Redcap data collection from for each eligible student. It is



anticipated that each form will take two minutes to fill out and each school will have between one and 15 eligible students.

7.2 Adverse Event Reporting

There are no foreseeable adverse events related to this study.

7.3 Handling of Withdrawals

If a school wishes to withdraw from the study at any time, consent will be sought to use any data already collected. If this is refused, all data related to this school will be destroyed.

8. Statistical Methods

8.1 Statistical Methods To Be Undertaken

Based on advice from CEBU at RCH, analysis will compare the difference in proportions and relative assessment measures between uptake of school immunisations in specialist school settings with the overall school immunisation uptake for that local government area. The school immunisation uptake for each local government area in Victoria can be calculated from information from DHHS on the number of vaccinations provided to schools, and the Year 7 enrolment data for local government areas provided by DET as denominator data.

Data Security & Handling

8.2 Details of where records will be kept & How long will they be stored

Access to Redcap will be limited to the study personnel and will be password protected. Each nominated immunisation contact from each school will only have access to enter data for their school. Data collected will not be identifiable to the individual. Results will be analysed according to local government area and/or the state of Victoria and individual schools will not be identified beyond the secure Redcap form. Data will be kept for 7 years from the date of collection.

9. Appendix

List of Attachments included:

Document Name	Version Number	Date (e.g., 18 January 2012)
Appendix A: Data collection form	2	6 Nov 2016
Invitation to participate letter	2	9 Nov 2016
Participant Information Statement and Consent	2	6 Nov 2016

Pre-submission (Peer) review proforma	1	19 Oct 2016
Response to peer review	1	8 Nov 2016

10. REFERENCES

Cody, P. and Lerand, S. (2013). HPV vaccination in female children with special health care needs. *Journal of Pediatr Adolesc Gynecol, 26*; 219-223.

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Raddish, M., Goldmann D., Lawrence, D., Kaplan, M. and Perrin, J. (1993). The immunization status of children with spina bifida. *AJDC, 147;* 846-853.

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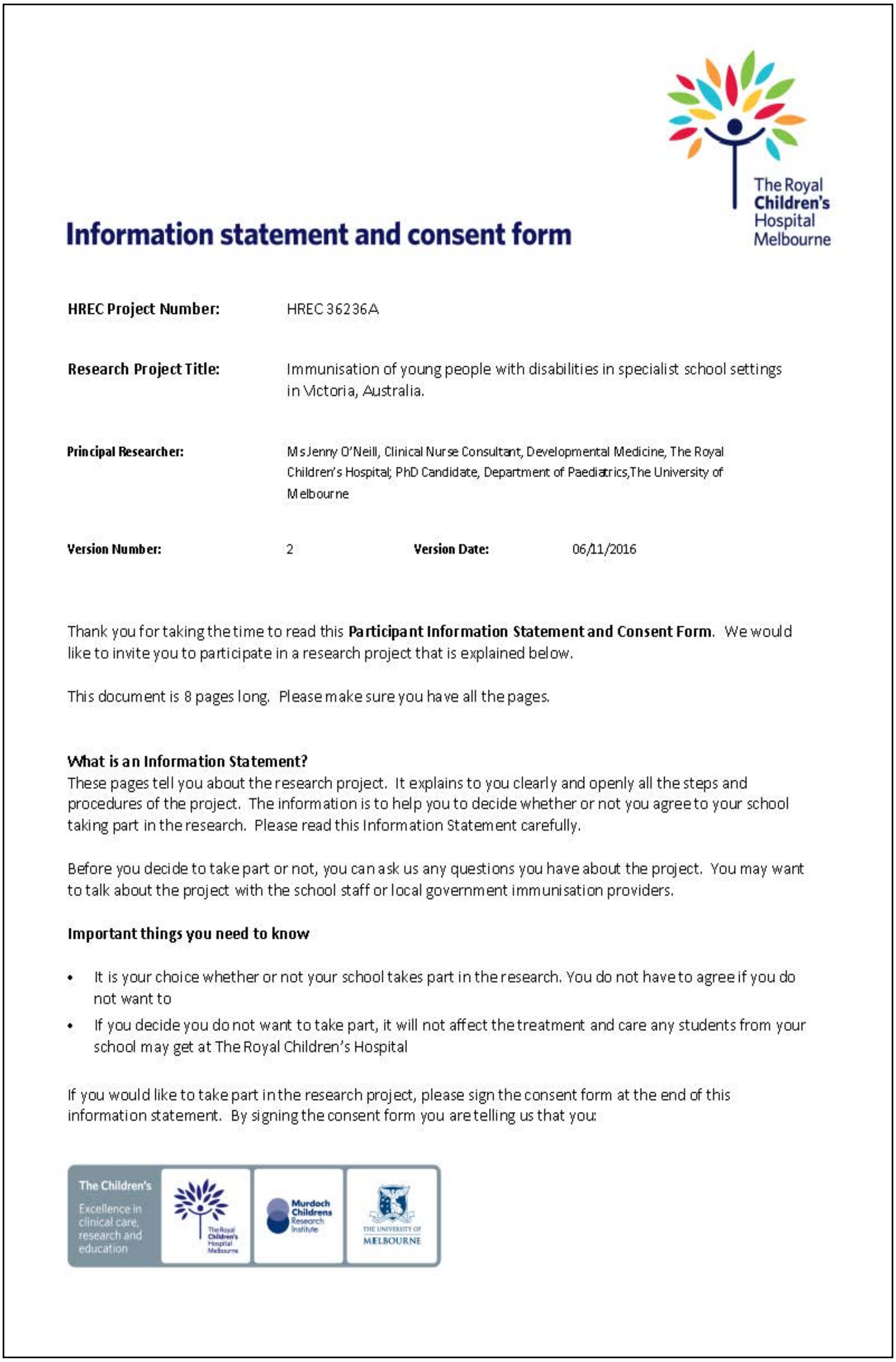
Tilmann, B., Tillmann, H., Heininger, U., Lutschg, J. and Weber, P. (2005). Acceptance and timeliness of standard vaccination in children with chronic neurological deficits in north-western Switzerland. *Eur J Pediatr, 164;* 320-325.

Tuffrey, C. and Finlay, F. (2001). Immunisation status amongst children attending special schools. *Ambulatory Child Health, 7*; 213-217.

Yen C., Hsu, S., Loh, C., Fang, W., Wu, C., Chu, C., and Lin, J. (2012). Analysis of seasonal influenza vaccine uptake among children and adolescents with an intellectual disability. *Research in Developmental Disabilities, 33;* 704-710.

APPENDIX E: PHASE ONE INFORMATION STATEMENT AND CONSENT FORM



The Royal Children's Hospital Melbourne

Information statement and consent form

HREC Project Number:	HREC 36236A		
Research Project Title:	Immunisation of young people with disabilities in specialist school settings in Victoria, Australia.		
Principal Researcher:	Ms Jenny O'Neill, Clinical Nurse Consultant, Developmental Medicine, The Royal Children's Hospital; PhD Candidate, Department of Paediatrics,The University of Melbourne		
Version Number:	2	**Version Date:**	06/11/2016

Thank you for taking the time to read this **Participant Information Statement and Consent Form**. We would like to invite you to participate in a research project that is explained below.

This document is 8 pages long. Please make sure you have all the pages.

What is an Information Statement?
These pages tell you about the research project. It explains to you clearly and openly all the steps and procedures of the project. The information is to help you to decide whether or not you agree to your school taking part in the research. Please read this Information Statement carefully.

Before you decide to take part or not, you can ask us any questions you have about the project. You may want to talk about the project with the school staff or local government immunisation providers.

Important things you need to know

- It is your choice whether or not your school takes part in the research. You do not have to agree if you do not want to
- If you decide you do not want to take part, it will not affect the treatment and care any students from your school may get at The Royal Children's Hospital

If you would like to take part in the research project, please sign the consent form at the end of this information statement. By signing the consent form you are telling us that you:

The Children's
Excellence in clinical care, research and education

The Royal Children's Hospital Melbourne | Murdoch Childrens Research Institute | The University of Melbourne

- understand what you have read
- had a chance to ask questions and received satisfactory answers
- consent to your school taking part in the project.

1. What is the research project about?

Victoria has a program of scheduled vaccinations, which are included in the National Immunisation Program (NIP) schedule and are paid for by the Australian government. Included in the NIP schedule is the school-based immunisation program, which offers all young people aged 12 to 13 years the Diphtheria/tetanus/pertussis (DTP) vaccine, the varicella (chickenpox) vaccine, if they have not already received one dose or have a clear history of prior varicella infection, and the Human Papillomavirus (HPV) vaccine, which is currently given as three doses within 6 months. These vaccinations are administered in schools by immunisation nurses arranged by the local government areas. In mainstream schools in Victoria, they are given in Year 7 with high rates of young people being vaccinated.

However, it is not clear if this is different for young people with disabilities in specialist school settings. There is very little information worldwide about vaccination in children with disabilities, but the limited studies that have been conducted suggest vaccination rates are lower in children with disabilities than for children in mainstream schools. Young people with disabilities in special schools may have specific factors which put them at greater risk of missing out on vaccinations, including missing more days at school, difficulty understanding the vaccination process, difficult behaviour on immunisation day due to anxiety, and specific concerns from their parents that prevent them giving consent for their child to be vaccinated. There is a clear gap in the literature and we need to collect information about young people's vaccination status in specialist schools in Victoria, in order to understand the size of the problem, and what factors are contributing to these young people remaining un-vaccinated. With this information, we can inform tailored interventions to ensure that young people with disabilities are able to achieve the same rate of vaccination as young people in mainstream schools. This is essential to ensure that young people with disabilities are protected against infectious diseases that can be prevented by immunisation.

Participants in this study will be attending specialist schools in Victoria and have a range of physical and/or intellectual disabilities. The specialist schools will be asked to collect information on immunisation days in 2017 about each student who is eligible to be vaccinated, whether they were vaccinated and what vaccines they received, their physical and intellectual ability, and the reason they were not vaccinated, if they weren't. The young people in the school will not be able to be identified from the information collected. This study will require a teacher or nurse at the school to fill in a short online data form for every student eligible for the school vaccinations on each immunisation day. Each form will take approximately two minutes to fill in.

2. **Who is funding this research project?**

   This project is being undertaken as part of a PhD study by the principal investigator, Jenny O'Neill. She is supported by an Australian Postgraduate Award through the University of Melbourne.

3. **Why am I being asked to take part?**

   Your school is being asked to take part as a specialist school in Victoria that enrols children with physical and/or intellectual disabilities. Approval from the Department of Education and Training (DET) has been granted to approach eligible schools to take part.

4. **What do I need to do in this research project?**

   If you agree to your school taking part in this research project, you will be asked to nominate the school nurse or teacher who is responsible for coordinating Immunisation days with the local government immunisation providers. We ask that they also sign this consent form to ensure we know they have read this Information Statement and are agreeable to taking part.

   The nominated contact will then be contacted by the principal investigator and provided with an online link to a data collection form which they are asked to fill out for each eligible student on each immunisation day. The questions that will be asked on the form are attached. It is expected that the form will take two minutes per student to fill in. None of the information collected can identify individual students.

5. **Can I withdraw from the project?**

   If you give your consent for your school to participate, and change your mind, the school can withdraw from the project. You do not need to tell us the reason why you want to stop being in the project. If you leave the project we will use any information already collected unless you tell us not to.

6. **What are the possible benefits for me and other people in the future?**

There will no direct immediate benefits from this research project for your students or your school. It is hoped that the findings from this PhD study will inform policy decisions and interventions to make it easier for young people undergoing immunisations in specialist school settings in the future. Depending on the findings, this may include, but is not limited to: implementing improved systems for tracking immunisation in young people with disabilities, developing specific information and education about immunisation for families of young people with disabilities, investigating alternative methods of immunising young people with disabilities who are very anxious and difficult to immunise in school settings, and improving communication with health care providers about immunisations in young people with disabilities.

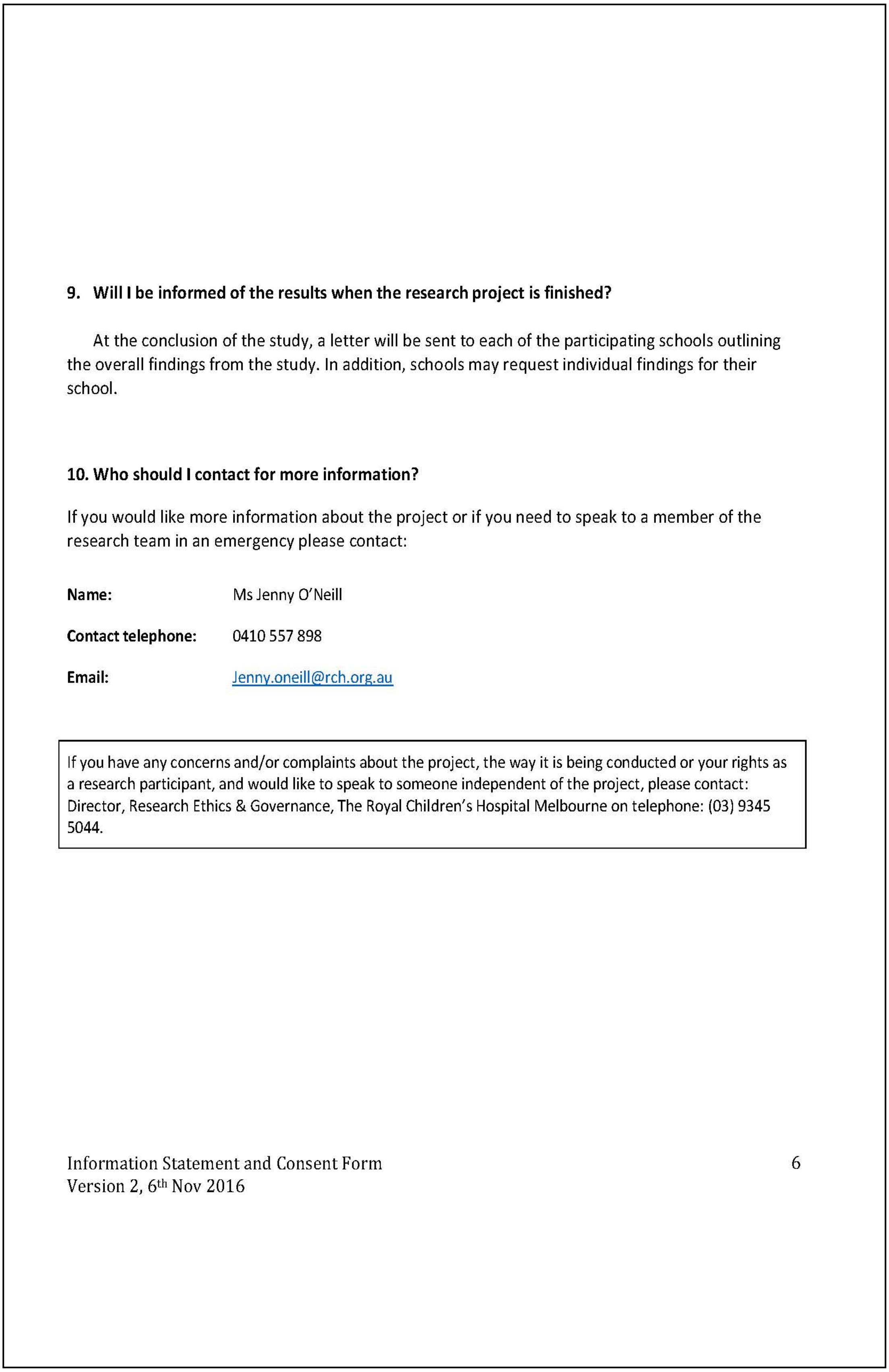
7. What are the possible risks, side-effects, discomforts and/or inconveniences?

There are no known risks, side-effects or discomforts expected by taking part in this research project. Inconveniences for the school include the time and effort it will take for the nominated immunisation contact at the school to fill in the data collection form for each eligible child on each immunisation day. This is expected to take two minutes for each child. The principal investigator will be available by telephone on each immunisation day if there are difficulties filling out these forms.

8. What will be done to make sure my information is confidential?

Information about immunisation for each student will be non-identifiable, that is, there will be no information collected which can identify any individual student. The nominated immunisation contact at the school will only have access to the data collection information of his or her school, and the study team and Ethics Department at the Royal Children's Hospital will be the only personnel to have access to the complete data set. This data will be stored electronically and password protected. Any hard copy data will be stored in a locked cabinet at the Royal Children's Hospital. This data will be kept for seven years after study completion then securely destroyed.

Results from this data will form part of a PhD thesis and may also be presented at conferences or printed in article format for peer reviewed journals. No published or presented results will name individual schools.



9. Will I be informed of the results when the research project is finished?

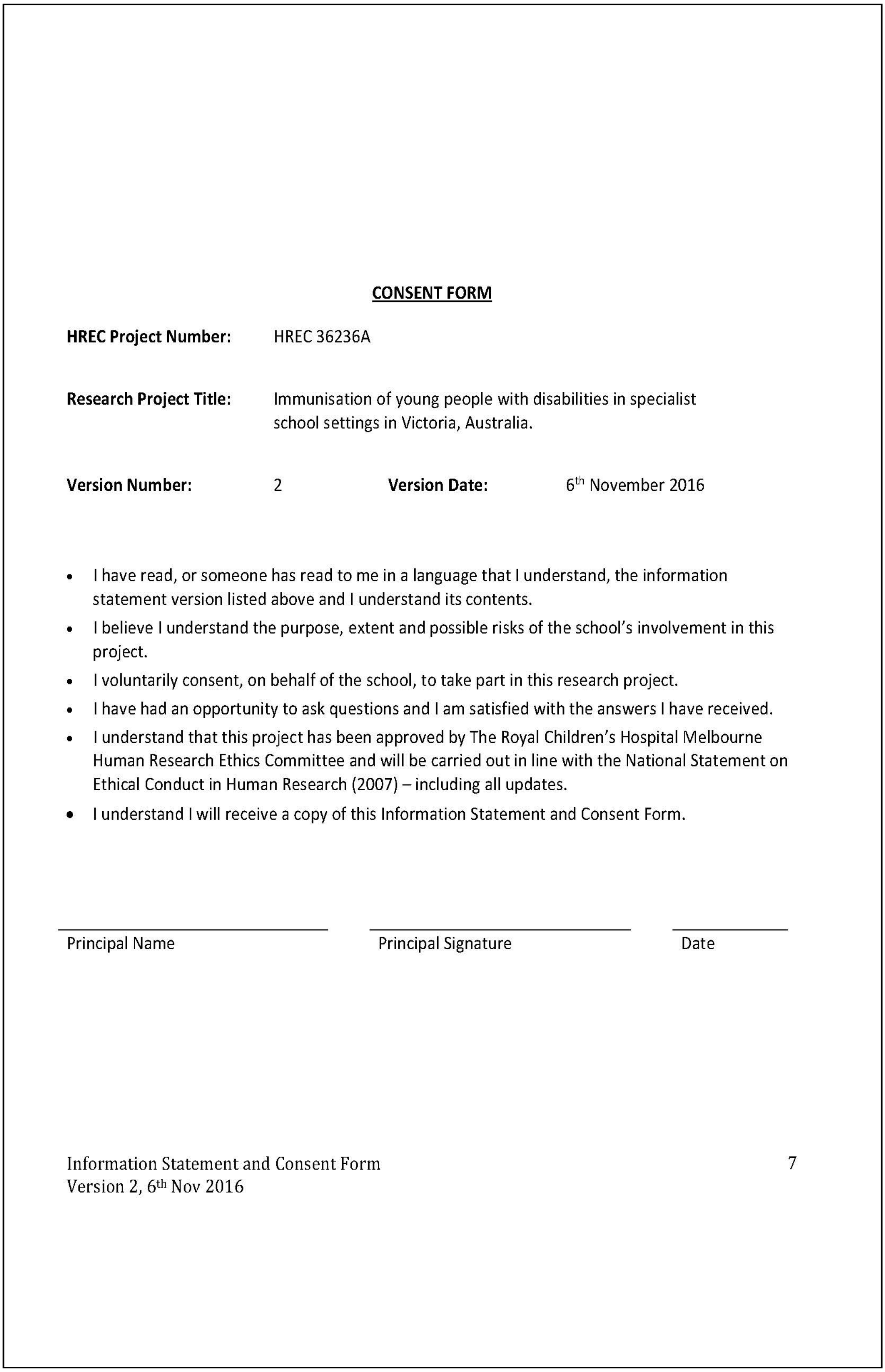
At the conclusion of the study, a letter will be sent to each of the participating schools outlining the overall findings from the study. In addition, schools may request individual findings for their school.

10. Who should I contact for more information?

If you would like more information about the project or if you need to speak to a member of the research team in an emergency please contact:

Name:	Ms Jenny O'Neill
Contact telephone:	0410 557 898
Email:	Jenny.oneill@rch.org.au

If you have any concerns and/or complaints about the project, the way it is being conducted or your rights as a research participant, and would like to speak to someone independent of the project, please contact: Director, Research Ethics & Governance, The Royal Children's Hospital Melbourne on telephone: (03) 9345 5044.



CONSENT FORM

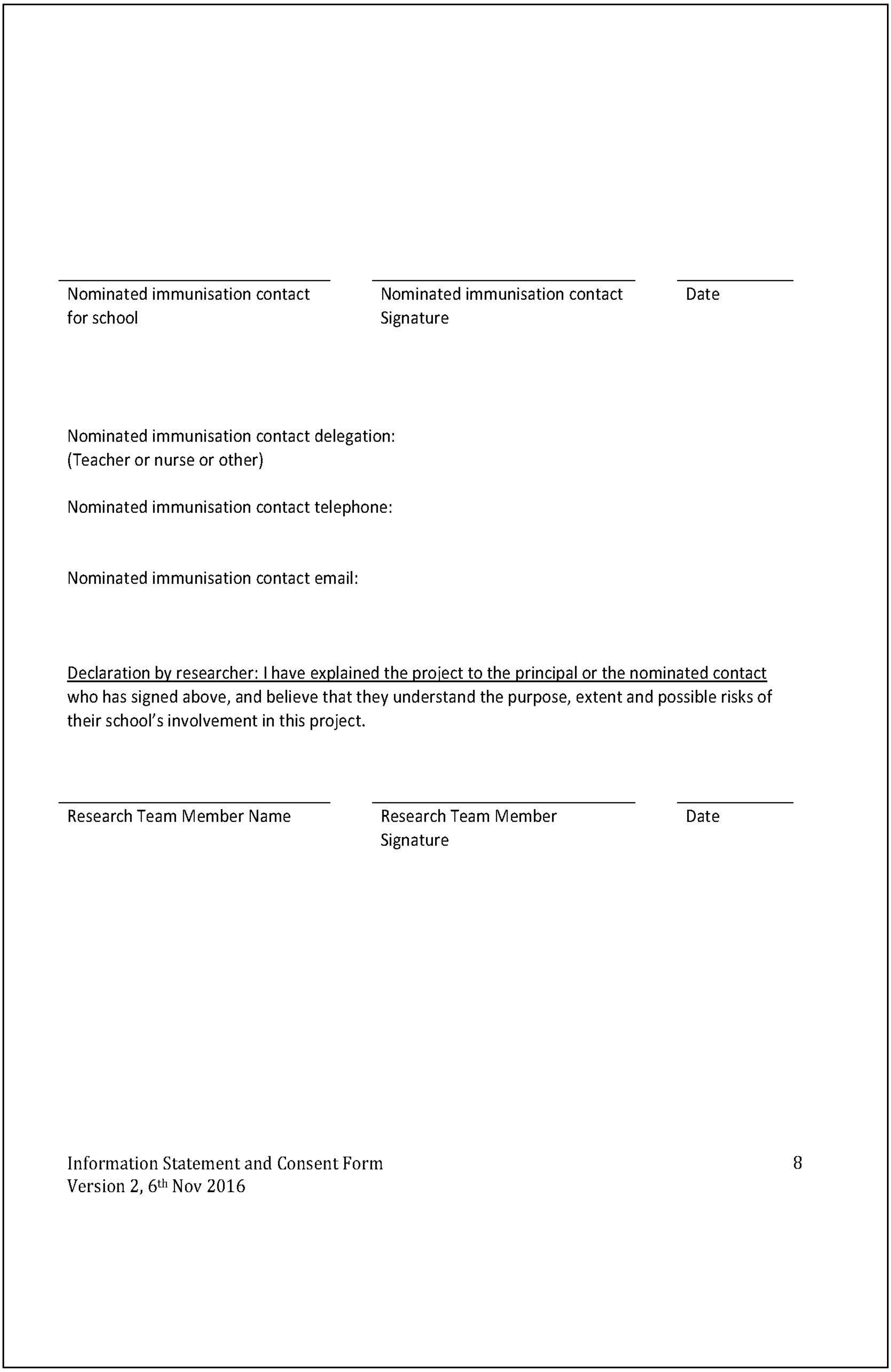
HREC Project Number: HREC 36236A

Research Project Title: Immunisation of young people with disabilities in specialist school settings in Victoria, Australia.

Version Number: 2 **Version Date:** 6th November 2016

- I have read, or someone has read to me in a language that I understand, the information statement version listed above and I understand its contents.
- I believe I understand the purpose, extent and possible risks of the school's involvement in this project.
- I voluntarily consent, on behalf of the school, to take part in this research project.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- I understand that this project has been approved by The Royal Children's Hospital Melbourne Human Research Ethics Committee and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2007) – including all updates.
- I understand I will receive a copy of this Information Statement and Consent Form.

Principal Name	Principal Signature	Date



Nominated immunisation contact for school	Nominated immunisation contact Signature	Date

Nominated immunisation contact delegation:
(Teacher or nurse or other)

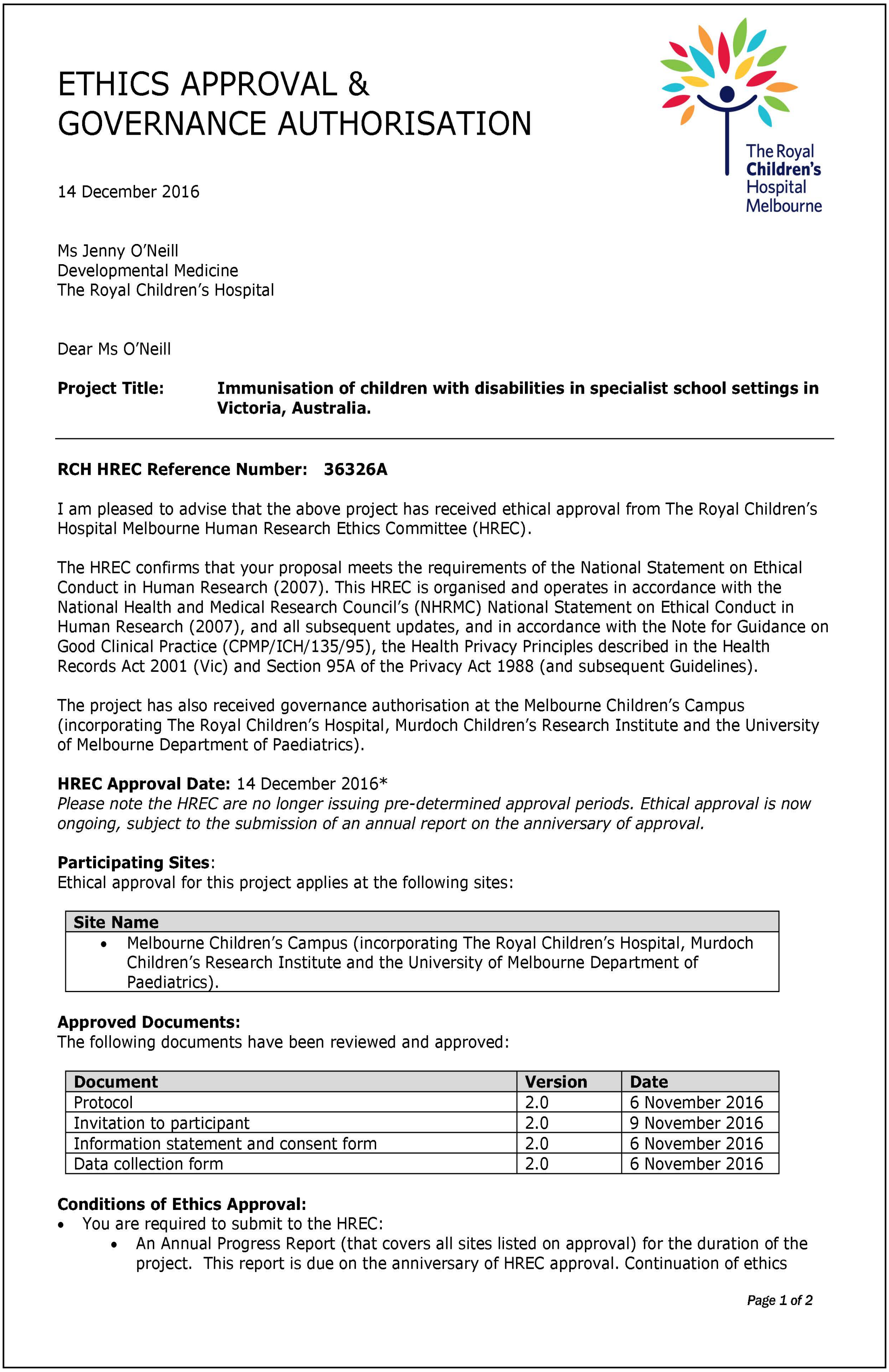
Nominated immunisation contact telephone:

Nominated immunisation contact email:

Declaration by researcher: I have explained the project to the principal or the nominated contact who has signed above, and believe that they understand the purpose, extent and possible risks of their school's involvement in this project.

Research Team Member Name	Research Team Member Signature	Date

APPENDIX F: PHASE ONE HREC APPROVAL



The Royal
Children's
Hospital
Melbourne

ETHICS APPROVAL & GOVERNANCE AUTHORISATION

14 December 2016

Ms Jenny O'Neill
Developmental Medicine
The Royal Children's Hospital

Dear Ms O'Neill

Project Title: **Immunisation of children with disabilities in specialist school settings in Victoria, Australia.**

RCH HREC Reference Number: 36326A

I am pleased to advise that the above project has received ethical approval from The Royal Children's Hospital Melbourne Human Research Ethics Committee (HREC).

The HREC confirms that your proposal meets the requirements of the National Statement on Ethical Conduct in Human Research (2007). This HREC is organised and operates in accordance with the National Health and Medical Research Council's (NHRMC) National Statement on Ethical Conduct in Human Research (2007), and all subsequent updates, and in accordance with the Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95), the Health Privacy Principles described in the Health Records Act 2001 (Vic) and Section 95A of the Privacy Act 1988 (and subsequent Guidelines).

The project has also received governance authorisation at the Melbourne Children's Campus (incorporating The Royal Children's Hospital, Murdoch Children's Research Institute and the University of Melbourne Department of Paediatrics).

HREC Approval Date: 14 December 2016*
Please note the HREC are no longer issuing pre-determined approval periods. Ethical approval is now ongoing, subject to the submission of an annual report on the anniversary of approval.

Participating Sites:
Ethical approval for this project applies at the following sites:

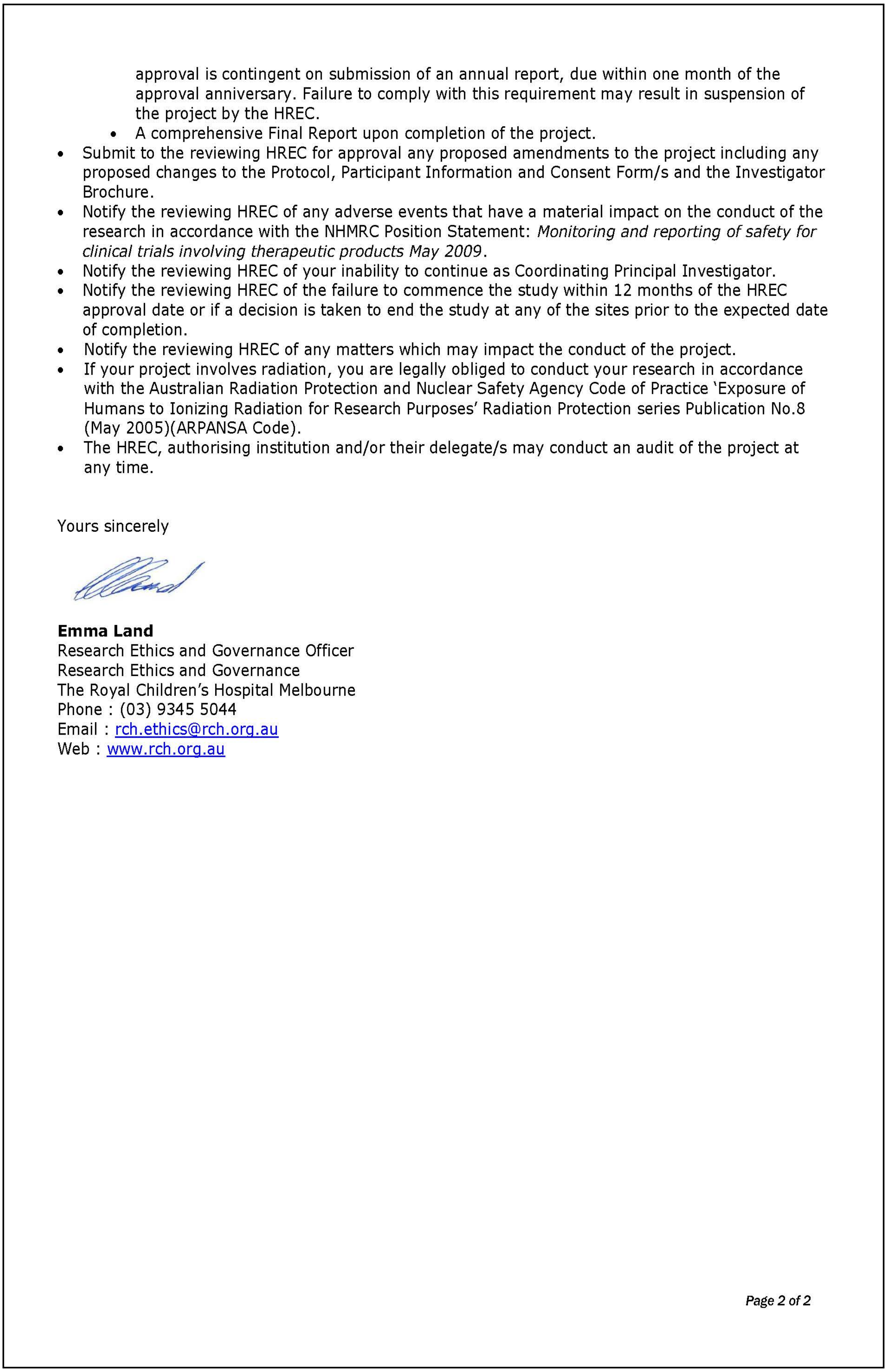
Site Name
• Melbourne Children's Campus (incorporating The Royal Children's Hospital, Murdoch Children's Research Institute and the University of Melbourne Department of Paediatrics).

Approved Documents:
The following documents have been reviewed and approved:

Document	Version	Date
Protocol	2.0	6 November 2016
Invitation to participant	2.0	9 November 2016
Information statement and consent form	2.0	6 November 2016
Data collection form	2.0	6 November 2016

Conditions of Ethics Approval:
- You are required to submit to the HREC:
    - An Annual Progress Report (that covers all sites listed on approval) for the duration of the project. This report is due on the anniversary of HREC approval. Continuation of ethics

Page 1 of 2



  approval is contingent on submission of an annual report, due within one month of the approval anniversary. Failure to comply with this requirement may result in suspension of the project by the HREC.
  - A comprehensive Final Report upon completion of the project.
- Submit to the reviewing HREC for approval any proposed amendments to the project including any proposed changes to the Protocol, Participant Information and Consent Form/s and the Investigator Brochure.
- Notify the reviewing HREC of any adverse events that have a material impact on the conduct of the research in accordance with the NHMRC Position Statement: *Monitoring and reporting of safety for clinical trials involving therapeutic products May 2009*.
- Notify the reviewing HREC of your inability to continue as Coordinating Principal Investigator.
- Notify the reviewing HREC of the failure to commence the study within 12 months of the HREC approval date or if a decision is taken to end the study at any of the sites prior to the expected date of completion.
- Notify the reviewing HREC of any matters which may impact the conduct of the project.
- If your project involves radiation, you are legally obliged to conduct your research in accordance with the Australian Radiation Protection and Nuclear Safety Agency Code of Practice 'Exposure of Humans to Ionizing Radiation for Research Purposes' Radiation Protection series Publication No.8 (May 2005)(ARPANSA Code).
- The HREC, authorising institution and/or their delegate/s may conduct an audit of the project at any time.

Yours sincerely

Emma Land
Research Ethics and Governance Officer
Research Ethics and Governance
The Royal Children's Hospital Melbourne
Phone : (03) 9345 5044
Email : rch.ethics@rch.org.au
Web : www.rch.org.au

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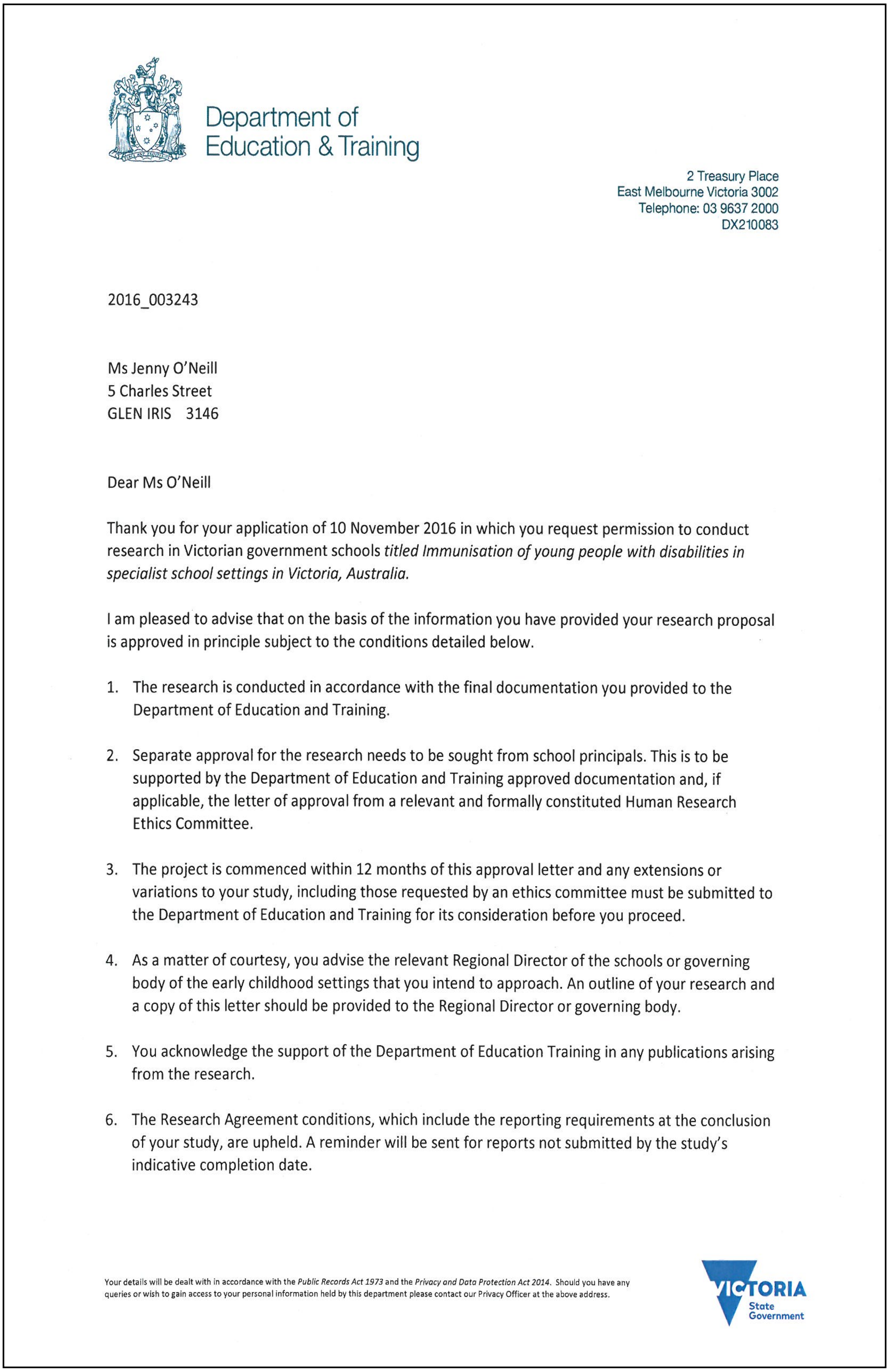
APPENDIX G: PHASE ONE DET APPROVAL



Department of
Education & Training

2 Treasury Place
East Melbourne Victoria 3002
Telephone: 03 9637 2000
DX210083

2016_003243

Ms Jenny O'Neill
5 Charles Street
GLEN IRIS 3146

Dear Ms O'Neill

Thank you for your application of 10 November 2016 in which you request permission to conduct research in Victorian government schools *titled Immunisation of young people with disabilities in specialist school settings in Victoria, Australia.*

I am pleased to advise that on the basis of the information you have provided your research proposal is approved in principle subject to the conditions detailed below.

1. The research is conducted in accordance with the final documentation you provided to the Department of Education and Training.
2. Separate approval for the research needs to be sought from school principals. This is to be supported by the Department of Education and Training approved documentation and, if applicable, the letter of approval from a relevant and formally constituted Human Research Ethics Committee.
3. The project is commenced within 12 months of this approval letter and any extensions or variations to your study, including those requested by an ethics committee must be submitted to the Department of Education and Training for its consideration before you proceed.
4. As a matter of courtesy, you advise the relevant Regional Director of the schools or governing body of the early childhood settings that you intend to approach. An outline of your research and a copy of this letter should be provided to the Regional Director or governing body.
5. You acknowledge the support of the Department of Education Training in any publications arising from the research.
6. The Research Agreement conditions, which include the reporting requirements at the conclusion of your study, are upheld. A reminder will be sent for reports not submitted by the study's indicative completion date.

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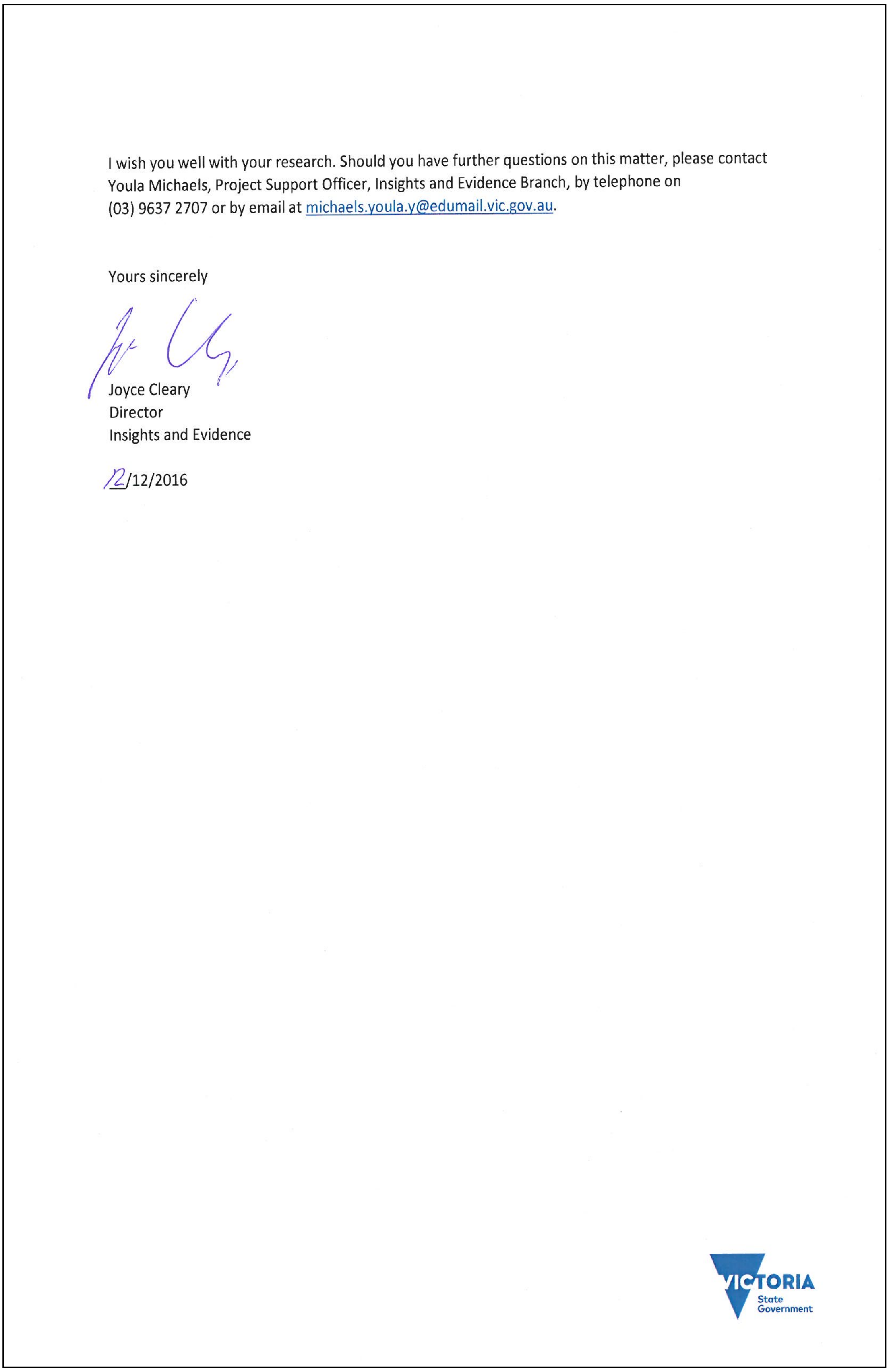

I wish you well with your research. Should you have further questions on this matter, please contact Youla Michaels, Project Support Officer, Insights and Evidence Branch, by telephone on (03) 9637 2707 or by email at michaels.youla.y@edumail.vic.gov.au.

Yours sincerely

Joyce Cleary
Director
Insights and Evidence

12/12/2016

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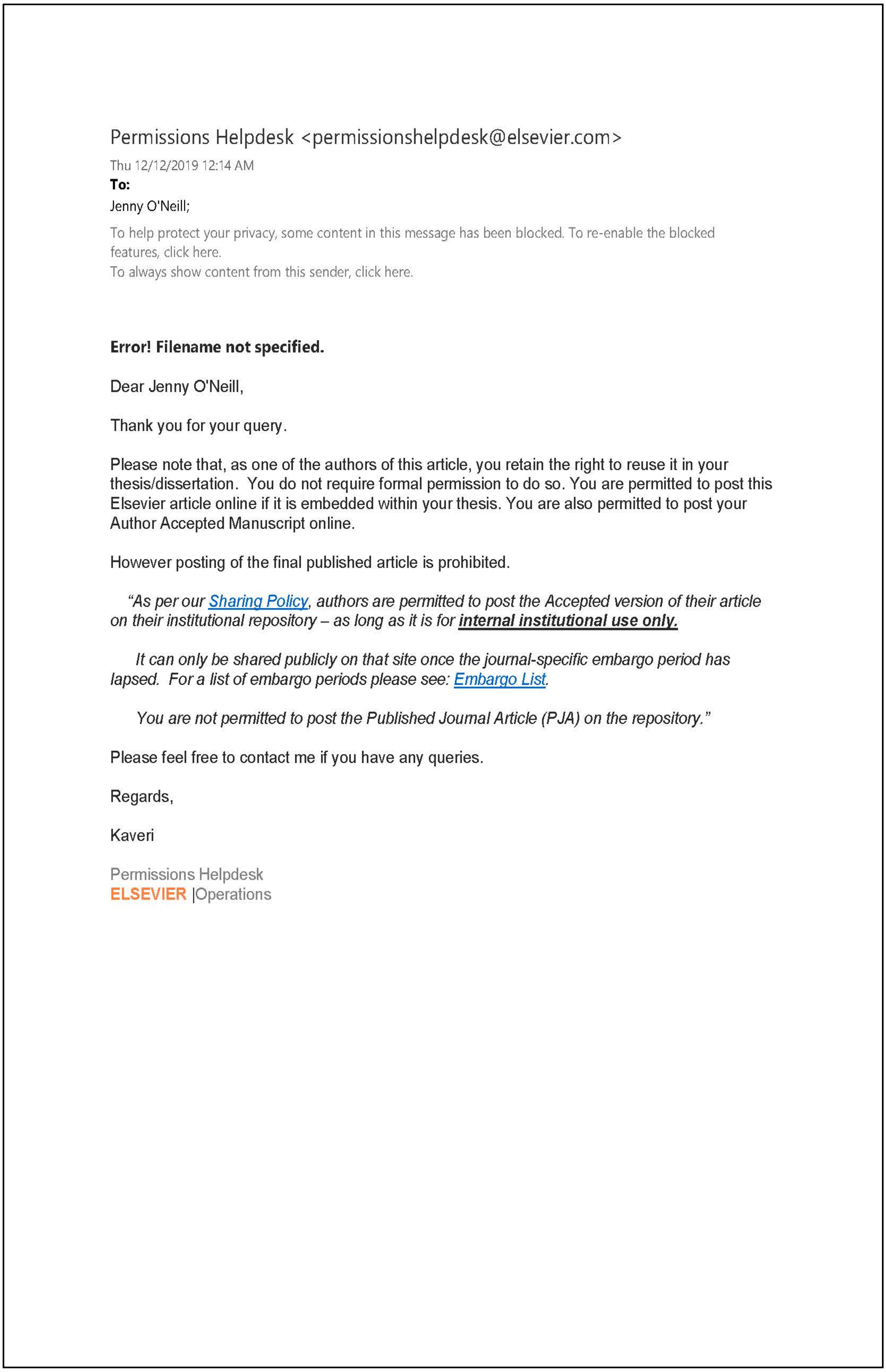
Appendix H: Elsevier Copyright Approval for Inclusion of Article in Chapter 4



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APPENDIX I: WILEY COPYRIGHT APPROVAL FOR INCLUSION OF ARTICLE IN CHAPTER 5

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Paisley Chesters
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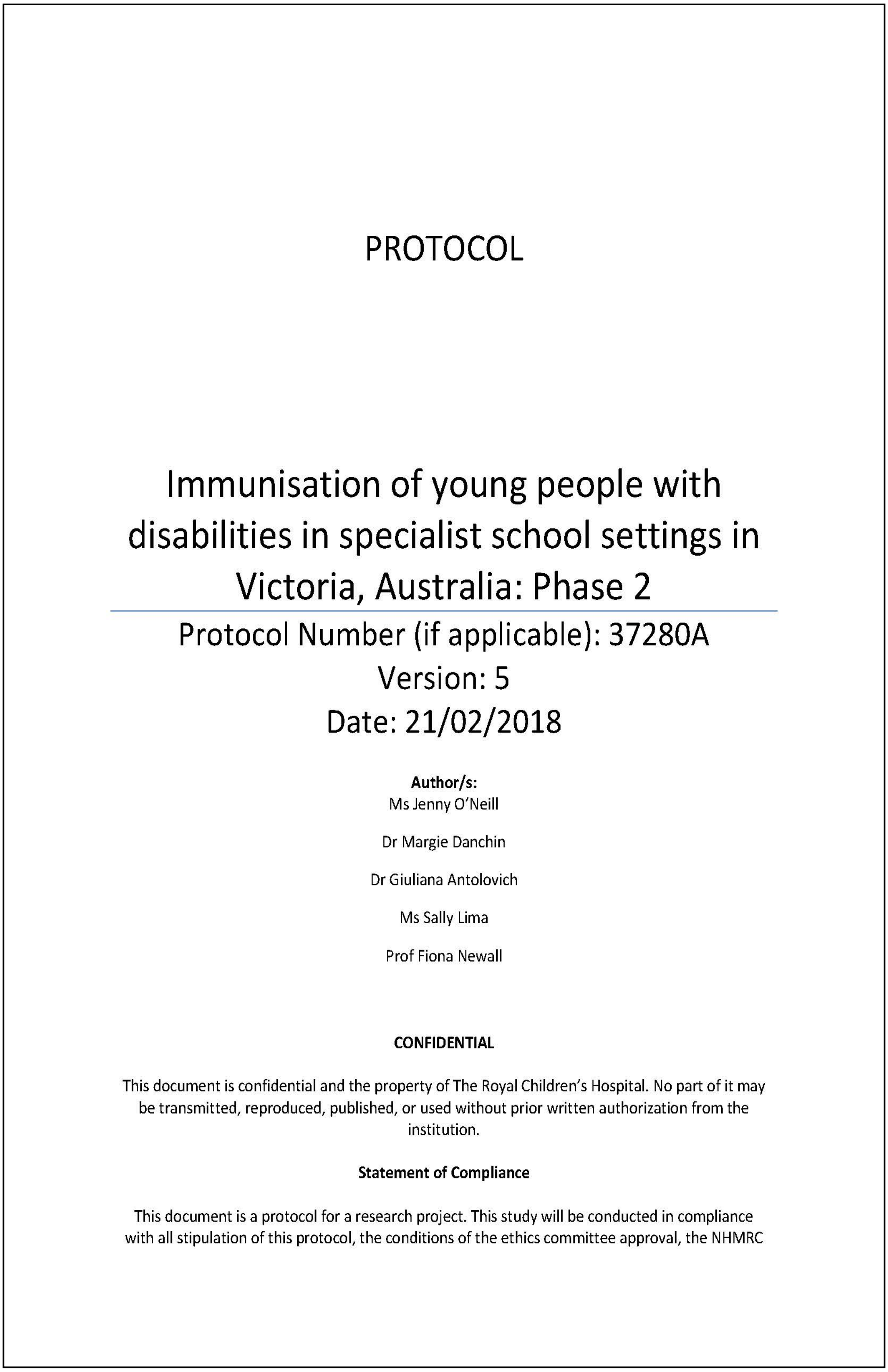
APPENDIX J: PHASE TWO HREC PROTOCOL



PROTOCOL

Immunisation of young people with disabilities in specialist school settings in Victoria, Australia: Phase 2

Protocol Number (if applicable): 37280A
Version: 5
Date: 21/02/2018

Author/s:
Ms Jenny O'Neill

Dr Margie Danchin

Dr Giuliana Antolovich

Ms Sally Lima

Prof Fiona Newall

CONFIDENTIAL

This document is confidential and the property of The Royal Children's Hospital. No part of it may be transmitted, reproduced, published, or used without prior written authorization from the institution.

Statement of Compliance

This document is a protocol for a research project. This study will be conducted in compliance with all stipulation of this protocol, the conditions of the ethics committee approval, the NHMRC

National Statement on ethical Conduct in Human Research (2007) and the Note for Guidance on Good Clinical Practice (CPMP/ICH-135/95).

TABLE OF CONTENTS

CONTENTS

1. GLOSSARY OF ABBREVIATIONS & TERMS

Abbreviation	Description (using lay language)
DHHS	Department of Health and Human Services
DET	Department of Education and Training
PI	Principal Investigator
LGAs	Local Government Areas
NIP	National Immunisation Program
DTP	Diptheria-tetanus-pertussis
HPV	Human Papillomavirus

2. STUDY SITES

2.1 STUDY LOCATION/S

While ethics approval is only required from the single site at The Royal Children's Hospital, interviews and/or focus groups will be held in a variety of locations with:

1. Up to 4 individuals working in the Department of Health and Human Services (DHHS) Immunisation Department, Victoria.

2. One individual from the Department of Education and Training (DET), Victoria.

3. Four to six Immunisation managers in Local Government Areas (LGAs) in Victoria and four to six groups of up to 8 immunisation nurses from LGAs in Victoria

4. Immunisation Coordinators of up to 10 public specialist schools in Victoria who enroll students with physical and/or intellectual disabilities

5. Up to 10 parents/carers of young people with physical and/or intellectual disabilities

6. Up to 10 young people with physical and/or intellectual disabilities

Therefore, locations of data collection may include state and local government offices, schools and family homes.

3. FUNDING AND RESOURCES

3.1 SOURCE/S OF FUNDING

The Principal Investigator (PI) is supported by a Research and Training Stipend from the University of Melbourne and a top-up scholarship from the Developmental Disability and Rehabilitation Research Group Gallie Trust, The Murdoch Childrens Research Institute. In addition, the PI has received a grant from DHHS Immunisation Victoria to assist with any costs of data collection and analysis.

4. INTRODUCTION/BACKGROUND INFORMATION

4.1 LAY SUMMARY

Victoria has a program of scheduled vaccinations, which are included in the National Immunisation Program (NIP) schedule and are paid for by the Australian government. Included in the NIP schedule is the school-based immunisation program, which offers all young people aged 12 to 13 years:

- the Diphtheria/tetanus/pertussis (DTP) vaccine;
- the varicella (chickenpox) vaccine if they have not already received one dose (<= 14 years old) or have a clear history of prior varicella infection; and
- the Human Papillomavirus (HPV) vaccine, which is currently given as three doses within 6 months.

In Victoria these vaccinations are given in Year 7, administered in schools by immunisation nurses arranged by the Local Government Areas (LGAs).

This school-based immunisation program is successful with high rates of young people being vaccinated. However, it is not clear if this is different for young people with disabilities in specialist school settings as there is very little information in Australia, or indeed internationally, about vaccination in children with disabilities. The limited studies that have been conducted suggest vaccination rates are lower in children with disabilities than for children in mainstream schools but they have not examined the reasons why this might be. The first phase of this research (HREC 36326B) is currently being undertaken, collecting information about young people's vaccination status in specialist schools in Victoria, in order to understand the size of the problem, and what factors are contributing to these young people remaining un-vaccinated. This second phase aims to understand the experiences of, concerns with, barriers and facilitators of acceptance and delivery immunisation for young people with disabilities, their parents, teachers and immunisation nurses and managers who deliver immunisation as well as policy makers. This ensures the viewpoint of all key stakeholders in the school-based immunisation program are included.

This information will be collected by in-depth interviews and focus groups. Participants will provide informed consent prior to taking part in interviews or focus groups. Focus groups will be undertaken at the participant's workplace, in the case of immunisation nurses, or at The Royal Children's Hospital, in the case of parents. Interview will be undertaken at a location that is mutually convenient. It is expected that the time commitment from adult participants will be 30 to 60 mins. For young people the time commitment will be 5 to 20 mins. The main consideration for participants taking part will be one of inconvenience and time commitment. No identifying information from this data will be published or presented.

This type of information about immunisations in specialist schools has not been collected previously and with this information, we hope to inform tailored interventions to ensure that young people with disabilities are able to have the same access, and optimal experiences in adolescent immunisation. This is essential to ensure that young people with disabilities are protected against infectious diseases that can be prevented by immunisation.

4.2 INTRODUCTION

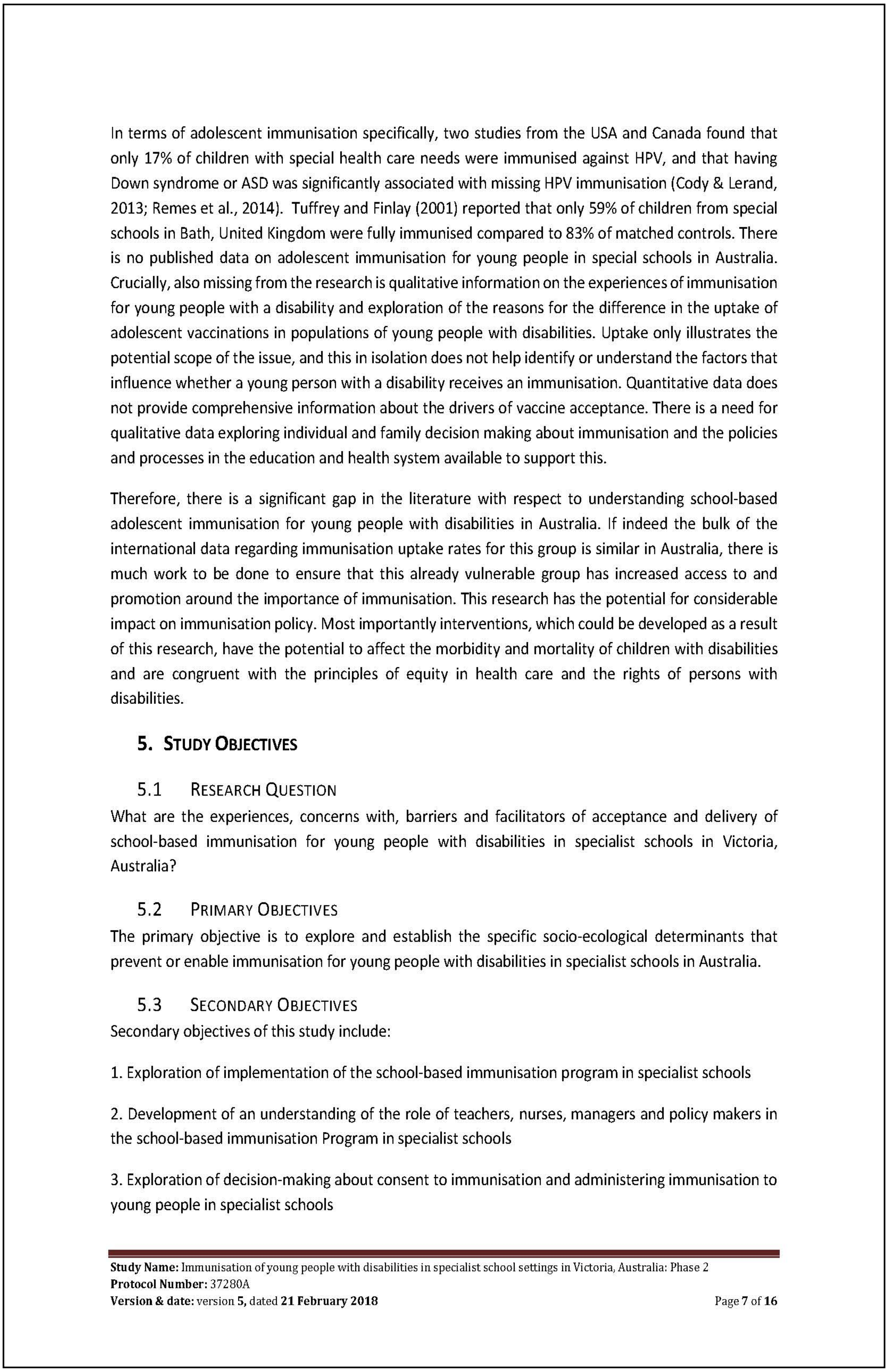
As part of the government-funded immunisation program in Australia, all young people aged 12 and 13 years are eligible to receive DTP, HPV and varicella immunisations through the school-based immunisaion program. In Victoria this is given in the first year of secondary school (Year 7), with DTP and varicella given as one dose each, and HPV given as three doses within six months (0, 1 and 6 months). Uptake of these vaccinations is recorded by the DHHS Immunisation in Victoria and through the HPV register. In 2015, 89.6% of eligible students received the adolescent dose of DTP and 77.4% of girls and 66.4% of boys received all three doses of HPV. Varicella is only necessary if the young person has not received one dose in childhood (<= 14 years) or does not have natural immunity or a strong clinical history of infection.

This study represents the second phase of a larger study aiming to explore the issues relation to school-based vaccination for young people with disabilities in specialist schools using the socio-ecological framework. The first phase focuses on collecting data on immunisation uptake in specialist schools. This second phase aims to answer the question: what are the experiences of, concerns with, barriers and facilitators to acceptance and delivery of school-based immunisation for young people with disabilities in specialist schools in Victoria, Australia?

The importance of understanding concerns, experiences, barriers and facilitators to immunisation delivery in the specialist school setting at all levels cannot be underestimated. In 2008, Australia ratified the United Nation Convention on the Rights of Persons with Disabilities, which recognises the need to provide health care for those with disabilities "in the same range, quality and standard of free or affordable health care and programs as provided to other persons" (United Nations, 2006, sec. 25). Without having accurate data to assess the delivery of the school-based immunisation program in non-mainstream schools, nor understanding the potential reasons for missed immunisations, and the concerns, barriers and enablers of the school-based immunisation program for this population, it is difficult to be certain that young people with disabilities are receiving equitable and acceptable preventative health care.

4.3 BACKGROUND INFORMATION

There is very little research in Australia or internationally, on immunisation in children and adolescents with a disability. When considering children of all ages, most studies suggest children with disabilities are at risk for under or non-immunisation. Lower rates of immunisation are recorded for children with disabilities in early childhood (Greenwood, Crawford, Walstab & Reddihough, 2013; Raddish, Goldmann, Lawrence, Kaplan & Perrin, 1993; Tillmann, Tillmann, Heininger, Lutschg & Weber, 2005), and for the seasonal influenza vaccine (Pandolfi et al., 2012; Yen et al., 2012). Of these studies only Greenwood et al. (2013) is Australian, with the focus on children with cerebral palsy under 7 years. Only one study in the USA (O'Connor & Bramlett, 2008), found that children with special health care needs, broadly defined to include children with developmental issues, emotional issues or needing any specialist care or medication, had immunisation rates similar to typically developing children. This was a data linkage study in the USA, which relied on parent report of vaccination coverage as opposed to data obtained from an immunisation register.



In terms of adolescent immunisation specifically, two studies from the USA and Canada found that only 17% of children with special health care needs were immunised against HPV, and that having Down syndrome or ASD was significantly associated with missing HPV immunisation (Cody & Lerand, 2013; Remes et al., 2014). Tuffrey and Finlay (2001) reported that only 59% of children from special schools in Bath, United Kingdom were fully immunised compared to 83% of matched controls. There is no published data on adolescent immunisation for young people in special schools in Australia. Crucially, also missing from the research is qualitative information on the experiences of immunisation for young people with a disability and exploration of the reasons for the difference in the uptake of adolescent vaccinations in populations of young people with disabilities. Uptake only illustrates the potential scope of the issue, and this in isolation does not help identify or understand the factors that influence whether a young person with a disability receives an immunisation. Quantitative data does not provide comprehensive information about the drivers of vaccine acceptance. There is a need for qualitative data exploring individual and family decision making about immunisation and the policies and processes in the education and health system available to support this.

Therefore, there is a significant gap in the literature with respect to understanding school-based adolescent immunisation for young people with disabilities in Australia. If indeed the bulk of the international data regarding immunisation uptake rates for this group is similar in Australia, there is much work to be done to ensure that this already vulnerable group has increased access to and promotion around the importance of immunisation. This research has the potential for considerable impact on immunisation policy. Most importantly interventions, which could be developed as a result of this research, have the potential to affect the morbidity and mortality of children with disabilities and are congruent with the principles of equity in health care and the rights of persons with disabilities.

5. STUDY OBJECTIVES

5.1 RESEARCH QUESTION

What are the experiences, concerns with, barriers and facilitators of acceptance and delivery of school-based immunisation for young people with disabilities in specialist schools in Victoria, Australia?

5.2 PRIMARY OBJECTIVES

The primary objective is to explore and establish the specific socio-ecological determinants that prevent or enable immunisation for young people with disabilities in specialist schools in Australia.

5.3 SECONDARY OBJECTIVES

Secondary objectives of this study include:

1. Exploration of implementation of the school-based immunisation program in specialist schools

2. Development of an understanding of the role of teachers, nurses, managers and policy makers in the school-based immunisation Program in specialist schools

3. Exploration of decision-making about consent to immunisation and administering immunisation to young people in specialist schools

4. Development of an understanding of the experience of young people with disability undergoing immunisation in specialist schools

5.4 OUTCOME MEASURES

Consistent with the methodology of qualitative inquiry outcome measures will not be objective measures, but will be the prevailing themes from the interviews and focus groups which will make up the qualitative data collection. The primary outcome measure will be a description of the understanding of specific socio-ecological determinants that prevent or enable immunisation for young people in specialist schools.

Secondary outcome measures with be a description of the themes relating to other aspects of the school-based immunisation program in specialist schools raised by participants.

6. STUDY DESIGN

6.1 STUDY TYPE & DESIGN & SCHEDULE

This is an exploratory qualitative study utlising a socio-ecological model adapted from Bronfenbrenner's Ecological Systems Theory. Bronfenbrenner's Ecological Systems Theory describes layers of influence from micro to macro levels. An adaptation of this, shown in Figure 1, is the socio-ecological model which has been widely used in health promotion to examine a range of factors which can affect health promotion or preventative health actions. This encompasses the individual's beliefs, attitudes and behaviours, the social influences of their immediate community, the organisational influences or arrangements, the broader community and structures and systems guiding policy. Most importantly the socio-ecological model emphasises the need to analyse the way these layers interact. Figure 1 illustrates the layers of the socio-ecological model. In this study, the stakeholders in each of the five layers of the socio-ecological model have been identified as:

Structures and systems: DHHS Immunisation and DET policy makers

Community: LGA Immunisation managers and nurses

Institutions: School immunisation co-ordinators

Interpersonal: Parents and family

Individual: Student

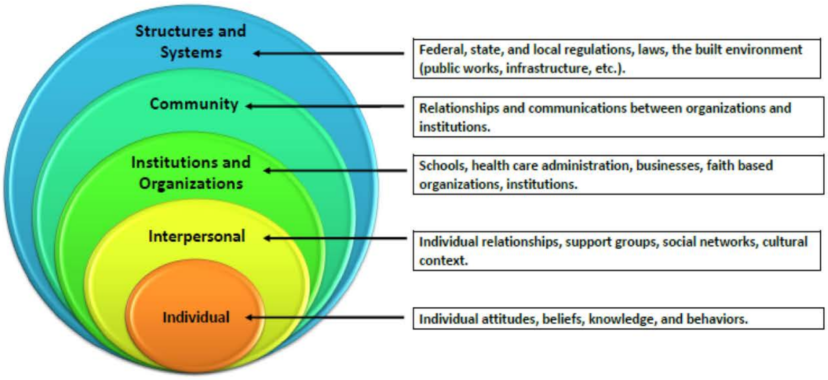


Figure 1: The socio-ecological model

Recruitment for this phase of the study will commence in October 2017 and will be continue until all interviews and focus groups are completed which is expected to be by May 2018. All participants will only have basic demographic data collected including: position in the socio-ecological model and job description relevant to school-based immunisation program, gender and age range. Participants will be provided with an alias and all data collected will be re-identifiable.

Only interviews will be offered for the policy, immunisation managers and immunisation schools co-ordinators as at these levels these stakeholders are key informants in immunisation for the state government, local government or school respectively. Key informants act as expert spokespeople for their group or population, therefore in-depth interviews are an appropriate method of gaining a comprehensive understanding of their perspective.

Key informants have been identified within Phase 1 of the study, through contact with government, LGAs and schools. The PI will approach key informant participants via email or phone to explain the research and invite participation. Contact details have been identified in Phase 1 of the research. If the participant agrees, the Information Statement and consent form will be sent electronically to the participant, and a time and location will be mutually agreed. The PI expects to most commonly travel to participant's place of work to conduct interviews. If there is no response to the initial invitation to participate a maximum of two follow up emails and/or phone calls to the key informant participants will be undertaken.

The rationale of using focus groups for immunisation nurses is because their job in the school immunisation program is within their team of immunisation nurses, which is different than the other stakeholders. Therefore, there is value in hearing their views within a team. However, for nurses who wish to participate outside the focus group and interview will be offered.

The rationale for including a focus group as well as interviews for parents as the group dynamic of parent discussion may both serve to add depth to the discussion, and will also enable more parent voices to be heard. However, for parents who prefer to be participate outside the focus group, interviews will be offered. Young people with a disability will be offered an interview and can participate with parental consent. Interviews with young people will take place after the interview with their parent/carer. The parent/carer can be present as a support person but will be asked not to take part in the young person's interview. This will be agreed upon by the young person and parent. These interviews will be held at the family home.

When undertaking interviews at the family home, the research team will adhere to the RCH Safety at Home Policy and Procedure. This will include
1. The interviewer having their car key and mobile on them at all times.
2. The interviewer assessing for any signs of violence or danger upon entering the home and exiting immediately if these are present.
3. The interviewer texting a nominated member of the research team on arrival to the family home and on depature.
4. The allocated member of the research team will have details of the time of arrival and expected depature and if the interviewer has not checked in within 15 minutes of these times, the member of the research team will text the interviewer. If there is no response in 10 minutes the member of the research team will call the interviewer. If there is no response the interviewer will escalate to the other members of the research team and the police.
5. All members of the research team will have access to a password protected spreadsheet with scheduled home interviews and addresses.

For all interviews and focus groups consent will be verbally re-visited in person prior to commencement of the discussion, and signed consent forms will be collected at that time. Interviews and focus groups will be recorded and transcribed. Transcription will be undertaken by a transcription service who will receive be required to sign a confidentiality agreement. Voice recordings will be destroyed once they are transcribed. Data will be coded and themed by the PI with consultation from the research team and the assistance of NVivo software. Data analysis of this stage is expected to be completed by June 2018. Phase 2 is the second part of a PhD study undertaken through the Department of Paediatrics at the Royal Children's Hospital which is due for completion in May 2019.

6.2 STUDY METHODOLOGY

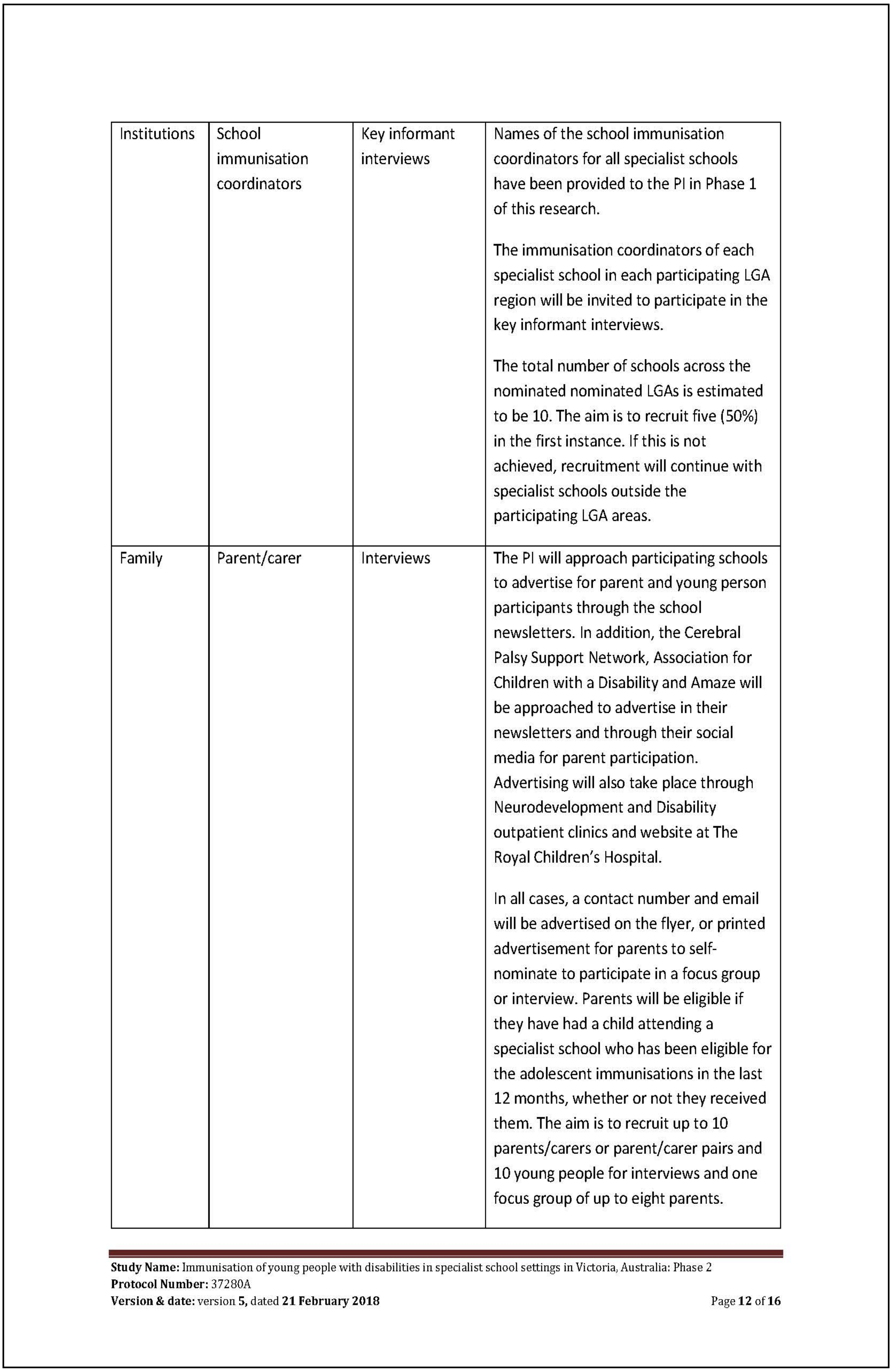
Data collection with be by in-depth semi-structured interviews and focus groups. Interview guides have been developed for both purposes to ensure consistency in data collection. This will allow broad themes to be covered, including: the experience of the participant's role in the school-based immunisation program in specialist schools, the perceived barriers and enablers to immunisation in specialist schools and particular concerns of the participants about immunisation in specialist schools. The semi-structured nature also allows for themes and topics to be initiated by participants, therefore ensuring the discussion is participant driven and not reliant on preconceived themes. Interview guides for each interview/focus group can be found in Appendix A.

7. STUDY POPULATION

7.1 RECRUITMENT PROCEDURE

Recruitment will be purposeful with the aim to capture key informants and diversity of experience. Recruitment strategy is set out below:

SEM level	Stakeholders	Data collection method	Recruitment strategy
Policy	DHHS Immunisation and DET	Key Informant interviews	Four individuals in DHHS Immunisation and one individual at DET have been identified as key informants in Phase 1 of the study. All of these individuals will be contacted and invited to participate in an in-depth interview
Community	LGA immunisation managers LGA immunisation nurses	Key informant interviews Focus groups	Six Victorian LGAs with specialist schools identified by the research team based on maximum diversity sampling. This includes consideration of diversity of: location (metropolitan, regional, and where applicable rural); population; a range of immunisation uptake levels (as recorded for mainstream schools); socioeconomic levels (as measured by index of relative economic advantage and disadvantage); and type of specialist schools. If less than 4 LGAs agree to participate the research team will nominate a mix of other LGAs that are representative of diversity to ensure a minimum of four LGAs. Immunisation managers of all LGAs with specialist schools have been identified in Phase 1 of the research. They will be the contact for LGAs and will be asked to participate in an in-depth interview. At the same time, they will be asked to invite their immunisation nurses to participate in a focus group or interview. Interviews and focus groups will be scheduled at a mutually convenient time. The individuals within the focus group will provide their own signed consent to participate. A maximum of eight nurses in each of the four to six LGAs will be included in a focus group.



Institutions	School immunisation coordinators	Key informant interviews	Names of the school immunisation coordinators for all specialist schools have been provided to the PI in Phase 1 of this research. The immunisation coordinators of each specialist school in each participating LGA region will be invited to participate in the key informant interviews. The total number of schools across the nominated nominated LGAs is estimated to be 10. The aim is to recruit five (50%) in the first instance. If this is not achieved, recruitment will continue with specialist schools outside the participating LGA areas.
Family	Parent/carer	Interviews	The PI will approach participating schools to advertise for parent and young person participants through the school newsletters. In addition, the Cerebral Palsy Support Network, Association for Children with a Disability and Amaze will be approached to advertise in their newsletters and through their social media for parent participation. Advertising will also take place through Neurodevelopment and Disability outpatient clinics and website at The Royal Children's Hospital. In all cases, a contact number and email will be advertised on the flyer, or printed advertisement for parents to self-nominate to participate in a focus group or interview. Parents will be eligible if they have had a child attending a specialist school who has been eligible for the adolescent immunisations in the last 12 months, whether or not they received them. The aim is to recruit up to 10 parents/carers or parent/carer pairs and 10 young people for interviews and one focus group of up to eight parents.

7.2 INCLUSION AND EXCLUSION CRITERIA

Exclusion criteria for all participants will include: need for an interpreter to participate, as interpreters will not be available for interviews or focus groups.

Exclusion criteria for young people with a disability will include: non-verbal communication system as the interviewer will require verbal answers to questions.

Inclusion criteria: For parents: inclusion criteria will include primary carers (including biological parents, adoptive or foster parents or grandparents) of young adolescents attending a specialist school in Victoria and eligible for the adolescent immunisations given at 12-14 years old in the last 12 months, whether or not they received them.

For young people: inclusion criteria will include any young person who attends a specialist school and was eligible to receive their adolescent immunisations in the last 12 months, whether or not they received them.

7.3 CONSENT

Signed consent will be obtained from all participants prior to the interview or focus group commencing.

8. PARTICIPANT SAFETY AND WITHDRAWAL

8.1 RISK MANAGEMENT AND SAFETY

There are minimal risks to participants involved in this study. The risk of psychological distress when recounting thoughts and experiences of immunisations of young people however must be considered. If this should occur the PI will stop the interview/focus group and allow the individual to have a break. The choice will be given to the participant whether to continue the interview or focus group. If the participant continues and appears to recover further support will be offered by way of a follow up phone call by the PI within the next week.

If the participant declines to continue or continues to appear distressed, the PI will encourage follow up by the individual's general practitioner or employee wellbeing scheme (for professionals). For parents, if the discussion provokes uncertainty about the choice they have made to vaccinate or not vaccinate their children, details of the Immunisation Service at The Royal Children's Hospital will be given to the parent in order for them to access the clinic in which they can review these decisions with an paediatrician or a senior nurse specialised in immunisation.

For the PI, safety will be ensured when travelling to different locations by:

1. Notifying the research team of all interviews and focus group, including time, date and locations

2. Having a charged mobile phone on person at all times

3. Organizing to notify a member of the research team via text message when entering an interview and on leaving

8.2 ADVERSE EVENT REPORTING

There are no foreseeable serious adverse events for this study.

Distress of any individuals taking part will be discussed with the research team and, if referral to supports is required the Research and Ethics department at The Royal Children's Hospital will also be notified and advice sought as to whether any further action is needed.

8.3 HANDLING OF WITHDRAWALS

At any time, participants may withdraw from the study. Any such participants will then be asked for verbal permission to include their response to any interview or focus group questions already recorded. If verbal permission is not given, any recordings of interviews will be destroyed, or in the case of focus groups, any responses they have given will not be transcribed or used.

9. DATA SECURITY & HANDLING

9.1 DETAILS OF WHERE RECORDS WILL BE KEPT & HOW LONG WILL THEY BE STORED

Audio-recordings, transcriptions and demographic data will be stored electronically on a password protected computer with locked cloud back-up, only accessible to the research team and the transcription service who will be asked to sign a confidentiality agreement. Transcriptions will be kept for 7 years after completion of the study. This computer will be in the possession of the PI who works between the Royal Children's Hospital and her home.

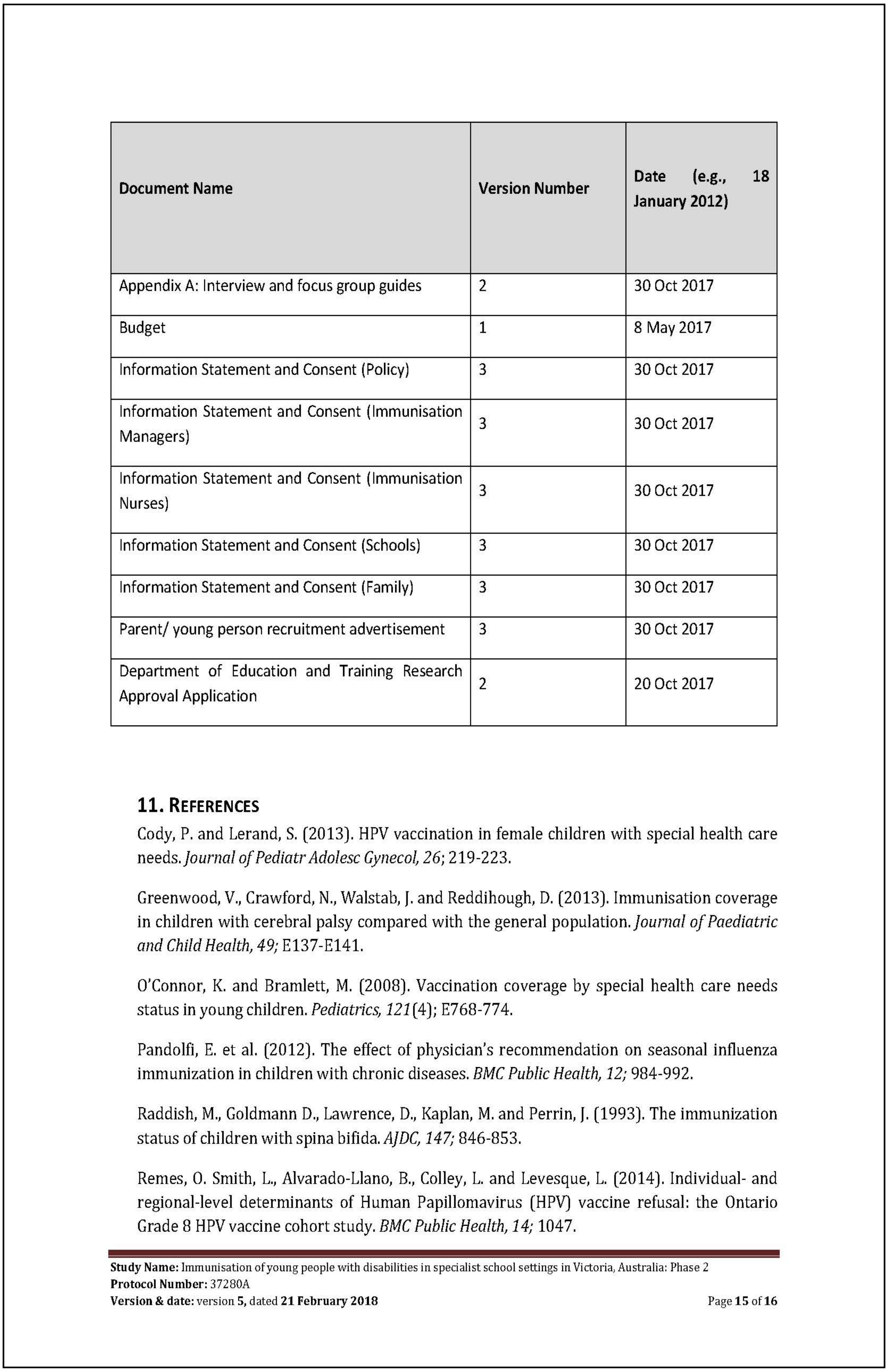
9.2 CONFIDENTIALITY AND SECURITY

Participants will be given an alias which will be assumed on all transcriptions and analyses of data. A spreadsheet will be maintained with allocation of alias in order the data is re-identifiable for the purposes of rechecking of data and meaning with participants if necessary. This spreadsheet will be password protected. No identifiable data will be included in any publications or presentations. This includes identifying individuals, schools or LGAs.

10 APPENDIX

Please see Appendix A attached for interview and focus group guides.

List of Attachments included:



Document Name	Version Number	Date (e.g., 18 January 2012)
Appendix A: Interview and focus group guides	2	30 Oct 2017
Budget	1	8 May 2017
Information Statement and Consent (Policy)	3	30 Oct 2017
Information Statement and Consent (Immunisation Managers)	3	30 Oct 2017
Information Statement and Consent (Immunisation Nurses)	3	30 Oct 2017
Information Statement and Consent (Schools)	3	30 Oct 2017
Information Statement and Consent (Family)	3	30 Oct 2017
Parent/ young person recruitment advertisement	3	30 Oct 2017
Department of Education and Training Research Approval Application	2	20 Oct 2017

11. REFERENCES

Cody, P. and Lerand, S. (2013). HPV vaccination in female children with special health care needs. *Journal of Pediatr Adolesc Gynecol, 26*; 219-223.

Greenwood, V., Crawford, N., Walstab, J. and Reddihough, D. (2013). Immunisation coverage in children with cerebral palsy compared with the general population. *Journal of Paediatric and Child Health, 49;* E137-E141.

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Pandolfi, E. et al. (2012). The effect of physician's recommendation on seasonal influenza immunization in children with chronic diseases. *BMC Public Health, 12;* 984-992.

Raddish, M., Goldmann D., Lawrence, D., Kaplan, M. and Perrin, J. (1993). The immunization status of children with spina bifida. *AJDC, 147;* 846-853.

Remes, O. Smith, L., Alvarado-Llano, B., Colley, L. and Levesque, L. (2014). Individual- and regional-level determinants of Human Papillomavirus (HPV) vaccine refusal: the Ontario Grade 8 HPV vaccine cohort study. *BMC Public Health, 14;* 1047.

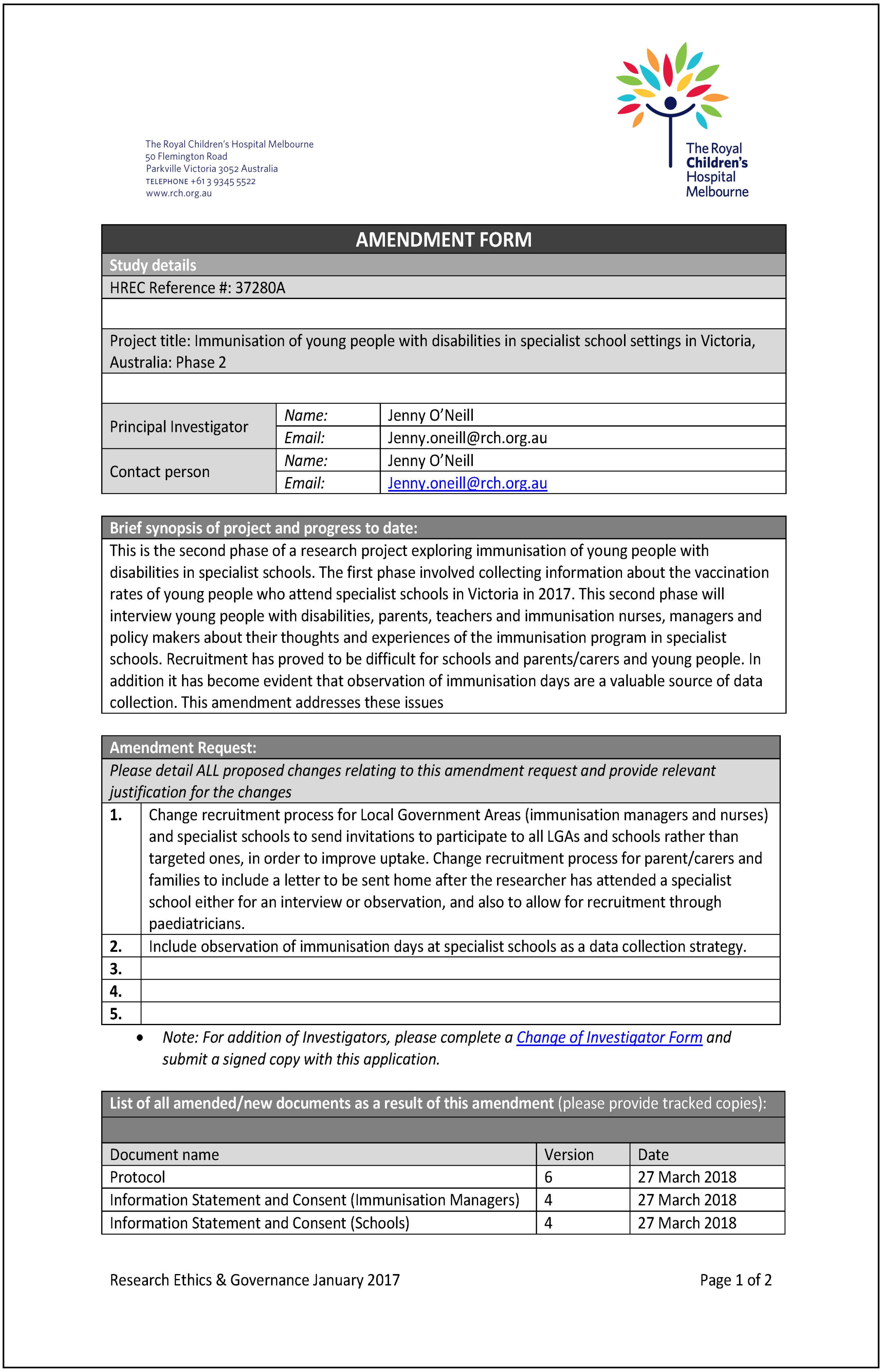
Tilmann, B., Tillmann, H., Heininger, U., Lutschg, J. and Weber, P. (2005). Acceptance and timeliness of standard vaccination in children with chronic neurological deficits in north-western Switzerland. *Eur J Pediatr, 164;* 320-325.

Tuffrey, C. and Finlay, F. (2001). Immunisation status amongst children attending special schools. *Ambulatory Child Health, 7*; 213-217.

Yen C., Hsu, S., Loh, C., Fang, W., Wu, C., Chu, C., and Lin, J. (2012). Analysis of seasonal influenza vaccine uptake among children and adolescents with an intellectual disability. *Research in Developmental Disabilities, 33;* 704-710.

United Nations (2006). *Convention on the rights of persons with disabilities.* United Nations.

APPENDIX K: PHASE TWO HREC PROTOCOL AMENDMENT



The Royal Children's Hospital Melbourne
50 Flemington Road
Parkville Victoria 3052 Australia
TELEPHONE +61 3 9345 5522
www.rch.org.au

The Royal Children's Hospital Melbourne

AMENDMENT FORM

Study details		
HREC Reference #: 37280A		
Project title: Immunisation of young people with disabilities in specialist school settings in Victoria, Australia: Phase 2		
Principal Investigator	*Name:*	Jenny O'Neill
	Email:	Jenny.oneill@rch.org.au
Contact person	*Name:*	Jenny O'Neill
	Email:	Jenny.oneill@rch.org.au

Brief synopsis of project and progress to date:

This is the second phase of a research project exploring immunisation of young people with disabilities in specialist schools. The first phase involved collecting information about the vaccination rates of young people who attend specialist schools in Victoria in 2017. This second phase will interview young people with disabilities, parents, teachers and immunisation nurses, managers and policy makers about their thoughts and experiences of the immunisation program in specialist schools. Recruitment has proved to be difficult for schools and parents/carers and young people. In addition it has become evident that observation of immunisation days are a valuable source of data collection. This amendment addresses these issues

Amendment Request:

Please detail ALL proposed changes relating to this amendment request and provide relevant justification for the changes

1.	Change recruitment process for Local Government Areas (immunisation managers and nurses) and specialist schools to send invitations to participate to all LGAs and schools rather than targeted ones, in order to improve uptake. Change recruitment process for parent/carers and families to include a letter to be sent home after the researcher has attended a specialist school either for an interview or observation, and also to allow for recruitment through paediatricians.
2.	Include observation of immunisation days at specialist schools as a data collection strategy.
3.	
4.	
5.	

- *Note: For addition of Investigators, please complete a Change of Investigator Form and submit a signed copy with this application.*

List of all amended/new documents as a result of this amendment (please provide tracked copies):

Document name	Version	Date
Protocol	6	27 March 2018
Information Statement and Consent (Immunisation Managers)	4	27 March 2018
Information Statement and Consent (Schools)	4	27 March 2018

Research Ethics & Governance January 2017 Page 1 of 2

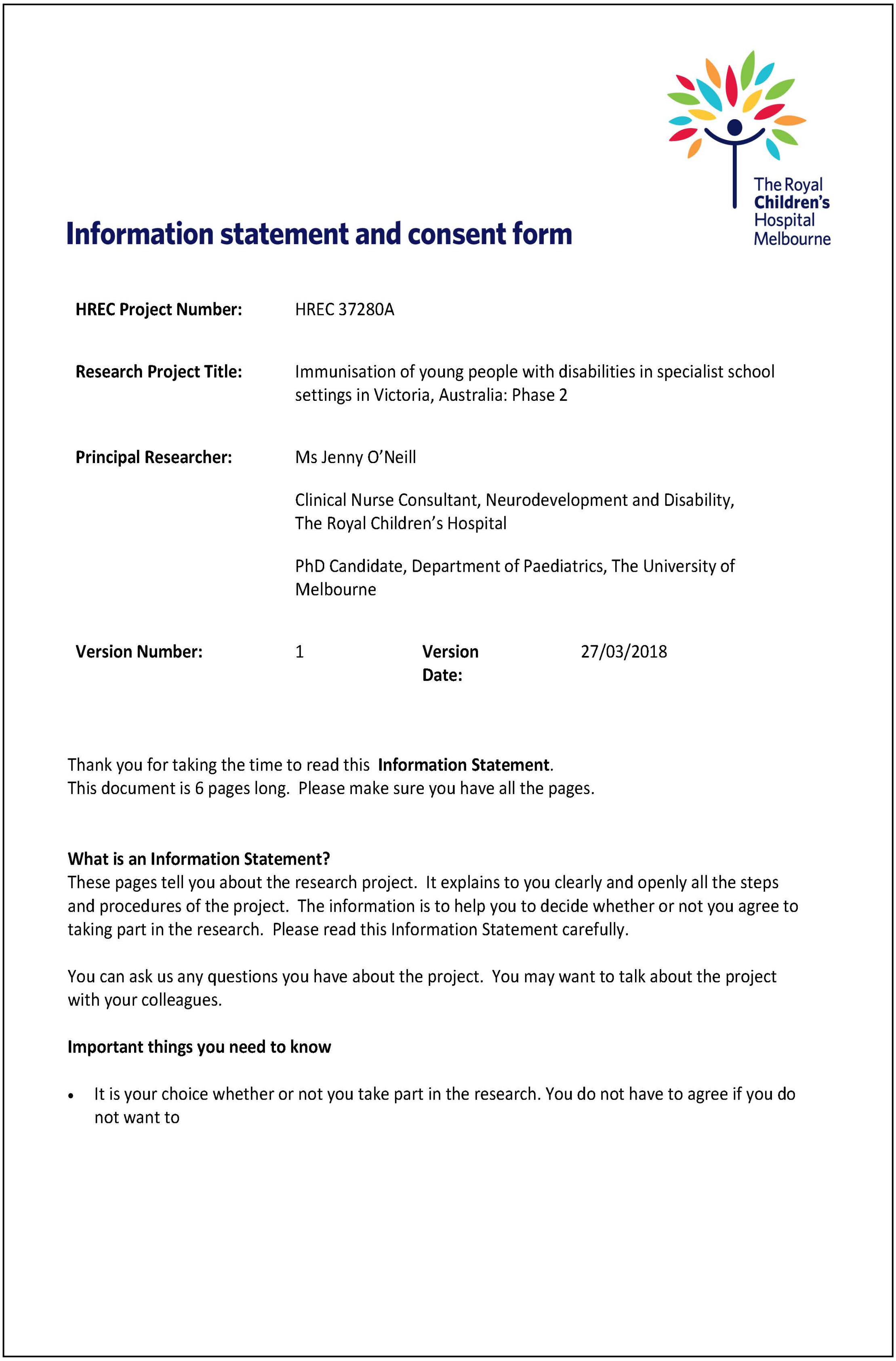
Information Statement and Consent (School observation)	1	27 March 2018
Parent/carer/young person recruitment letter	1	27 March 2018

- *Please note that if this form has not been completed with appropriate justification, that the REG team will not commence a REG review until this information has been provided.*
- *Please submit an electronic copy <u>signed by the PI (or emailed from or cc'd to the PI)</u> to <u>rch.ethics@rch.org.au</u>*
- *If a fee applies to this submission, as per the <u>schedule</u>, please ensure that you complete the <u>Invoicing Authorisation form</u>. Please note that you do no need to submit this form if no fee apply.*

PI Signature: Jenny O'Neill	**Date: 27.03.2018**

OFFICE USE ONLY			
Reviewer comments:			
Recommendation *(please tick <u>one</u> option below)*:			
Recommend approval ☐ Recommend approval subject to above ☐ HREC review ☐			
Name:		**Date:**	
Signature:			
Chair/Director comments:			
Decision *(please tick <u>one</u> option below)*:			
Approved ☐ Approved subject to above ☐ HREC review ☐			
Name:		**Date:**	
Signature:			

APPENDIX L: PHASE TWO INFORMATION STATEMENT AND CONSENT FORM FOR SCHOOL OBSERVATIONS



The Royal
Children's
Hospital
Melbourne

Information statement and consent form

HREC Project Number:	HREC 37280A		
Research Project Title:	Immunisation of young people with disabilities in specialist school settings in Victoria, Australia: Phase 2		
Principal Researcher:	Ms Jenny O'Neill Clinical Nurse Consultant, Neurodevelopment and Disability, The Royal Children's Hospital PhD Candidate, Department of Paediatrics, The University of Melbourne		
Version Number:	1	**Version Date:**	27/03/2018

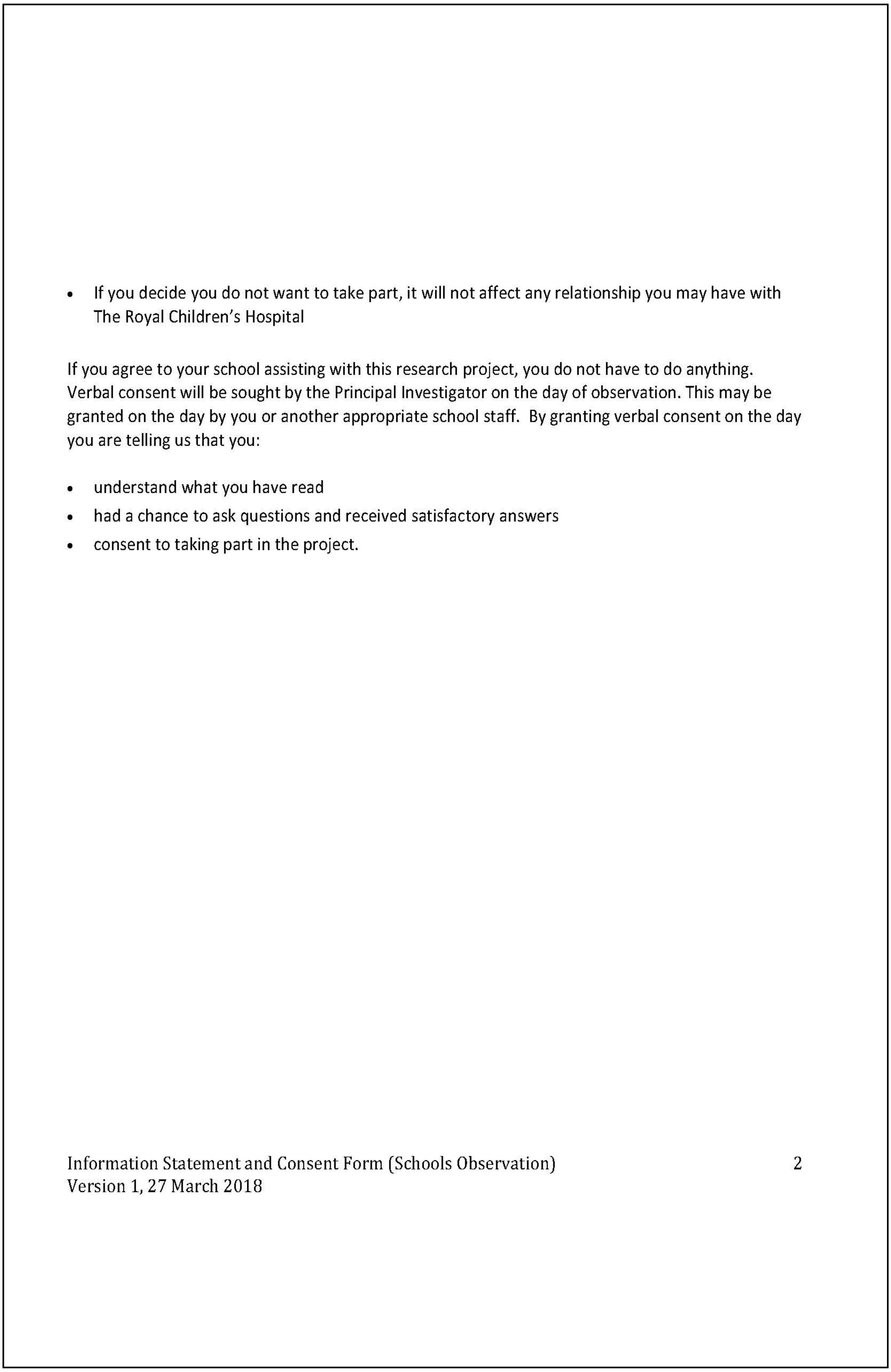
Thank you for taking the time to read this **Information Statement**.
This document is 6 pages long. Please make sure you have all the pages.

What is an Information Statement?
These pages tell you about the research project. It explains to you clearly and openly all the steps and procedures of the project. The information is to help you to decide whether or not you agree to taking part in the research. Please read this Information Statement carefully.

You can ask us any questions you have about the project. You may want to talk about the project with your colleagues.

Important things you need to know

- It is your choice whether or not you take part in the research. You do not have to agree if you do not want to



- If you decide you do not want to take part, it will not affect any relationship you may have with The Royal Children's Hospital

If you agree to your school assisting with this research project, you do not have to do anything. Verbal consent will be sought by the Principal Investigator on the day of observation. This may be granted on the day by you or another appropriate school staff. By granting verbal consent on the day you are telling us that you:

- understand what you have read
- had a chance to ask questions and received satisfactory answers
- consent to taking part in the project.

1. What is the research project about?

The School Immunisation Program is part of the scheduled vaccinations in Australia. Young people aged 12 to 13 years are offered the Diphtheria/Tetanus/Pertussis (DTP) vaccine, and the Human Papillomavirus (HPV) through this program. Vaccinations are given in schools by immunisation nurses from the council. Vaccinations are offered for young people who are 12 to 13 years old, or in Year 7 with high rates of young people in mainstream schools being vaccinated.

However, there is very little information worldwide about vaccination in young people with disabilities. Some studies show that vaccination rates are lower in young people with disabilities than for young people in mainstream schools. No studies have examined the reasons why this might be. This research aims to understand the experiences of, concerns with, barriers and facilitators of acceptance and delivery of immunisations given in early adolescence for young people with disabilities in specialist schools. The information we collect from this research will help to ensure that young people with disabilities are able to have the same access to vaccines, and to improve immunisation experiences and outcomes.

This information statement applies to the second phase of this research. The first phase involved collecting information about the vaccination rates of young people who attend specialist schools in Victoria in 2017. The second phase will interview young people with disabilities, parents, teachers and immunisation nurses, managers and policy makers about their thoughts and experiences of the immunisation program in specialist schools. In addition, the research team will observe immunisation days in specialist schools. This Information Statement applies only to observation of an immunisation session in your school.

2. Who is funding this research project?

This project is being undertaken as part of a PhD study by the principal investigator, Jenny O'Neill. The Principal Investigator (PI) is a Clinical Nurse Consultant in Neurodevelopment and Disability at The Royal Children's Hospital. She is supported by a Research and Training Stipend from the University of Melbourne and a top-up scholarship from the Developmental Disability and Rehabilitation Research Group Gallie Trust, The Murdoch Childrens Research Institute. In addition, the PI has received a grant from the Department of Health and Human Services Immunisation Department to assist with any costs of data collection and analysis.

3. Why am I being asked to take part?

We are asking you to take part as a specialist school in Victoria that enrols children with physical and/or intellectual disabilities. The immunisation nurses in your Local Government Area have agreed to allow the Principal Investigator attend an immunisation day at your school with them.

> We have Approval from the Department of Education and Training to approach eligible schools to take part.

4. What do I need to do in this research project?

a. Agree to the Principal Investigator attending with the local government immunisation team on an immunisation day as an observer.

Verbal agreement from the school will be sought at the start of the immunisation session. Observation will involve no physical contact with the students. The researcher will NOT be assisting in any way to administer vaccinations nor have any discussion with students with regards to vaccinations. Students will not be identified to the researcher and she will not have access to any immunisation paperwork. Notes and reflections will be recorded by the researchers. No student or staff member will be identified in these notes and no individual, school or local government area will be identified in any publication arising from this study.

b. Distribute a letter for students eligible for immunisations to take home to request participation in an interview by the family

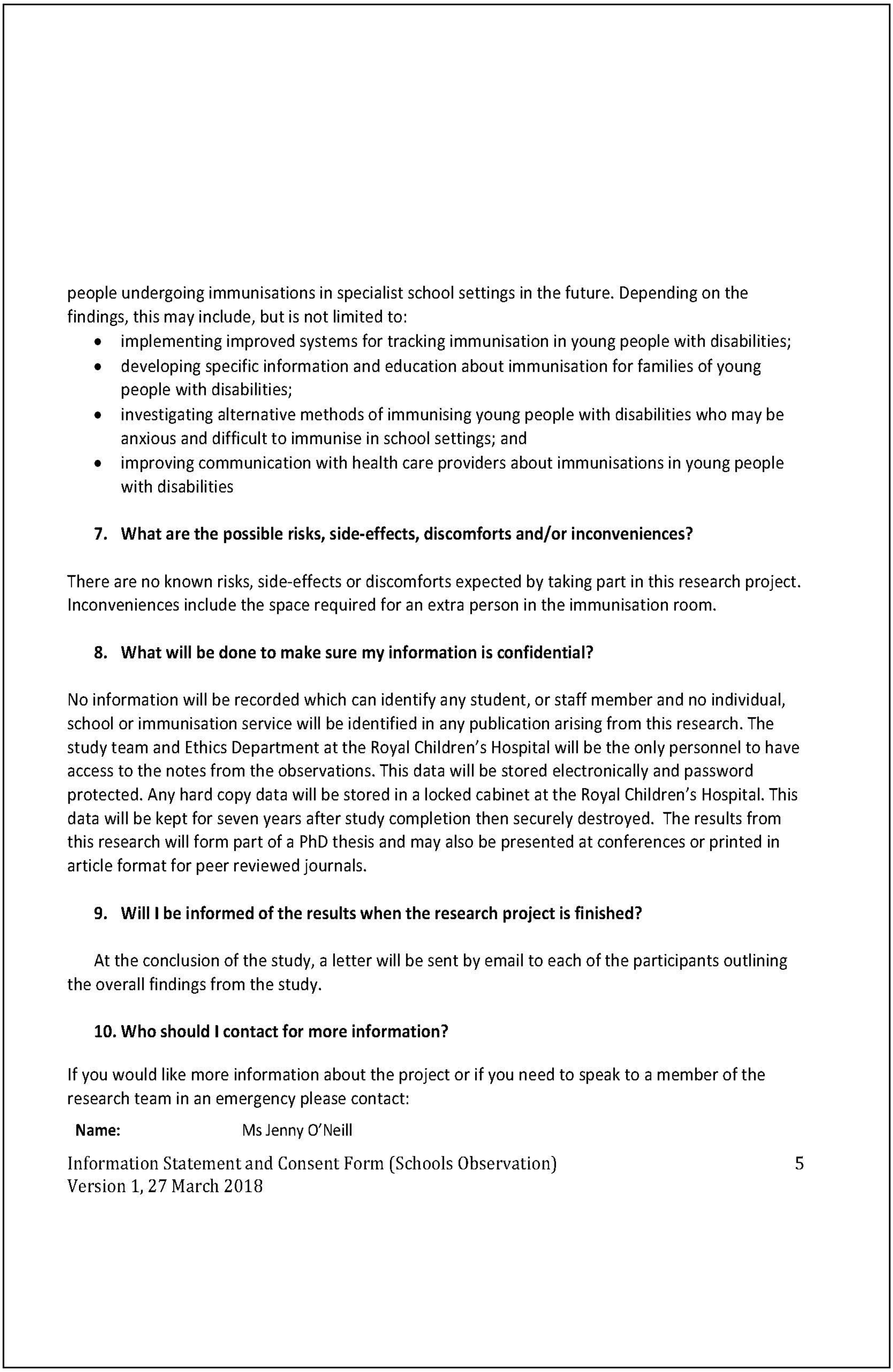
This letter invites families to contact the researcher directly and any interview will take place outside the school environment.

5. Can I withdraw from the project?

If you give your consent to participate, and change your mind, you can withdraw from the project. You do not need to tell us the reason why you want to stop being in the project. If you leave the project we will use any information already collected unless you tell us not to

6. What are the possible benefits for me and other people in the future?

There will no direct immediate benefits from this research project for you. We hope that the findings from this PhD study will inform policy decisions and interventions. This may make it easier for young



people undergoing immunisations in specialist school settings in the future. Depending on the findings, this may include, but is not limited to:

- implementing improved systems for tracking immunisation in young people with disabilities;
- developing specific information and education about immunisation for families of young people with disabilities;
- investigating alternative methods of immunising young people with disabilities who may be anxious and difficult to immunise in school settings; and
- improving communication with health care providers about immunisations in young people with disabilities

7. What are the possible risks, side-effects, discomforts and/or inconveniences?

There are no known risks, side-effects or discomforts expected by taking part in this research project. Inconveniences include the space required for an extra person in the immunisation room.

8. What will be done to make sure my information is confidential?

No information will be recorded which can identify any student, or staff member and no individual, school or immunisation service will be identified in any publication arising from this research. The study team and Ethics Department at the Royal Children's Hospital will be the only personnel to have access to the notes from the observations. This data will be stored electronically and password protected. Any hard copy data will be stored in a locked cabinet at the Royal Children's Hospital. This data will be kept for seven years after study completion then securely destroyed. The results from this research will form part of a PhD thesis and may also be presented at conferences or printed in article format for peer reviewed journals.

9. Will I be informed of the results when the research project is finished?

At the conclusion of the study, a letter will be sent by email to each of the participants outlining the overall findings from the study.

10. Who should I contact for more information?

If you would like more information about the project or if you need to speak to a member of the research team in an emergency please contact:

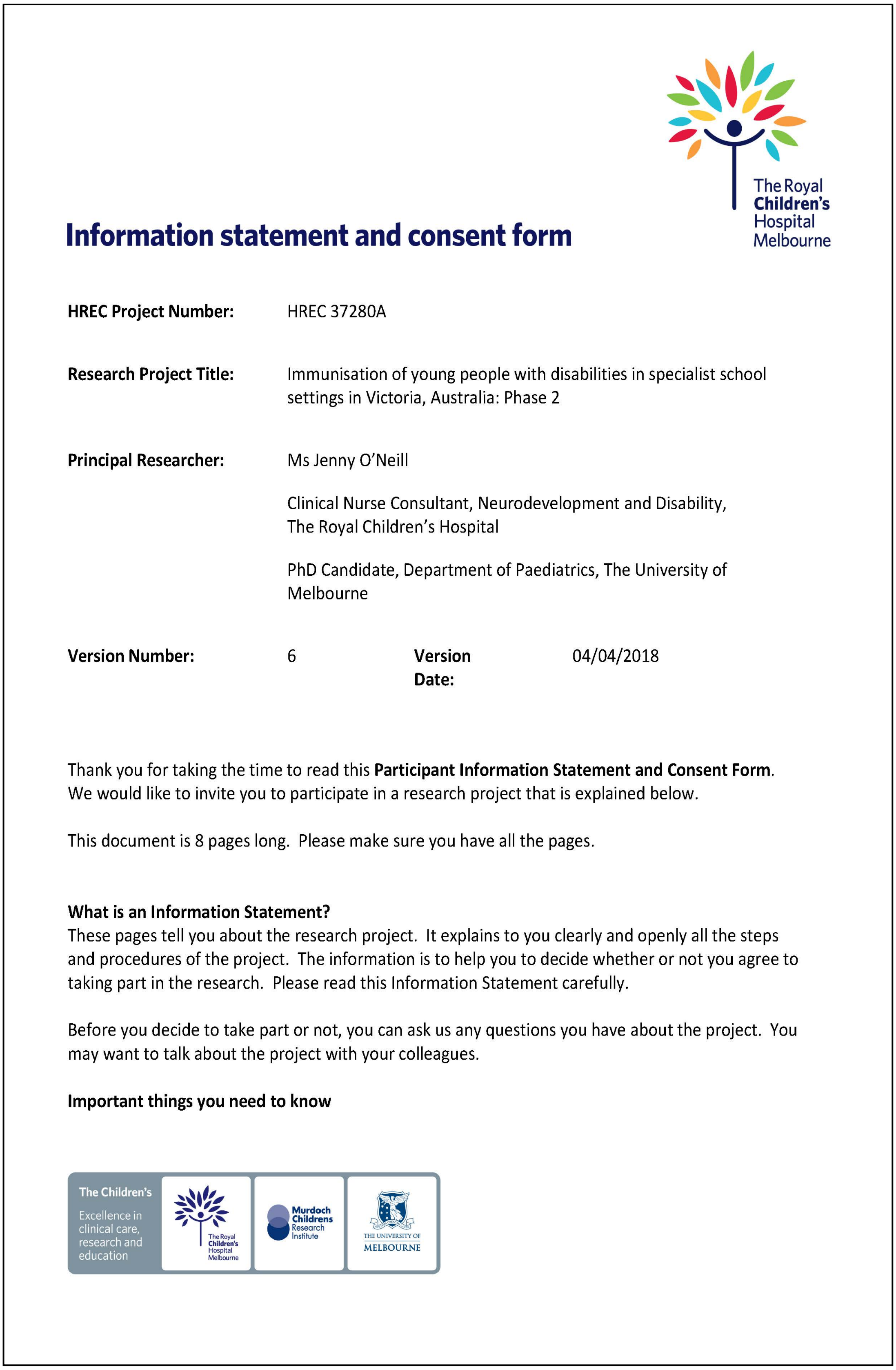
Name: Ms Jenny O'Neill

Contact telephone: 0410 557 898

Email: Immunisation.research@rch.org.au

If you have any concerns and/or complaints about the project, the way it is being conducted or your rights as a research participant, and would like to speak to someone independent of the project, please contact: Director, Research Ethics & Governance, The Royal Children's Hospital Melbourne

APPENDIX M: PHASE TWO INFORMATION STATEMENT AND CONSENT FORM FOR IMMUNISATION MANAGERS



Information statement and consent form

HREC Project Number:	HREC 37280A		
Research Project Title:	Immunisation of young people with disabilities in specialist school settings in Victoria, Australia: Phase 2		
Principal Researcher:	Ms Jenny O'Neill Clinical Nurse Consultant, Neurodevelopment and Disability, The Royal Children's Hospital PhD Candidate, Department of Paediatrics, The University of Melbourne		
Version Number:	6	**Version Date:**	04/04/2018

Thank you for taking the time to read this **Participant Information Statement and Consent Form**. We would like to invite you to participate in a research project that is explained below.

This document is 8 pages long. Please make sure you have all the pages.

What is an Information Statement?
These pages tell you about the research project. It explains to you clearly and openly all the steps and procedures of the project. The information is to help you to decide whether or not you agree to taking part in the research. Please read this Information Statement carefully.

Before you decide to take part or not, you can ask us any questions you have about the project. You may want to talk about the project with your colleagues.

Important things you need to know

- It is your choice whether or not you take part in the research. You do not have to agree if you do not want to
- If you decide you do not want to take part, it will not affect any relationship you may have with The Royal Children's Hospital

If you would like to take part in the research project, please sign the consent form at the end of this information statement. By signing the consent form you are telling us that you:

- understand what you have read
- had a chance to ask questions and received satisfactory answers
- consent to taking part in the project.

1. What is the research project about?

The School Immunisation Program is part of the scheduled vaccinations in Australia. Young people aged 12 to 13 years are offered the Diphtheria/Tetanus/Pertussis (DTP) vaccine, and the Human Papillomavirus (HPV) through this program. Vaccinations are given in schools by immunisation nurses from the council. Vaccinations are offered for young people who are 12 to 13 years old, or in Year 7 with high rates of young people in mainstream schools being vaccinated.

However, there is very little information worldwide about vaccination in young people with disabilities. Some studies show that vaccination rates are lower in young people with disabilities than for young people in mainstream schools. No studies have examined the reasons why this might be. This research aims to understand the experiences of, concerns with, barriers and facilitators of acceptance and delivery of immunisations given in early adolescence for young people with disabilities in specialist schools. The information we collect from this research will help to ensure that young people with disabilities are able to have the same access to vaccines, and to improve immunisation experiences and outcomes.

This information statement applies to the second phase of this research. The first phase involved collecting information about the vaccination rates of young people who attend specialist schools in Victoria in 2017. The second phase will interview young people with disabilities, parents, teachers and immunisation nurses, managers and policy makers about their thoughts and experiences of the immunisation program in specialist schools. In addition the Principal Investigator will undertake observation of immunisation days in specialist schools.

2. Who is funding this research project?

This project is being undertaken as part of a PhD study by the principal investigator, Jenny O'Neill. The Principal Investigator (PI) is a Clinical Nurse Consultant in Neurodevelopment and Disability at The Royal Children's Hospital. She is supported by a Research and Training Stipend from the University of Melbourne and a top-up scholarship from the Developmental Disability and Rehabilitation Research Group Gallie Trust, The Murdoch Childrens Research Institute. In addition, the PI has received a grant from the Department of Health and Human Services Immunisation Department to assist with any costs of data collection and analysis.

3. Why am I being asked to take part?

We are asking you to take part as an immunisation manager in a Local Government Area that undertakes immunisations in specialist schools.

We have approval from the Department of Education and Training for eligible schools to take part.

4. What do I need to do in this research project?

a. Return the signed consent form

If you want to take part in this research please scan and email the signed consent to the Principal Investigator Jenny O'Neill at immunisation.research@rch.org.au .

b. Allow the Principal Investigator to attend an scheduled immunisation day with your team at a specialist school

We ask you to provide the Principal Investigator, Jenny O'Neill, with the date, and time and specialist school you are attending and she will join you as an observer. The Principal Investigator will record general notes and reflections on the day. No names of students, school staff or immunisation staff will be noted. The name of the school and immunisation service will not be published.

If you consent to this observation, the principal of the school will be notified of this and will be sent an information statement about the research. Verbal permission will be sought by the Principal Investigator on the day from the school to observe the immunsiations.

c. Take part in an interview

You will be asked questions in the interview about your role in the school immunisation program in specialist schools. The main focus of the interview will be your perception of the experiences, challenges and barriers to immunising young people with disabilities in the specialist school setting. We will contact you to organise a mutually agreeable time and location to undertake an interview. If you agree to the Principal Investigator attending an immunisation session the interview can occur on this day if convenient. It is expected that the interview will last 30 minutes. Your interview will be recorded so that we can transcribe what is said and find common themes. You will be given another name, or an alias, and will not be identifiable in transcriptions or any published results from this research.

d. Assist with promoting this research to immunisation nurses in your team

If you agree to participate in this research we also request your assistance to invite immunisation nurses from your team to take part in a separate interview or focus group, by distributing the Immunisation Nurse Information Statement and Consent. Immunisation nurses can contact the Principal Investigator directly and provide individual consent to take part. If you do not want to assist with this recruitment it does not affect your ability to take part in this research. If you agree to the Principal Investigator to attending an immunisation session the interview/focus group can occur on this day with the nurses present, if convenient.

5. Can I withdraw from the project?

If you give your consent to participate, and change your mind, you can withdraw from the project. You do not need to tell us the reason why you want to stop being in the project. If you leave the project we will use any information already collected unless you tell us not to

6. What are the possible benefits for me and other people in the future?

There will be no direct immediate benefits from this research project for you. We hope that the findings from this PhD study will inform policy decisions and interventions. This may make it easier for young people undergoing immunisations in specialist school settings in the future. Depending on the findings, this may include, but is not limited to:

- implementing improved systems for tracking immunisation in young people with disabilities;
- developing specific information and education about immunisation for families of young people with disabilities;
- investigating alternative methods of immunising young people with disabilities who may be anxious and difficult to immunise in school settings; and
- improving communication with health care providers about immunisations in young people with disabilities

7. What are the possible risks, side-effects, discomforts and/or inconveniences?

There are no known risks, side-effects or discomforts expected by taking part in this research project. Inconveniences include the time and effort it will take for you to participate in the interview. The interview is expected to take 30 to 45 minutes.

8. What will be done to make sure my information is confidential?

You will be allocated an alternative name, or alias. Any data published or presented will refer to you by this alias. No information will be recorded which can identify you, or any student or school you refer to. The study team and Ethics Department at the Royal Children's Hospital will be the only personnel to have access to the complete data set. Interviews will be transcribed and then the voice recordings will be destroyed. This data will be stored electronically and password protected. Any hard copy data will be stored in a locked cabinet at the Royal Children's Hospital. This data will be kept for seven years after study completion then securely destroyed. The results from this research will form part of a PhD thesis and may also be presented at conferences or printed in article format for peer reviewed journals.

9. Will I be informed of the results when the research project is finished?

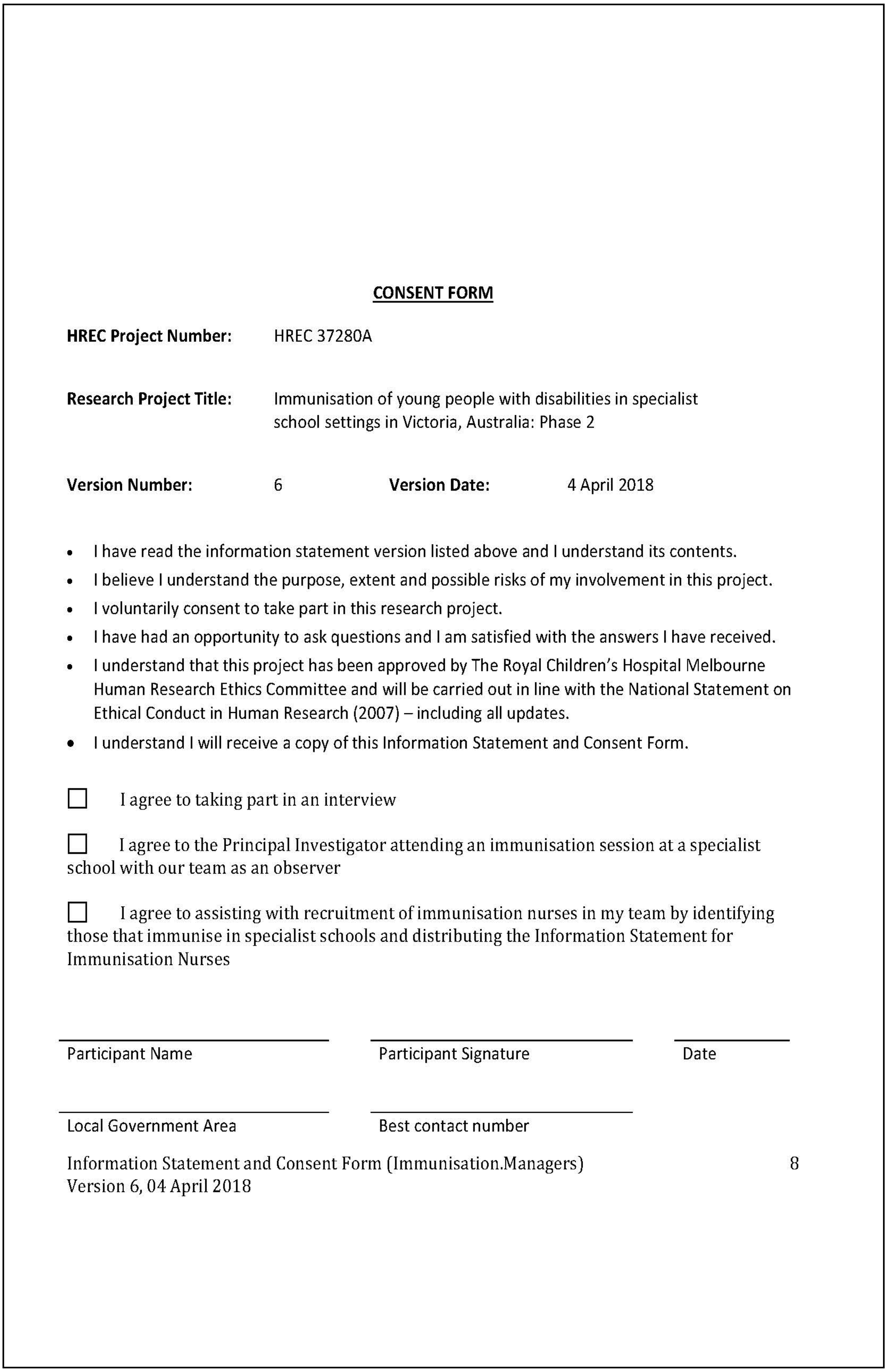
At the conclusion of the study, a letter will be sent by email to each of the participants outlining the overall findings from the study.

10. Who should I contact for more information?

If you would like more information about the project or if you need to speak to a member of the research team in an emergency please contact:

Name:	Ms Jenny O'Neill
Contact telephone:	0410 557 898
Email:	Immunisation.research@rch.org.au

If you have any concerns and/or complaints about the project, the way it is being conducted or your rights as a research participant, and would like to speak to someone independent of the project, please contact: Director, Research Ethics & Governance, The Royal Children's Hospital Melbourne on telephone: (03) 9345 5044.



CONSENT FORM

HREC Project Number: HREC 37280A

Research Project Title: Immunisation of young people with disabilities in specialist school settings in Victoria, Australia: Phase 2

Version Number: 6 **Version Date:** 4 April 2018

- I have read the information statement version listed above and I understand its contents.
- I believe I understand the purpose, extent and possible risks of my involvement in this project.
- I voluntarily consent to take part in this research project.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- I understand that this project has been approved by The Royal Children's Hospital Melbourne Human Research Ethics Committee and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2007) – including all updates.
- I understand I will receive a copy of this Information Statement and Consent Form.

☐ I agree to taking part in an interview

☐ I agree to the Principal Investigator attending an immunisation session at a specialist school with our team as an observer

☐ I agree to assisting with recruitment of immunisation nurses in my team by identifying those that immunise in specialist schools and distributing the Information Statement for Immunisation Nurses

Participant Name	Participant Signature	Date
Local Government Area	Best contact number	

APPENDIX N: PHASE TWO INFORMATION STATEMENT AND CONSENT FOR IMMUNISATION NURSES

The Royal
Children's
Hospital
Melbourne

Information statement and consent form

HREC Project Number: HREC 37280A

Research Project Title: Immunisation of young people with disabilities in specialist school settings in Victoria, Australia: Phase 2

Principal Researcher: Ms Jenny O'Neill

Clinical Nurse Consultant, Neurodevelopment and Disability, The Royal Children's Hospital

PhD Candidate, Department of Paediatrics, The University of Melbourne

Version Number: 4 **Version Date:** 17/11/2017

Thank you for taking the time to read this **Participant Information Statement and Consent Form**. We would like to invite you to participate in a research project that is explained below.

This document is 7 pages long. Please make sure you have all the pages.

What is an Information Statement?
These pages tell you about the research project. It explains to you clearly and openly all the steps and procedures of the project. The information is to help you to decide whether or not you agree to taking part in the research. Please read this Information Statement carefully.

Before you decide to take part or not, you can ask us any questions you have about the project. You may want to talk about the project with your colleagues.

Important things you need to know

The Children's
Excellence in clinical care, research and education

The Royal Children's Hospital Melbourne

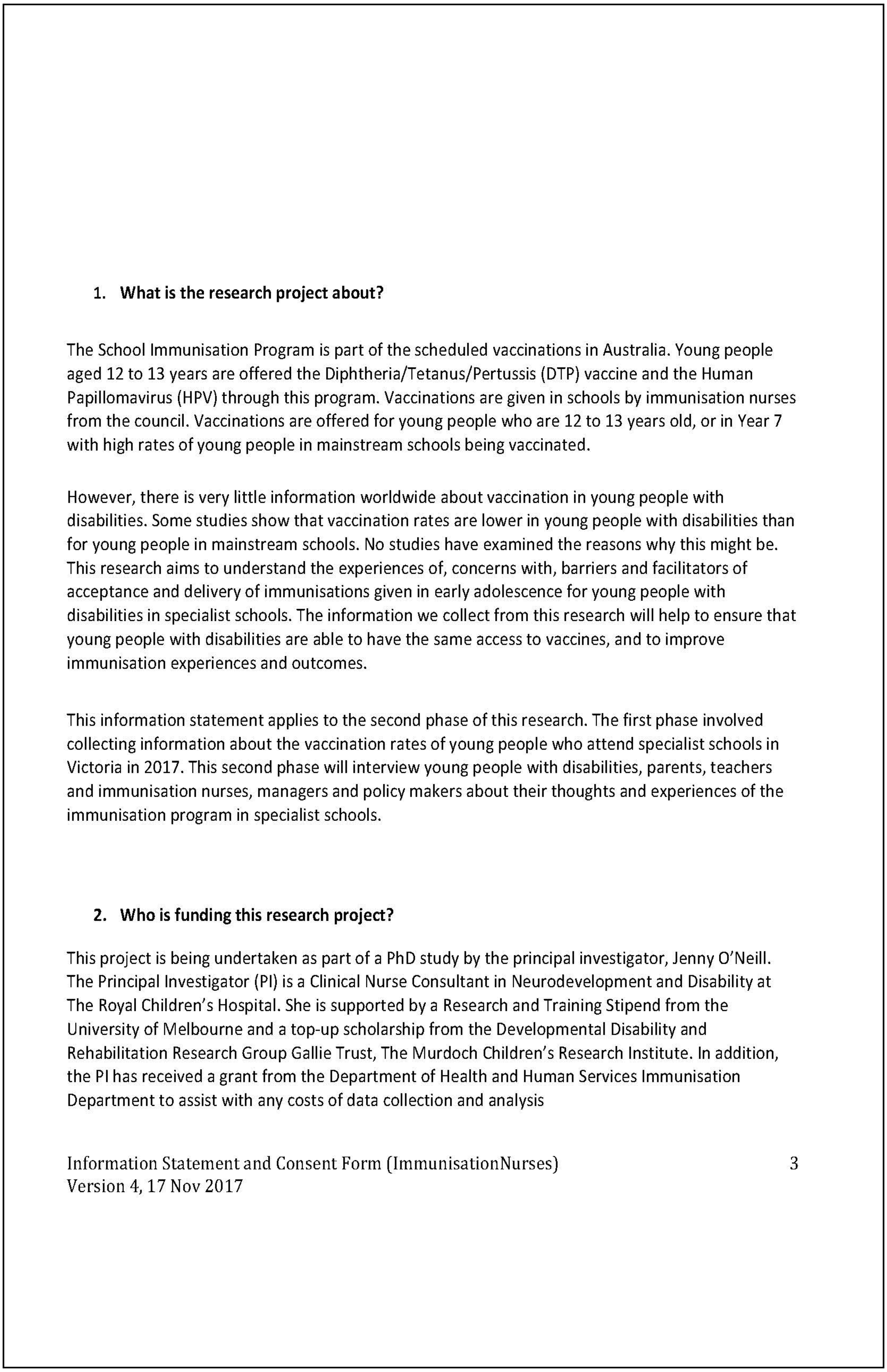
Murdoch Childrens Research Institute

THE UNIVERSITY OF MELBOURNE

- It is your choice whether or not you take part in the research. You do not have to agree if you do not want to
- If you decide you do not want to take part, it will not affect any relationship you may have with The Royal Children's Hospital

If you would like to take part in the research project, please sign the consent form at the end of this information statement. By signing the consent form you are telling us that you:

- understand what you have read
- had a chance to ask questions and received satisfactory answers
- consent to taking part in the project.



1. **What is the research project about?**

The School Immunisation Program is part of the scheduled vaccinations in Australia. Young people aged 12 to 13 years are offered the Diphtheria/Tetanus/Pertussis (DTP) vaccine and the Human Papillomavirus (HPV) through this program. Vaccinations are given in schools by immunisation nurses from the council. Vaccinations are offered for young people who are 12 to 13 years old, or in Year 7 with high rates of young people in mainstream schools being vaccinated.

However, there is very little information worldwide about vaccination in young people with disabilities. Some studies show that vaccination rates are lower in young people with disabilities than for young people in mainstream schools. No studies have examined the reasons why this might be. This research aims to understand the experiences of, concerns with, barriers and facilitators of acceptance and delivery of immunisations given in early adolescence for young people with disabilities in specialist schools. The information we collect from this research will help to ensure that young people with disabilities are able to have the same access to vaccines, and to improve immunisation experiences and outcomes.

This information statement applies to the second phase of this research. The first phase involved collecting information about the vaccination rates of young people who attend specialist schools in Victoria in 2017. This second phase will interview young people with disabilities, parents, teachers and immunisation nurses, managers and policy makers about their thoughts and experiences of the immunisation program in specialist schools.

2. **Who is funding this research project?**

This project is being undertaken as part of a PhD study by the principal investigator, Jenny O'Neill. The Principal Investigator (PI) is a Clinical Nurse Consultant in Neurodevelopment and Disability at The Royal Children's Hospital. She is supported by a Research and Training Stipend from the University of Melbourne and a top-up scholarship from the Developmental Disability and Rehabilitation Research Group Gallie Trust, The Murdoch Children's Research Institute. In addition, the PI has received a grant from the Department of Health and Human Services Immunisation Department to assist with any costs of data collection and analysis

3. Why am I being asked to take part?

We are asking you to take part as an immunisation nurse in a nominated Local Government Area that undertakes immunisations in specialist schools. Your immunisation manager has assisted us by distributing this information to you as part of their team.

We have approval from the Department of Education and Training for eligible schools to take part.

4. What do I need to do in this research project?

a. Return the signed consent form

If you want to take part in this research please scan and email the signed consent to the Principal Investigator Jenny O'Neill at immunisation.research@rch.org.au . We will contact you to organise a mutually agreeable time and location to undertake an interview or focus group. You will have the choice whether to participate in an interview or a focus group. Most commonly interviews and focus groups will be conducted at your workplace within your work hours. It is expected that your time commitment for a focus group will be 45 minutes and for an interview will be 30 minutes.

b) Take part in an interview or focus group

You will be asked questions in the interview or focus group about your role in the school immunisation program in specialist schools. The main focus of the interview or focus group will be your perception of the experiences, challenges and barriers to immunising young people with disabilities in the specialist school setting. Your interview or focus group will be recorded so that we can transcribe what is said and find common themes. You will be given another name, or an alias, and will not be identifiable in transcriptions or any published results from this research. If you attend a focus group you will be identifiable to the other participants in the group.

5. Can I withdraw from the project?

If you give your consent to participate, and change your mind, you can withdraw from the project. You do not need to tell us the reason why you want to stop being in the project. If you leave the project we will use any information already collected unless you tell us not to

6. What are the possible benefits for me and other people in the future?

There will no direct immediate benefits from this research project for you. We hope that the findings from this PhD study will inform policy decisions and interventions. This may make it easier for young people undergoing immunisations in specialist school settings in the future. Depending on the findings, this may include, but is not limited to:

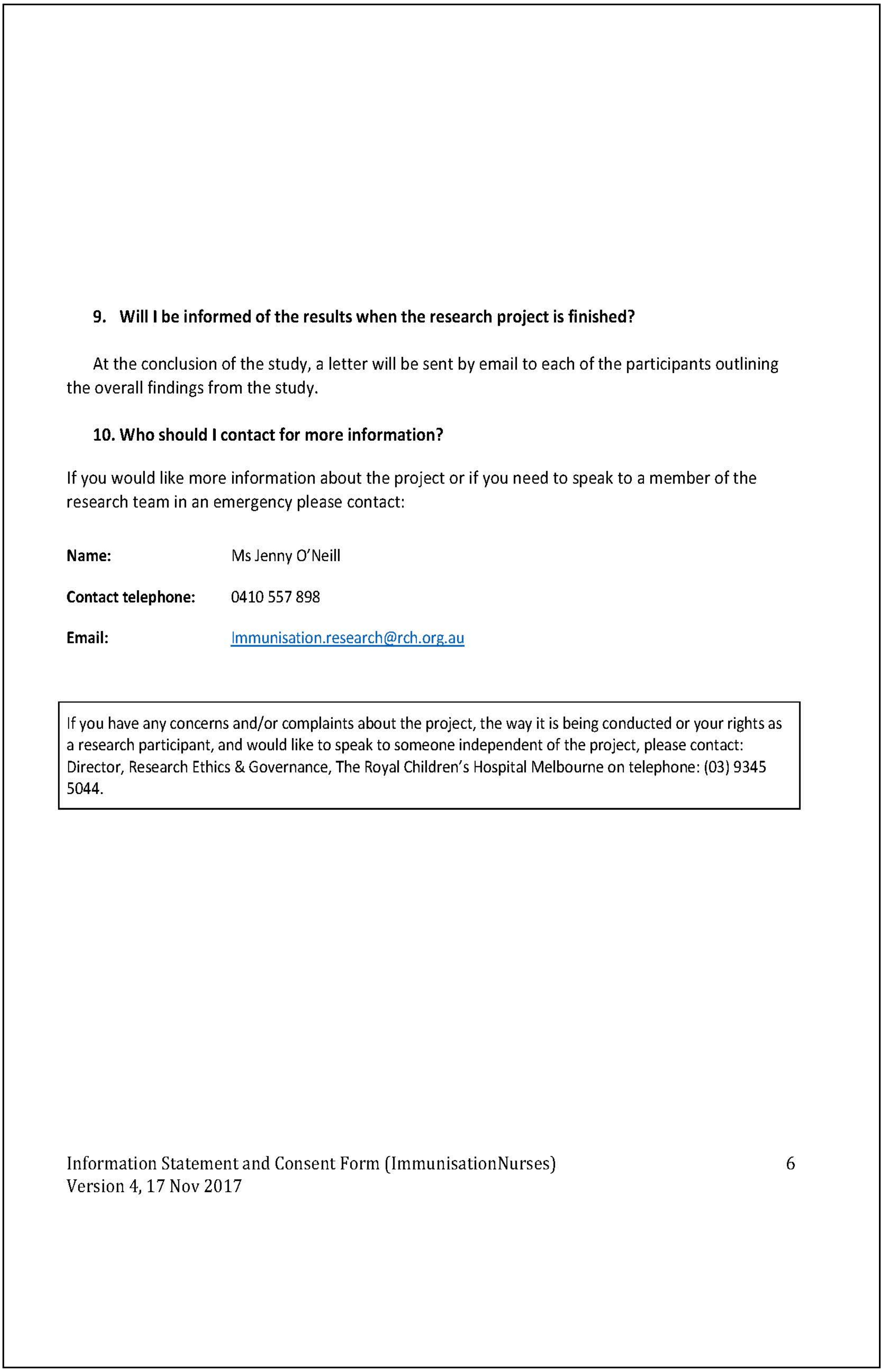
- implementing improved systems for tracking immunisation in young people with disabilities;
- developing specific information and education about immunisation for families of young people with disabilities;
- investigating alternative methods of immunising young people with disabilities who may be anxious and difficult to immunise in school settings; and
- improving communication with health care providers about immunisations in young people with disabilities

7. What are the possible risks, side-effects, discomforts and/or inconveniences?

There are no known risks, side-effects or discomforts expected by taking part in this research project. Inconveniences include the time and effort it will take for you to participate in the interview or focus group. The focus group is expected to take up to 45 minutes and the interview is expected to take minutes.

8. What will be done to make sure my information is confidential?

You will be allocated an alternative name, or alias. Any data published or presented will refer to you by this alias. No information will be recorded which can identify you, or any student or school you refer to. The study team and Ethics Department at the Royal Children's Hospital will be the only personnel to have access to the complete data set. Interviews and focus groups will be transcribed and then the voice recordings will be destroyed. This data will be stored electronically and password protected. Any hard copy data will be stored in a locked cabinet at the Royal Children's Hospital. This data will be kept for seven years after study completion then securely destroyed. The results from this research will form part of a PhD thesis and may also be presented at conferences or printed in article format for peer reviewed journals.



9. Will I be informed of the results when the research project is finished?

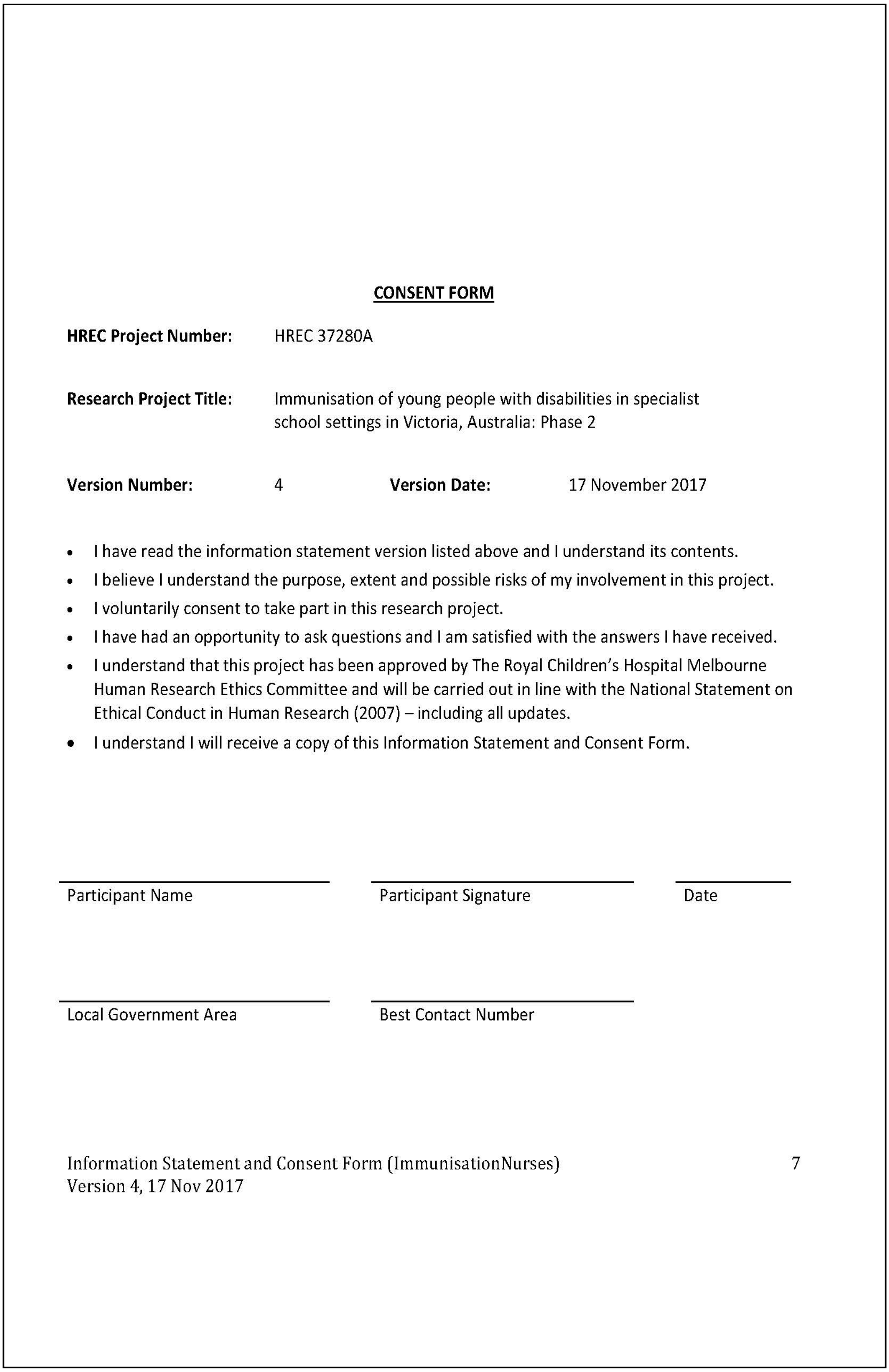
At the conclusion of the study, a letter will be sent by email to each of the participants outlining the overall findings from the study.

10. Who should I contact for more information?

If you would like more information about the project or if you need to speak to a member of the research team in an emergency please contact:

Name:	Ms Jenny O'Neill
Contact telephone:	0410 557 898
Email:	Immunisation.research@rch.org.au

If you have any concerns and/or complaints about the project, the way it is being conducted or your rights as a research participant, and would like to speak to someone independent of the project, please contact: Director, Research Ethics & Governance, The Royal Children's Hospital Melbourne on telephone: (03) 9345 5044.



CONSENT FORM

HREC Project Number: HREC 37280A

Research Project Title: Immunisation of young people with disabilities in specialist school settings in Victoria, Australia: Phase 2

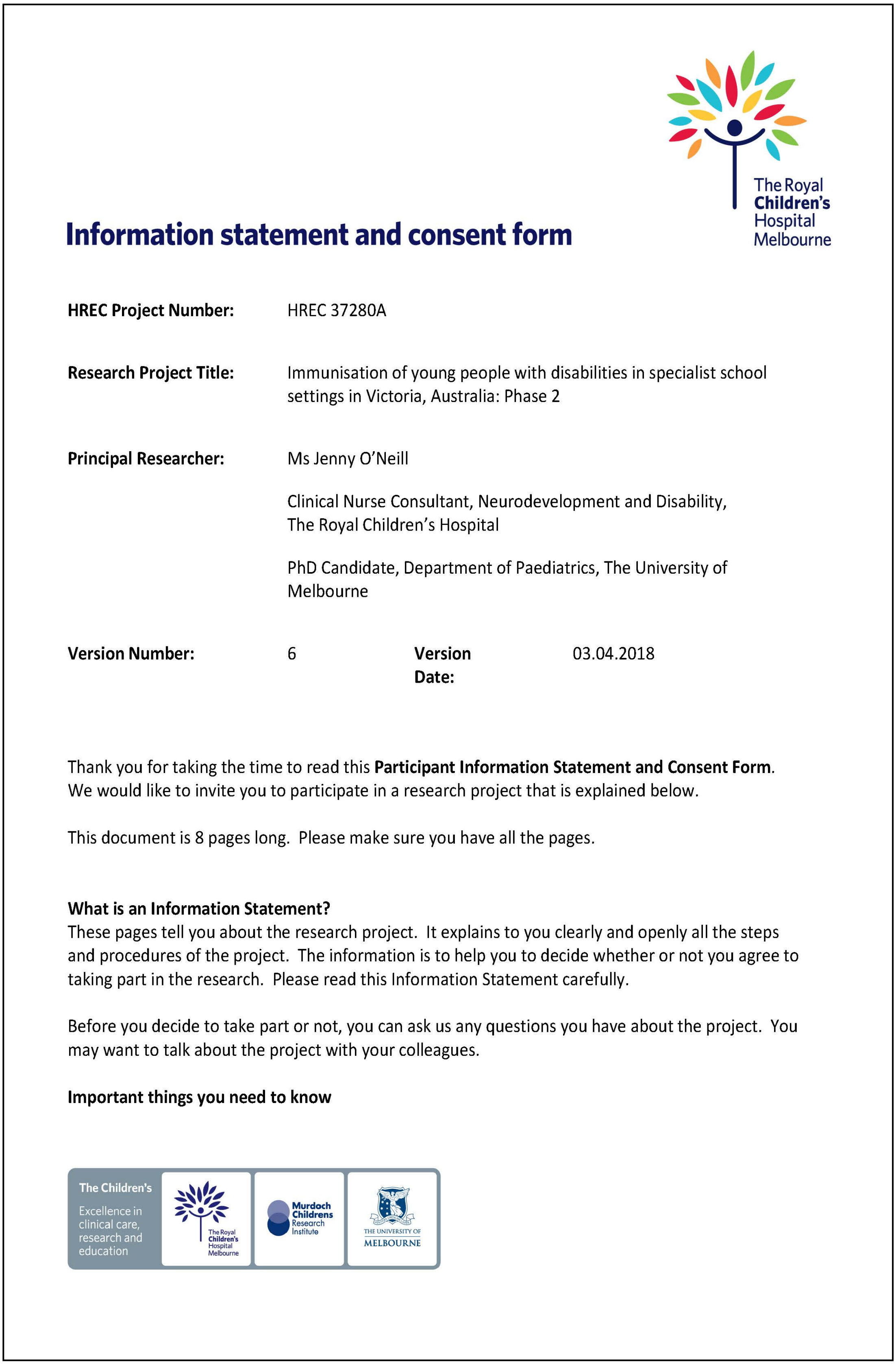
Version Number: 4 **Version Date:** 17 November 2017

- I have read the information statement version listed above and I understand its contents.
- I believe I understand the purpose, extent and possible risks of my involvement in this project.
- I voluntarily consent to take part in this research project.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- I understand that this project has been approved by The Royal Children's Hospital Melbourne Human Research Ethics Committee and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2007) – including all updates.
- I understand I will receive a copy of this Information Statement and Consent Form.

Participant Name ______ Participant Signature ______ Date ______

Local Government Area ______ Best Contact Number ______

APPENDIX O: PHASE TWO INFORMATION STATEMENT AND CONSENT FORM FOR SCHOOL IMMUNISATION COORDINATORS



Information statement and consent form

HREC Project Number: HREC 37280A

Research Project Title: Immunisation of young people with disabilities in specialist school settings in Victoria, Australia: Phase 2

Principal Researcher: Ms Jenny O'Neill

Clinical Nurse Consultant, Neurodevelopment and Disability,
The Royal Children's Hospital

PhD Candidate, Department of Paediatrics, The University of Melbourne

Version Number: 6 **Version Date:** 03.04.2018

Thank you for taking the time to read this **Participant Information Statement and Consent Form**. We would like to invite you to participate in a research project that is explained below.

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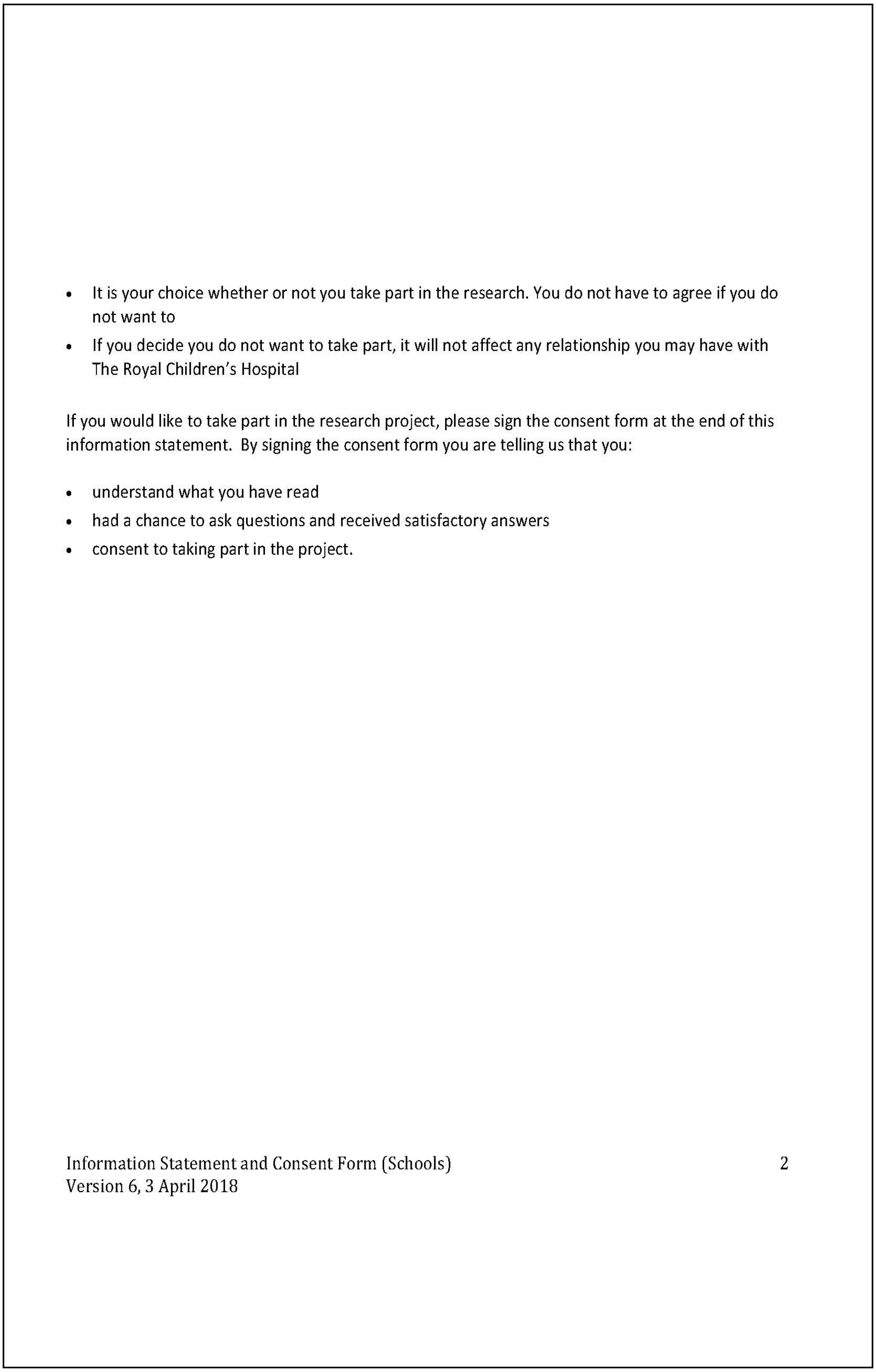
These pages tell you about the research project. It explains to you clearly and openly all the steps and procedures of the project. The information is to help you to decide whether or not you agree to taking part in the research. Please read this Information Statement carefully.

Before you decide to take part or not, you can ask us any questions you have about the project. You may want to talk about the project with your colleagues.

Important things you need to know



- It is your choice whether or not you take part in the research. You do not have to agree if you do not want to
- If you decide you do not want to take part, it will not affect any relationship you may have with The Royal Children's Hospital

If you would like to take part in the research project, please sign the consent form at the end of this information statement. By signing the consent form you are telling us that you:

- understand what you have read
- had a chance to ask questions and received satisfactory answers
- consent to taking part in the project.

1. What is the research project about?

The School Immunisation Program is part of the scheduled vaccinations in Australia. Young people aged 12 to 13 years are offered the Diphtheria/Tetanus/Pertussis (DTP) vaccine, and the Human Papillomavirus (HPV) through this program. Vaccinations are given in schools by immunisation nurses from the council. Vaccinations are offered for young people who are 12 to 13 years old, or in Year 7 with high rates of young people in mainstream schools being vaccinated.

However, there is very little information worldwide about vaccination in young people with disabilities. Some studies show that vaccination rates are lower in young people with disabilities than for young people in mainstream schools. No studies have examined the reasons why this might be. This research aims to understand the experiences of, concerns with, barriers and facilitators of acceptance and delivery of immunisations given in early adolescence for young people with disabilities in specialist schools. The information we collect from this research will help to ensure that young people with disabilities are able to have the same access to vaccines, and to improve immunisation experiences and outcomes.

This information statement applies to the second phase of this research. The first phase involved collecting information about the vaccination rates of young people who attend specialist schools in Victoria in 2017. The second phase will interview young people with disabilities, parents, teachers and immunisation nurses, managers and policy makers about their thoughts and experiences of the immunisation program in specialist schools. In addition, the Principal Investigator will observe immunisation sessions in specialist schools. This information and consent refers only to the interview/focus groups aspect of participation.

2. Who is funding this research project?

This project is being undertaken as part of a PhD study by the principal investigator, Jenny O'Neill. The Principal Investigator (PI) is a Clinical Nurse Consultant in Neurodevelopment and Disability at The Royal Children's Hospital. She is supported by a Research and Training Stipend from the University of Melbourne and a top-up scholarship from the Developmental Disability and Rehabilitation Research Group Gallie Trust, The Murdoch Childrens Research Institute. In addition, the PI has received a grant from the Department of Health and Human Services Immunisation Department to assist with any costs of data collection and analysis.

3. Why am I being asked to take part?

We are asking you to take part as an immunisation co-ordinator in a specialist school in Victoria that enrols children with physical and/or intellectual disabilities.

We have Approval from the Department of Education and Training to approach eligible schools to take part.

4. What do I need to do in this research project?

a. Return the signed consent form

If you would like to take part in this research, you need to discuss this with the principal of your school. We ask that they also sign this consent form to ensure we know they have read this Information Statement and are agreeable to you taking part in your role as immunisation coordinator for your school.

You then need to please scan and email the signed consent to the Principal Investigator Jenny O'Neill at immunisation.research@rch.org.au . We will contact you to organise a mutually agreeable time and location to undertake an interview. Most commonly interviews will be conducted at your workplace within your work hours. It is expected that the interview will last 30 to 45 mins.

b) Take part in an interview

You will be asked questions in the interview about your role in the school immunisation program in specialist schools. The main focus of the interview will be your perception of the experiences, challenges and barriers to immunising young people with disabilities in the specialist school setting. Your interview will be recorded so that we can transcribe what is said and find common themes. You will be given another name, or an alias, and will not be identifiable in transcriptions or any published results from this research.

c) Assist with advertising the study to potential parent and young person participants

In addition to taking part in an interview, we are requesting the assistance of your school in advertising the study to potential parents and young person participants, by placing the advertisement attached in your school newsletter. Interested families can then contact the research team directly by email or phone number provided. Interviews with families will take place outside the school setting. There is place on the consent form to indicate agreement to place this advertisement in the school newsletter. If your school does not wish to place the attached advertisement in the school newsletter you can still participate in the interview.

5. Can I withdraw from the project?

If you give your consent to participate, and change your mind, you can withdraw from the project. You do not need to tell us the reason why you want to stop being in the project. If you leave the project we will use any information already collected unless you tell us not to

6. What are the possible benefits for me and other people in the future?

There will no direct immediate benefits from this research project for you. We hope that the findings from this PhD study will inform policy decisions and interventions. This may make it easier for young people undergoing immunisations in specialist school settings in the future. Depending on the findings, this may include, but is not limited to:

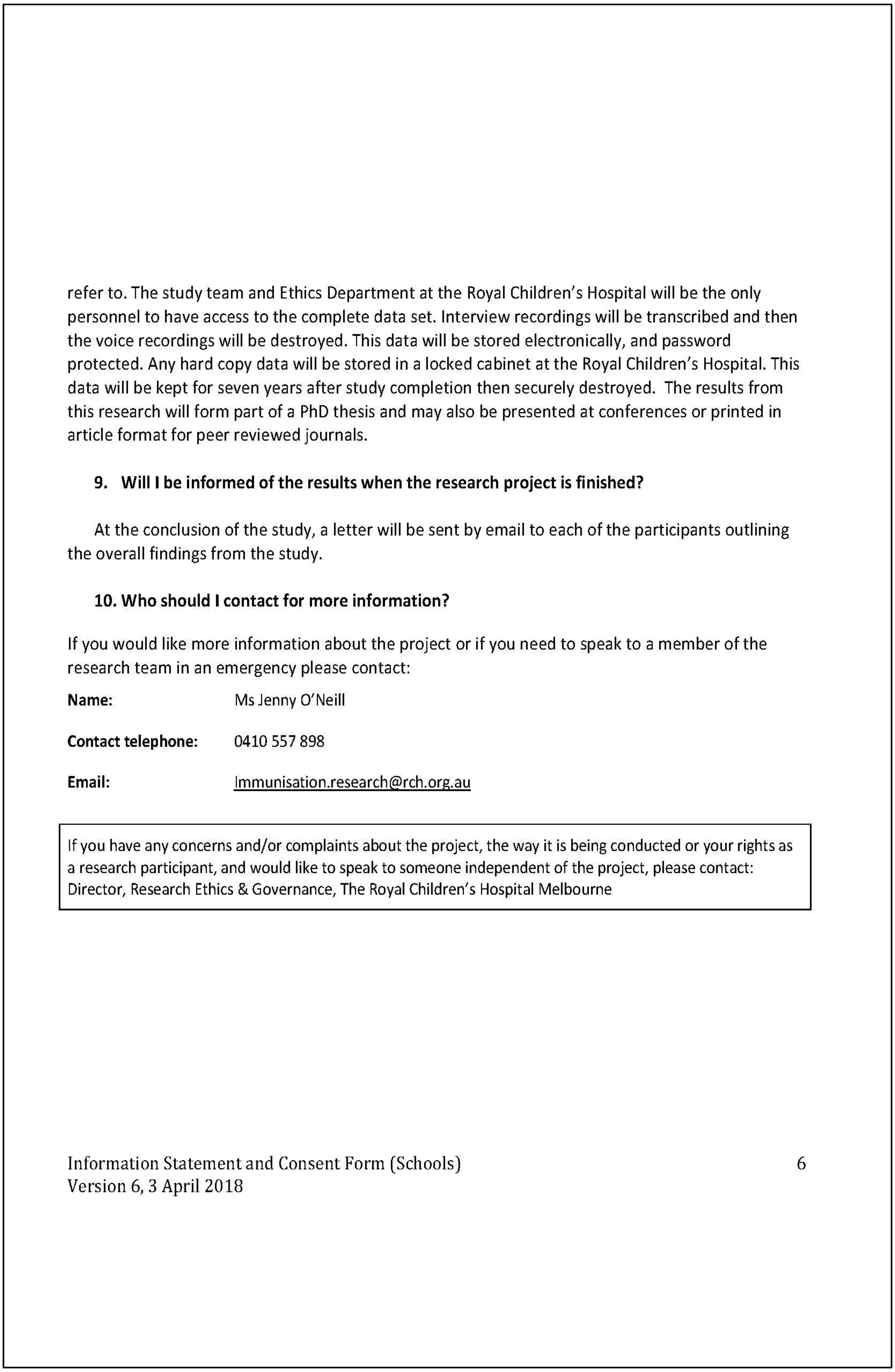
- implementing improved systems for tracking immunisation in young people with disabilities;
- developing specific information and education about immunisation for families of young people with disabilities;
- investigating alternative methods of immunising young people with disabilities who may be anxious and difficult to immunise in school settings; and
- improving communication with health care providers about immunisations in young people with disabilities

7. What are the possible risks, side-effects, discomforts and/or inconveniences?

There are no known risks, side-effects or discomforts expected by taking part in this research project. Inconveniences include the time and effort it will take for you to participate in the interview. The interview is expected to take 30 to 45 minutes.

8. What will be done to make sure my information is confidential?

You will be allocated an alternative name, or alias. Any data published or presented will refer to you by this alias. No information will be recorded which can identify you, or any student or school you



refer to. The study team and Ethics Department at the Royal Children's Hospital will be the only personnel to have access to the complete data set. Interview recordings will be transcribed and then the voice recordings will be destroyed. This data will be stored electronically, and password protected. Any hard copy data will be stored in a locked cabinet at the Royal Children's Hospital. This data will be kept for seven years after study completion then securely destroyed. The results from this research will form part of a PhD thesis and may also be presented at conferences or printed in article format for peer reviewed journals.

9. Will I be informed of the results when the research project is finished?

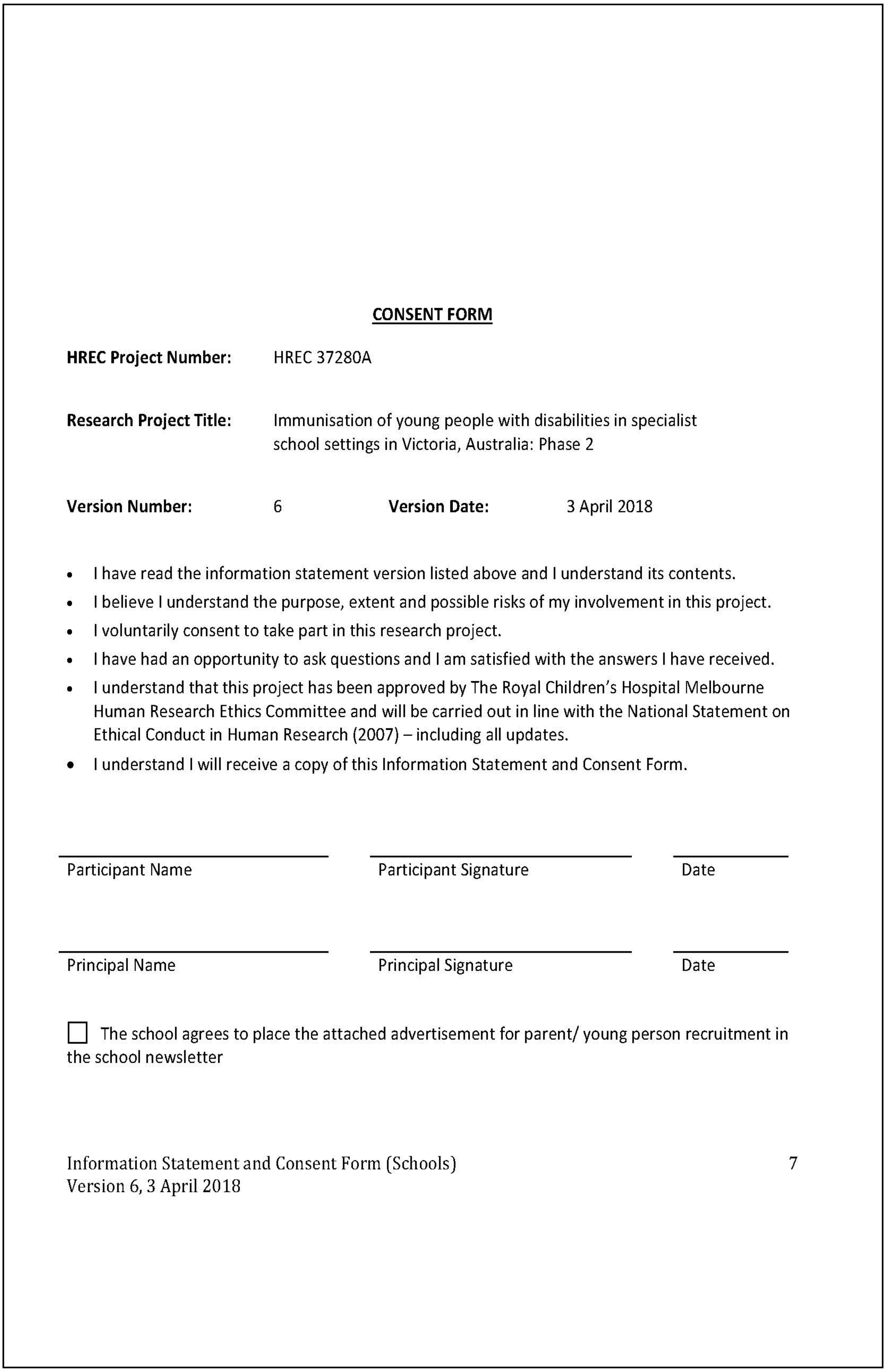
At the conclusion of the study, a letter will be sent by email to each of the participants outlining the overall findings from the study.

10. Who should I contact for more information?

If you would like more information about the project or if you need to speak to a member of the research team in an emergency please contact:

Name:	Ms Jenny O'Neill
Contact telephone:	0410 557 898
Email:	Immunisation.research@rch.org.au

If you have any concerns and/or complaints about the project, the way it is being conducted or your rights as a research participant, and would like to speak to someone independent of the project, please contact: Director, Research Ethics & Governance, The Royal Children's Hospital Melbourne



CONSENT FORM

HREC Project Number: HREC 37280A

Research Project Title: Immunisation of young people with disabilities in specialist school settings in Victoria, Australia: Phase 2

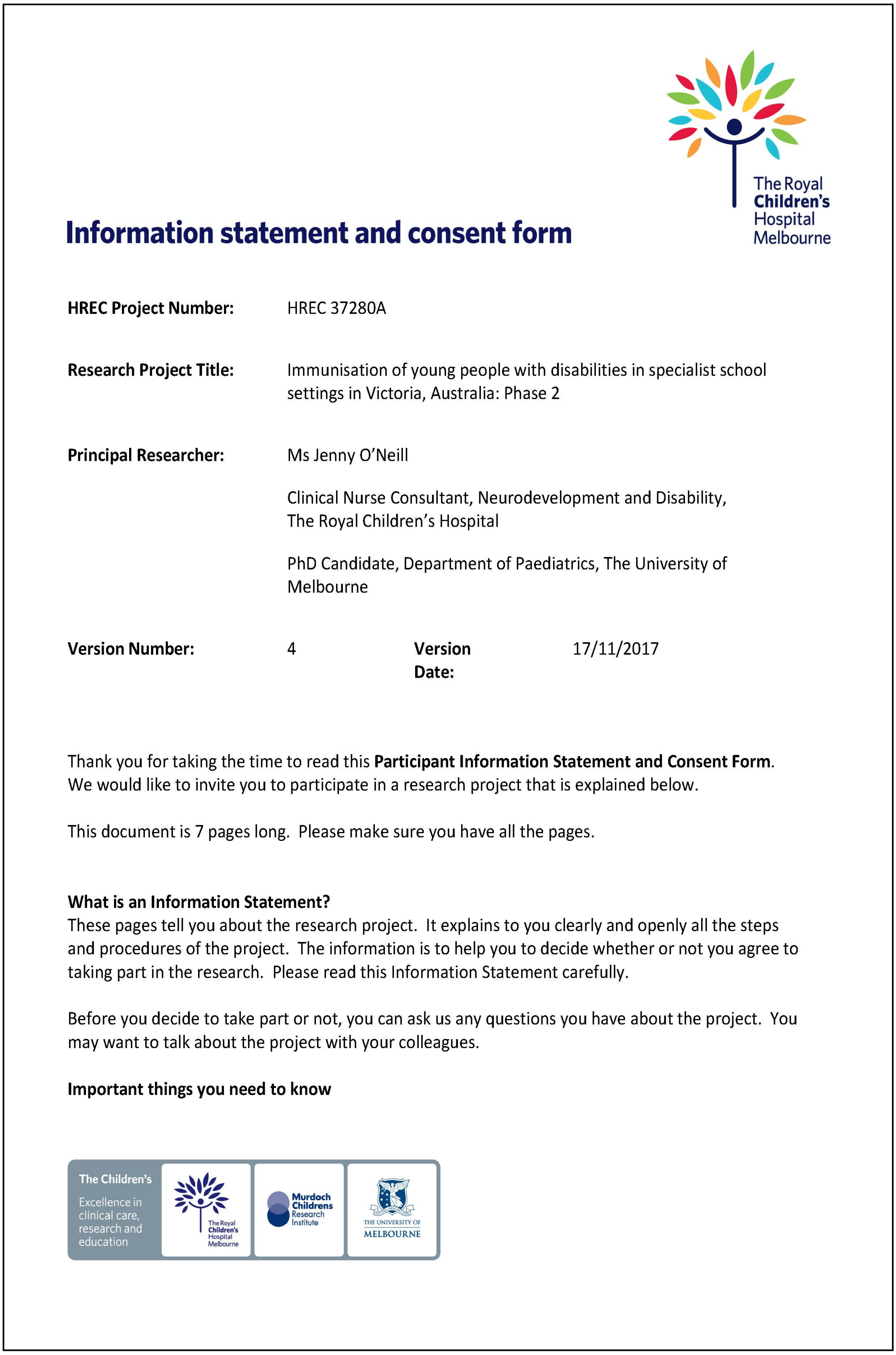
Version Number: 6 **Version Date:** 3 April 2018

- I have read the information statement version listed above and I understand its contents.
- I believe I understand the purpose, extent and possible risks of my involvement in this project.
- I voluntarily consent to take part in this research project.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- I understand that this project has been approved by The Royal Children's Hospital Melbourne Human Research Ethics Committee and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2007) – including all updates.
- I understand I will receive a copy of this Information Statement and Consent Form.

Participant Name	Participant Signature	Date
Principal Name	Principal Signature	Date

☐ The school agrees to place the attached advertisement for parent/ young person recruitment in the school newsletter

APPENDIX P: PHASE TWO INFORMATION STATEMENT AND CONSENT FORM FOR POLICY PARTICIPANTS



Information statement and consent form

The Royal
Children's
Hospital
Melbourne

HREC Project Number: HREC 37280A

Research Project Title: Immunisation of young people with disabilities in specialist school settings in Victoria, Australia: Phase 2

Principal Researcher: Ms Jenny O'Neill

Clinical Nurse Consultant, Neurodevelopment and Disability, The Royal Children's Hospital

PhD Candidate, Department of Paediatrics, The University of Melbourne

Version Number: 4 **Version Date:** 17/11/2017

Thank you for taking the time to read this **Participant Information Statement and Consent Form**. We would like to invite you to participate in a research project that is explained below.

This document is 7 pages long. Please make sure you have all the pages.

What is an Information Statement?
These pages tell you about the research project. It explains to you clearly and openly all the steps and procedures of the project. The information is to help you to decide whether or not you agree to taking part in the research. Please read this Information Statement carefully.

Before you decide to take part or not, you can ask us any questions you have about the project. You may want to talk about the project with your colleagues.

Important things you need to know

The Children's
Excellence in clinical care, research and education

The Royal Children's Hospital Melbourne

Murdoch Childrens Research Institute

THE UNIVERSITY OF MELBOURNE

- It is your choice whether or not you take part in the research. You do not have to agree if you do not want to
- If you decide you do not want to take part, it will not affect any relationship you may have with The Royal Children's Hospital

If you would like to take part in the research project, please sign the consent form at the end of this information statement. By signing the consent form you are telling us that you:

- understand what you have read
- had a chance to ask questions and received satisfactory answers
- consent to taking part in the project.

1. What is the research project about?

The School Immunisation Program is part of the scheduled vaccinations in Australia. Young people aged 12 to 13 years are offered the Diphtheria/Tetanus/Pertussis (DTP) vaccine, and the Human Papillomavirus (HPV) through this program. Vaccinations are given in schools by immunisation nurses from the council. Vaccinations are offered for young people who are 12 to 13 years old, or in Year 7 with high rates of young people in mainstream schools being vaccinated.

However, there is very little information worldwide about vaccination in young people with disabilities. Some studies show that vaccination rates are lower in young people with disabilities than for young people in mainstream schools. No studies have examined the reasons why this might be. This research aims to understand the experiences of, concerns with, barriers and facilitators of acceptance and delivery of immunisations given in early adolescence for young people with disabilities in specialist schools. The information we collect from this research will help to ensure that young people with disabilities are able to have the same access to vaccines, and to improve immunisation experiences and outcomes.

This information statement applies to the second phase of this research. The first phase involved collecting information about the vaccination rates of young people who attend specialist schools in Victoria. The second phase will interview young people with disabilities, parents, teachers and immunisation nurses, managers and policy makers about their thoughts and experiences of the immunisation program in specialist schools.

2. Who is funding this research project?

This project is being undertaken as part of a PhD study by the principal investigator, Jenny O'Neill. The Principal Investigator (PI) is a Clinical Nurse Consultant in Neurodevelopment and Disability at The Royal Children's Hospital. She is supported by a Research and Training Stipend from the University of Melbourne and a top-up scholarship from the Developmental Disability and Rehabilitation Research Group Gallie Trust, The Murdoch Childrens Research Institute. In addition, the PI has received a grant from the Department of Health and Human Services Immunisation Department to assist with any costs of data collection and analysis.

3. Why am I being asked to take part?

We are asking you to take part as you have been identified as having a key role in the school immunisation program at the policy level. This has been identified in Phase 1 of this study.

4. What do I need to do in this research project?

a. Return the signed consent form

If you want to take part in this research please scan and email the signed consent to the Principal Investigator Jenny O'Neill at immunisation.research@rch.org.au . We will contact you to organise a mutually agreeable time and location to undertake an interview. Most commonly interviews will be conducted at your workplace within your work hours. It is expected that the interview will last 30 minutes.

b) Take part in an interview

You will be asked questions in the interview about your role in the school immunisation program in specialist schools. You will also be asked about your perception of the experiences, challenges and barriers to immunising young people with disabilities in the specialist school setting. Your interview will be recorded so that we can transcribe what is said and find common themes. You will be given another name, or an alias, and will not be identifiable in transcriptions or any published results from this research.

5. Can I withdraw from the project?

If you give your consent to participate, and change your mind, you can withdraw from the project. You do not need to tell us the reason why you want to stop being in the project. If you leave the project we will use any information already collected unless you tell us not to

6. What are the possible benefits for me and other people in the future?

There will no direct immediate benefits from this research project for you. We hope that the findings from this PhD study will inform policy decisions and interventions. This may make it easier for young people undergoing immunisations in specialist school settings in the future. Depending on the findings, this may include, but is not limited to:

- implementing improved systems for tracking immunisation in young people with disabilities;
- developing specific information and education about immunisation for families of young people with disabilities;
- investigating alternative methods of immunising young people with disabilities may be anxious and difficult to immunise in school settings; and
- improving communication with health care providers about immunisations in young people with disabilities

7. What are the possible risks, side-effects, discomforts and/or inconveniences?

There are no known risks, side-effects or discomforts expected by taking part in this research project. Inconveniences include the time and effort it will take for you to participate in the interview. The interview is expected to take 30 minutes.

8. What will be done to make sure my information is confidential?

You will be allocated an alternative name, or alias. Any data published or presented will refer to you by this alias. No information will be recorded which can identify you, or any student or school you refer to. The study team and Ethics Department at the Royal Children's Hospital will be the only personnel to have access to the complete data set. Interviews will be transcribed then the voice recordings will be destroyed. This data will be stored electronically and password protected. Any hard copy data will be stored in a locked cabinet at the Royal Children's Hospital. This data will be kept for seven years after study completion then securely destroyed. The results from this research will form part of a PhD thesis and may also be presented at conferences or printed in article format for peer reviewed journals.

9. Will I be informed of the results when the research project is finished?

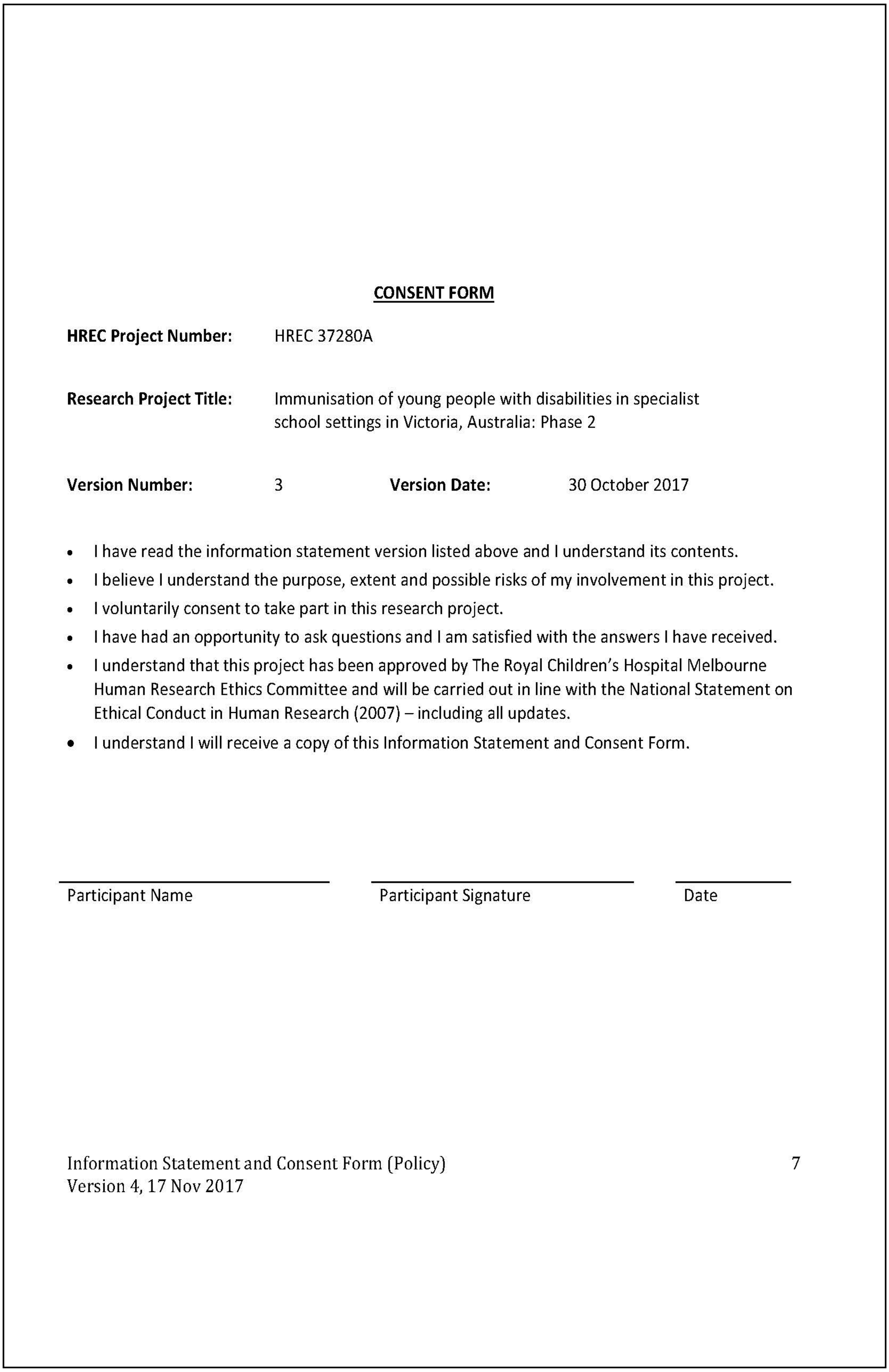
At the conclusion of the study, a letter will be sent by email to each of the participants outlining the overall findings from the study.

10. Who should I contact for more information?

If you would like more information about the project or if you need to speak to a member of the research team in an emergency please contact:

Name:	Ms Jenny O'Neill
Contact telephone:	0410 557 898
Email:	Immunisation.research@rch.org.au

If you have any concerns and/or complaints about the project, the way it is being conducted or your rights as a research participant, and would like to speak to someone independent of the project, please contact: Director, Research Ethics & Governance, The Royal Children's Hospital Melbourne on telephone: (03) 9345 5044.



CONSENT FORM

HREC Project Number: HREC 37280A

Research Project Title: Immunisation of young people with disabilities in specialist school settings in Victoria, Australia: Phase 2

Version Number: 3 **Version Date:** 30 October 2017

- I have read the information statement version listed above and I understand its contents.
- I believe I understand the purpose, extent and possible risks of my involvement in this project.
- I voluntarily consent to take part in this research project.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- I understand that this project has been approved by The Royal Children's Hospital Melbourne Human Research Ethics Committee and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2007) – including all updates.
- I understand I will receive a copy of this Information Statement and Consent Form.

Participant Name	Participant Signature	Date

APPENDIX Q: SCHOOL NEWSLETTER ADVERTISEMENT

The Royal
Children's
Hospital
Melbourne

Are you the parent/ carer of an adolescent aged 12 to 18 with a disability who was offered immunisations at a specialist school in Victoria in the last 12 months?

If yes, we would like to hear from you and your child about their experience. Your views will assist us to better understand and improve the immunisation experience of young people with disabilities, and may help us inform state-wide immunisation policy.

Participation in the research study would involve an interview about your experience and perceptions of the immunisation process and the vaccines offered to your child through the school immunisation program. This would take 30 to 45 minutes at a time and location convenient to you.

We would also be interested in talking to your child about their immunisation experience. This would take between 5 and 20 minutes and can be conducted at the same time as your interview with you in attendance.

You can participate whether or not your child received their adolescent immunisations.

This is independent non-government commissioned research led by a Nurse Consultant in Developmental Disabilities at The Royal Children's Hospital, who is undertaking a PhD at The University of Melbourne.

For more information please contact:
Jenny O'Neill
Ph: 0410557898
Email: immunisation.research@rch.org.au

Appendix R: Recruitment Letter for Parents

The Royal
Children's
Hospital
Melbourne

Dear Parent/ Carer,

You are receiving this letter as you have a child in a specialist school who has been offered or given the secondary school vaccinations recently. We are conducting some research about immunisation in specialist schools and are very keen to hear from parents and the young people.

Your views are vital in assisting us to better understand and improve the immunisation experience of young people with disabilities, and may help us inform state-wide immunisation policy.

Participation in the research study would involve an interview about your experience and perceptions of the immunisation process and the vaccines offered to your child through the school immunisation program. This would take 30 to 45 minutes at a time and location convenient to you.

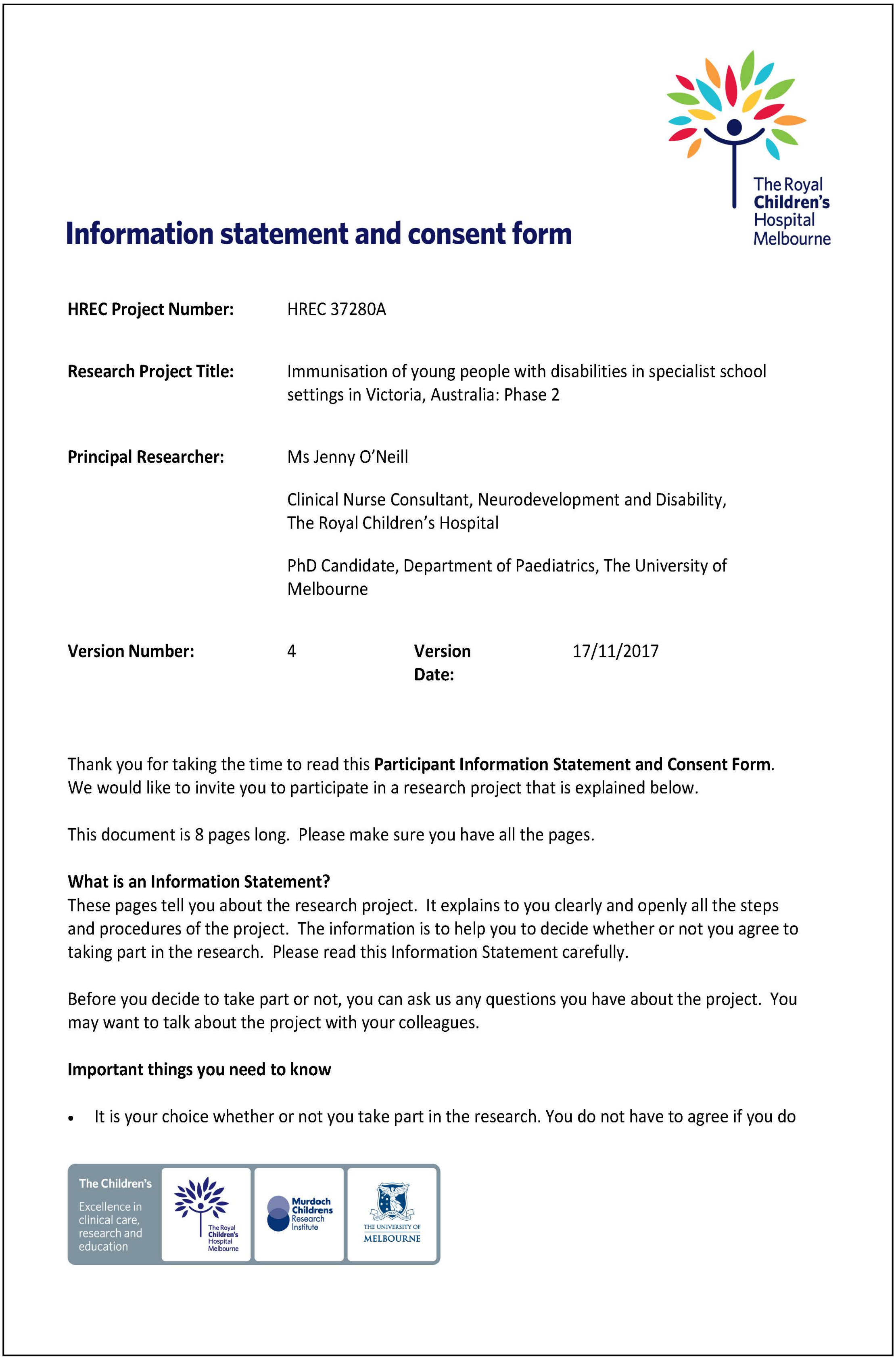
We would also be interested in talking to your child about their immunisation experience, if appropriate. This would take between 5 and 20 minutes and can be conducted at the same time as your interview, with you in attendance.

You can participate whether or not your child received their adolescent immunisations.

This is independent non-government commissioned research led by a Nurse Consultant in Developmental Disabilities at The Royal Children's Hospital, who is undertaking a PhD at The University of Melbourne.

For more information please contact:
Jenny O'Neill
Ph: 0410557898
Email: immunisation.research@rch.org.au

APPENDIX S: PHASE TWO INFORMATION STATEMENT AND CONSENT FORM FOR PARENTS AND YOUNG PEOPLE



Information statement and consent form

HREC Project Number:	HREC 37280A
Research Project Title:	Immunisation of young people with disabilities in specialist school settings in Victoria, Australia: Phase 2
Principal Researcher:	Ms Jenny O'Neill Clinical Nurse Consultant, Neurodevelopment and Disability, The Royal Children's Hospital PhD Candidate, Department of Paediatrics, The University of Melbourne
Version Number:	4
Version Date:	17/11/2017

Thank you for taking the time to read this **Participant Information Statement and Consent Form**. We would like to invite you to participate in a research project that is explained below.

This document is 8 pages long. Please make sure you have all the pages.

What is an Information Statement?
These pages tell you about the research project. It explains to you clearly and openly all the steps and procedures of the project. The information is to help you to decide whether or not you agree to taking part in the research. Please read this Information Statement carefully.

Before you decide to take part or not, you can ask us any questions you have about the project. You may want to talk about the project with your colleagues.

Important things you need to know

- It is your choice whether or not you take part in the research. You do not have to agree if you do

not want to
- If you decide you do not want to take part, it will not affect any relationship you or your child may have with The Royal Children's Hospital

If you would like to take part in the research project, please sign the consent form at the end of this information statement. By signing the consent form you are telling us that you:

- understand what you have read
- had a chance to ask questions and received satisfactory answers
- consent to taking part in the project.

1. What is the research project about?

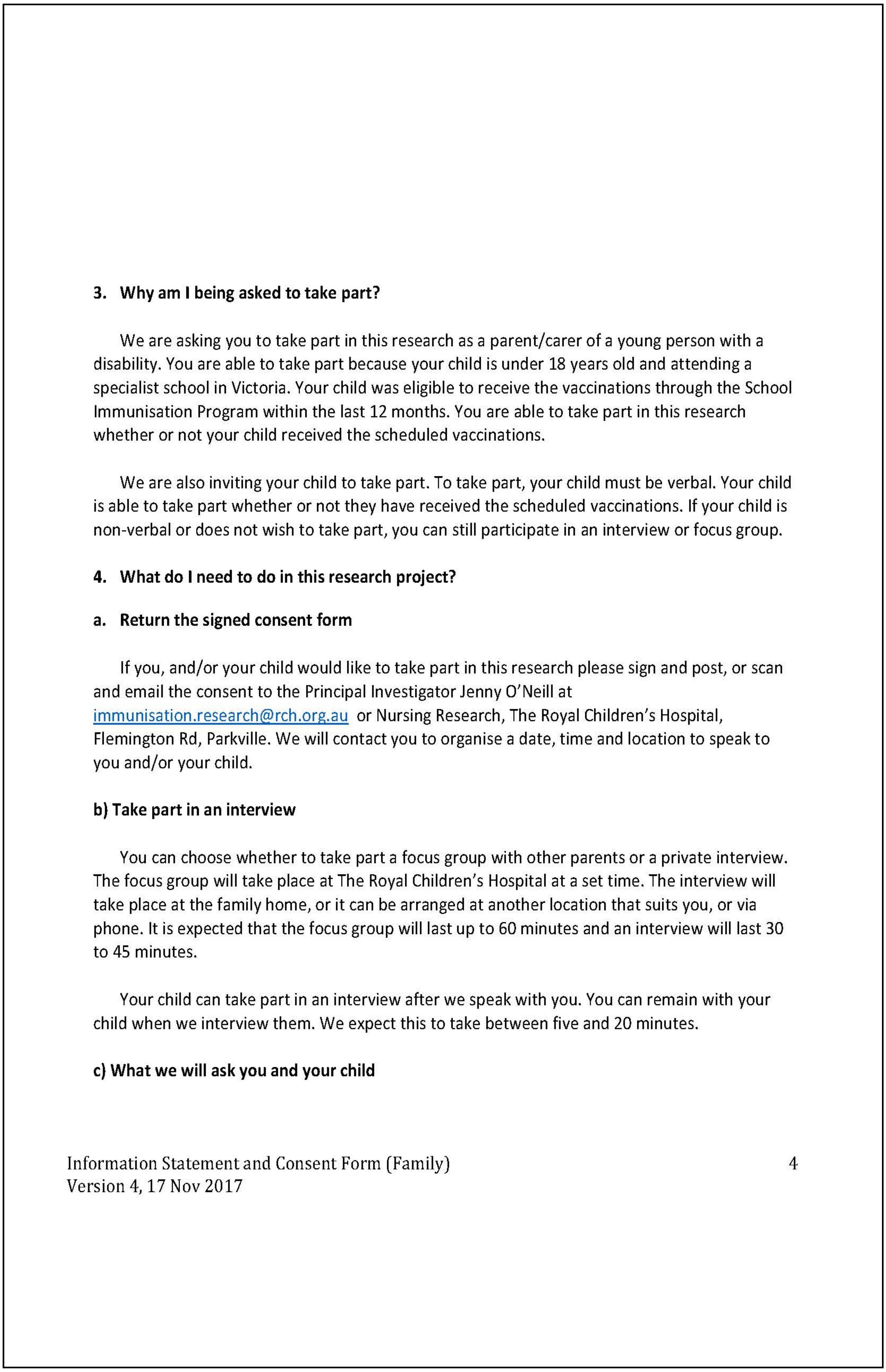
The School Immunisation Program is part of the scheduled vaccinations in Australia. Young people are offered the Diphtheria/Tetanus/Pertussis (DTP) vaccine, Human Papillomavirus (HPV) vaccine, and Meningococcal ACWY through this program. Vaccinations are given in schools by immunisation nurses from the council. Vaccinations are offered for young people who are 12 to 13 years old, or in Year 7 (DTP and HPV) and 15 to 16 years old, or in Year 10 (Men ACWY) with high rates of young people in mainstream schools being vaccinated.

However, there is very little information worldwide about vaccination in young people with disabilities. Some studies show that vaccination rates are lower in young people with disabilities than for young people in mainstream schools. No studies have examined the reasons why this might be. This research aims to understand the experiences of, concerns with, barriers and facilitators of acceptance and delivery of immunisations given in early adolescence for young people with disabilities in specialist schools. The information we collect from this research will help to ensure that young people with disabilities are able to have the same access to vaccines, and to improve immunisation experiences and outcomes.

This information statement applies to the second phase of this research. The first phase involved collecting information about the vaccination rates of young people who attend specialist schools in Victoria. The second phase will interview young people with disabilities, parents, teachers and immunisation nurses, managers and policy makers about their thoughts and experiences of the immunisation program in specialist schools.

2. Who is funding this research project?

This project is being undertaken as part of a PhD study by the principal investigator, Jenny O'Neill. The Principal Investigator (PI) is a Clinical Nurse Consultant in Neurodevelopment and Disability at The Royal Children's Hospital. She is supported by a Research and Training Stipend from the University of Melbourne and a top-up scholarship from the Developmental Disability and Rehabilitation Research Group Gallie Trust, The Murdoch Childrens Research Institute. In addition, the PI has received a grant from the Department of Health and Human Services Immunisation Department to assist with any costs of data collection and analysis.



3. Why am I being asked to take part?

We are asking you to take part in this research as a parent/carer of a young person with a disability. You are able to take part because your child is under 18 years old and attending a specialist school in Victoria. Your child was eligible to receive the vaccinations through the School Immunisation Program within the last 12 months. You are able to take part in this research whether or not your child received the scheduled vaccinations.

We are also inviting your child to take part. To take part, your child must be verbal. Your child is able to take part whether or not they have received the scheduled vaccinations. If your child is non-verbal or does not wish to take part, you can still participate in an interview or focus group.

4. What do I need to do in this research project?

a. Return the signed consent form

If you, and/or your child would like to take part in this research please sign and post, or scan and email the consent to the Principal Investigator Jenny O'Neill at immunisation.research@rch.org.au or Nursing Research, The Royal Children's Hospital, Flemington Rd, Parkville. We will contact you to organise a date, time and location to speak to you and/or your child.

b) Take part in an interview

You can choose whether to take part a focus group with other parents or a private interview. The focus group will take place at The Royal Children's Hospital at a set time. The interview will take place at the family home, or it can be arranged at another location that suits you, or via phone. It is expected that the focus group will last up to 60 minutes and an interview will last 30 to 45 minutes.

Your child can take part in an interview after we speak with you. You can remain with your child when we interview them. We expect this to take between five and 20 minutes.

c) What we will ask you and your child

We will ask you about your view of the immunisation experience of your child. We will also ask you about your view of the challenges and barriers to immunising young people with disabilities in the specialist school setting. Your focus group or interview will be recorded so that we can transcribe what is said and find common themes. You will be given another name, or an alias, and you, your child and their school will not be identifiable in transcriptions or any published results from this research.

We will ask your child about how what they understand about immunisations, how they feel about immunisations at school and if there is anything they would like done differently on immunisation day. Their interview will be recorded so that we can transcribe what is said and find common themes. They will be given another name, or an alias, and you, your child and their school will not be identifiable in transcriptions or any published results from this research.

5. Can I withdraw from the project?

If you give your consent to participate, or for your child to participate, and change your mind, you can withdraw from the project or withdraw your child from the project. You do not need to tell us the reason why you or your child want to stop being in the project. If you or your child withdraw from the project it will not affect any care or treatment your child may receive at The Royal Children's Hospital. If you or your child leave the project we will use any information already collected unless you tell us not to.

6. What are the possible benefits for me and other people in the future?

There will no direct immediate benefits from this research project for you. We hope that the findings from this PhD study will inform policy decisions and interventions. This may make it easier for young people undergoing immunisations in specialist school settings in the future. Depending on the findings, this may include, but is not limited to:

- implementing improved systems for tracking immunisation in young people with disabilities;
- developing specific information and education about immunisation for families of young people with disabilities;
- investigating alternative methods of immunising young people with disabilities who may be anxious and difficult to immunise in school settings; and
- improving communication with health care providers about immunisations in young people with disabilities

7. What are the possible risks, side-effects, discomforts and/or inconveniences?

There are no known side-effects expected by taking part in this research project. You or your child may experience some emotional distress if your child has had difficult immunisations. If this occurs you or your child will be offered support after the focus group or interview and if required, referral to support services. You may question your choices regarding immunisations for your child as a result of discussing this in a focus group or interview. If this occurs you will be given the contact details of the immunsiaton service at The Royal Children's Hospital who can discuss this further with you. Inconveniences include the time and effort it will take for you to participate in the focus group or interview.

8. What will be done to make sure my information is confidential?

You and your child will be allocated an alternative name, or alias. Any data published or presented will refer to you and your child by this alias. No information will be recorded which can identify you, or your child. The study team and Ethics Department at the Royal Children's Hospital will be the only personnel to have access to the complete data set. Interviews and focus group recordings will be transcribed and then the voice recordings will be destroyed. The transcriptions will be stored electronically and password protected. Any hard copy data will be stored in a locked cabinet at the Royal Children's Hospital. This data will be kept for seven years after study completion then securely destroyed. The results from this research will form part of a PhD thesis and may also be presented at conferences or printed in article format for peer reviewed journals.

9. Will I be informed of the results when the research project is finished?

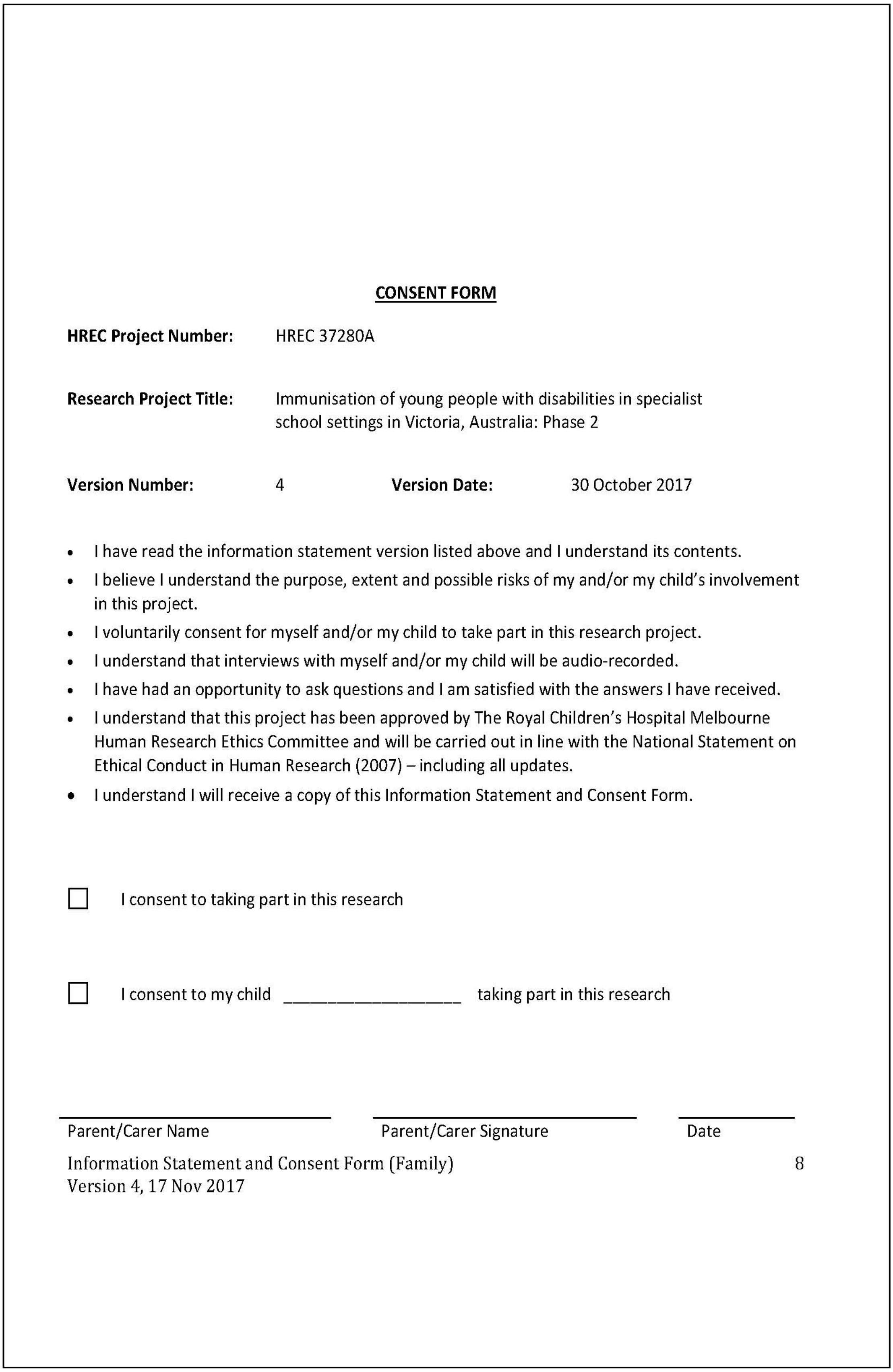
At the conclusion of the study, a letter will be sent by email to each of the participants outlining the overall findings from the study.

10. Who should I contact for more information?

If you would like more information about the project or if you need to speak to a member of the research team in an emergency please contact:

Name:	Ms Jenny O'Neill
Contact telephone:	0410 557 898
Email:	Immunisation.research@rch.org.au

If you have any concerns and/or complaints about the project, the way it is being conducted or your rights as a research participant, and would like to speak to someone independent of the project, please contact: Director, Research Ethics & Governance, The Royal Children's Hospital Melbourne on telephone: (03) 9345 5044.



CONSENT FORM

HREC Project Number: HREC 37280A

Research Project Title: Immunisation of young people with disabilities in specialist school settings in Victoria, Australia: Phase 2

Version Number: 4 **Version Date:** 30 October 2017

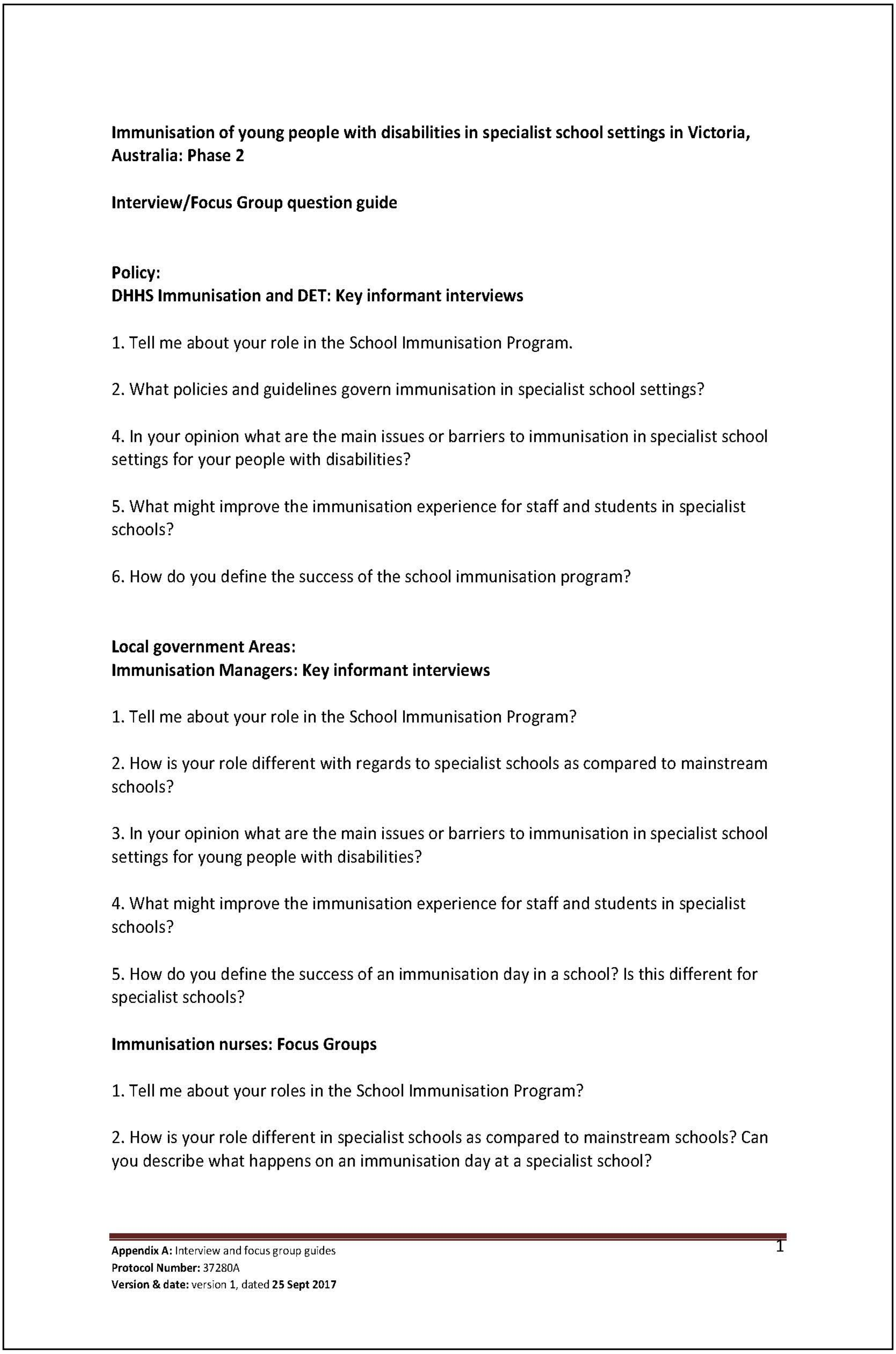
- I have read the information statement version listed above and I understand its contents.
- I believe I understand the purpose, extent and possible risks of my and/or my child's involvement in this project.
- I voluntarily consent for myself and/or my child to take part in this research project.
- I understand that interviews with myself and/or my child will be audio-recorded.
- I have had an opportunity to ask questions and I am satisfied with the answers I have received.
- I understand that this project has been approved by The Royal Children's Hospital Melbourne Human Research Ethics Committee and will be carried out in line with the National Statement on Ethical Conduct in Human Research (2007) – including all updates.
- I understand I will receive a copy of this Information Statement and Consent Form.

☐ I consent to taking part in this research

☐ I consent to my child ___________________ taking part in this research

Parent/Carer Name	Parent/Carer Signature	Date

APPENDIX T: INTERVIEW QUESTIONS GUIDE AND EXAMPLE OF REVISED QUESTIONS



Immunisation of young people with disabilities in specialist school settings in Victoria, Australia: Phase 2

Interview/Focus Group question guide

Policy:
DHHS Immunisation and DET: Key informant interviews

1. Tell me about your role in the School Immunisation Program.

2. What policies and guidelines govern immunisation in specialist school settings?

4. In your opinion what are the main issues or barriers to immunisation in specialist school settings for your people with disabilities?

5. What might improve the immunisation experience for staff and students in specialist schools?

6. How do you define the success of the school immunisation program?

Local government Areas:
Immunisation Managers: Key informant interviews

1. Tell me about your role in the School Immunisation Program?

2. How is your role different with regards to specialist schools as compared to mainstream schools?

3. In your opinion what are the main issues or barriers to immunisation in specialist school settings for young people with disabilities?

4. What might improve the immunisation experience for staff and students in specialist schools?

5. How do you define the success of an immunisation day in a school? Is this different for specialist schools?

Immunisation nurses: Focus Groups

1. Tell me about your roles in the School Immunisation Program?

2. How is your role different in specialist schools as compared to mainstream schools? Can you describe what happens on an immunisation day at a specialist school?

3. In your opinion what are the main issues or barriers to immunisation in specialist school settings for young people with disabilities?

4. What might improve the immunisation experience for staff and students in specialist schools?

5. How do you define the success of an immunisation day in a school? Is this different for specialist schools?

Schools:
Immunisation Co-ordinator: Key informant interviews

1. Tell me about your role in the School Immunisation Program?

2. How do you prepare students for Immunisation day? What information or education do they receive?

3. Can you describe what happens on Immunisation day?

4. In your opinion what are the main issues or barriers to immunisation in specialist school settings for young people with disabilities?

5. What might improve the immunisation experience for staff and students in specialist schools?

Families:
Parent/Carer: Interviews

1. If your child received immunisations in the last year, how do you think the immunisation experience was for your child? Was there anything that could have been done to improve this experience?

2. How do you feel about immunisations being given at school rather than the doctor or a community setting?

3. How did you make the decision whether or not to consent to your child having their adolescent immunisations?

4. What information did you receive about the adolescent immunisations? Who was this from?

5. Did you feel the information you received was relevant and appropriate?

6. Did you seek out other information about immunisations?

7. Did you have any unanswered questions or concerns about the immunisations?

8. How did you prepare your child for immunisations?

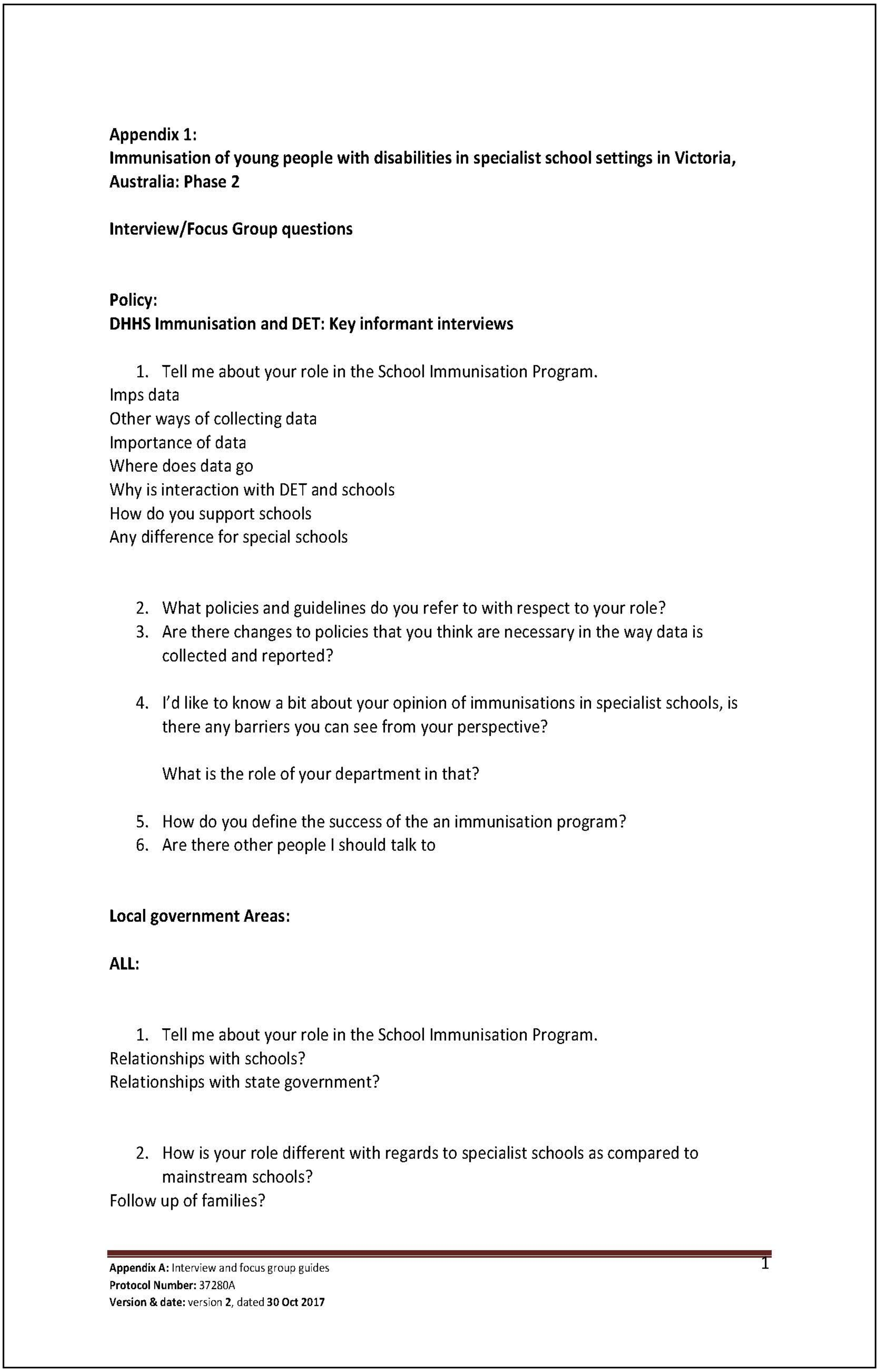
9. In your opinion what are the main issues or barriers to immunisation in specialist school settings for young people with disabilities?

Individual:
Young person interviews

1. Can you tell me about immunisations/needles? Do you know what they are for?

2. Do you remember having the needles at school? Can you tell me about that?

3. Is there anything you wish was better about the immunisations at school?



Appendix 1:
Immunisation of young people with disabilities in specialist school settings in Victoria, Australia: Phase 2

Interview/Focus Group questions

Policy:
DHHS Immunisation and DET: Key informant interviews

1. Tell me about your role in the School Immunisation Program.

Imps data
Other ways of collecting data
Importance of data
Where does data go
Why is interaction with DET and schools
How do you support schools
Any difference for special schools

2. What policies and guidelines do you refer to with respect to your role?
3. Are there changes to policies that you think are necessary in the way data is collected and reported?

4. I'd like to know a bit about your opinion of immunisations in specialist schools, is there any barriers you can see from your perspective?

   What is the role of your department in that?

5. How do you define the success of the an immunisation program?
6. Are there other people I should talk to

Local government Areas:

ALL:

1. Tell me about your role in the School Immunisation Program.

Relationships with schools?
Relationships with state government?

2. How is your role different with regards to specialist schools as compared to mainstream schools?

Follow up of families?

3. Can you describe what happens on an immunisation day at a specialist school?

4. Are there aspects of immunising in a specialist school which you find difficult/ confronting/ unsure of? Do you receive different or extra training in immunisation of young people with disabilities?

5. I am interested to hear whether safety is a concern when you immunise in specialist schools - in regard to unpredictable behaviour from students

6. What is the understanding amongst nurses about procedural holding of young people with disabilities in the school setting for immunisations? What happens in practice?

7. In your opinion what are the main issues or barriers to immunisation in specialist school settings for young people with disabilities?

8. How do you define the success of an immunisation day in a school? Is this different for specialist schools?

Immunisation Managers: Key informant interviews

1. Tell me about your role in the School Immunisation Program?

2. How is your role different with regards to specialist schools as compared to mainstream schools?

3. How have you supported the vaccination of young people in specialist schools?

4. In your opinion what are the main issues or barriers to immunisation in specialist school settings for young people with disabilities?

5. What might improve the immunisation experience for staff and students in specialist schools?

   7. How do you define the success of an immunisation day in a school? Is this different for specialist schools?

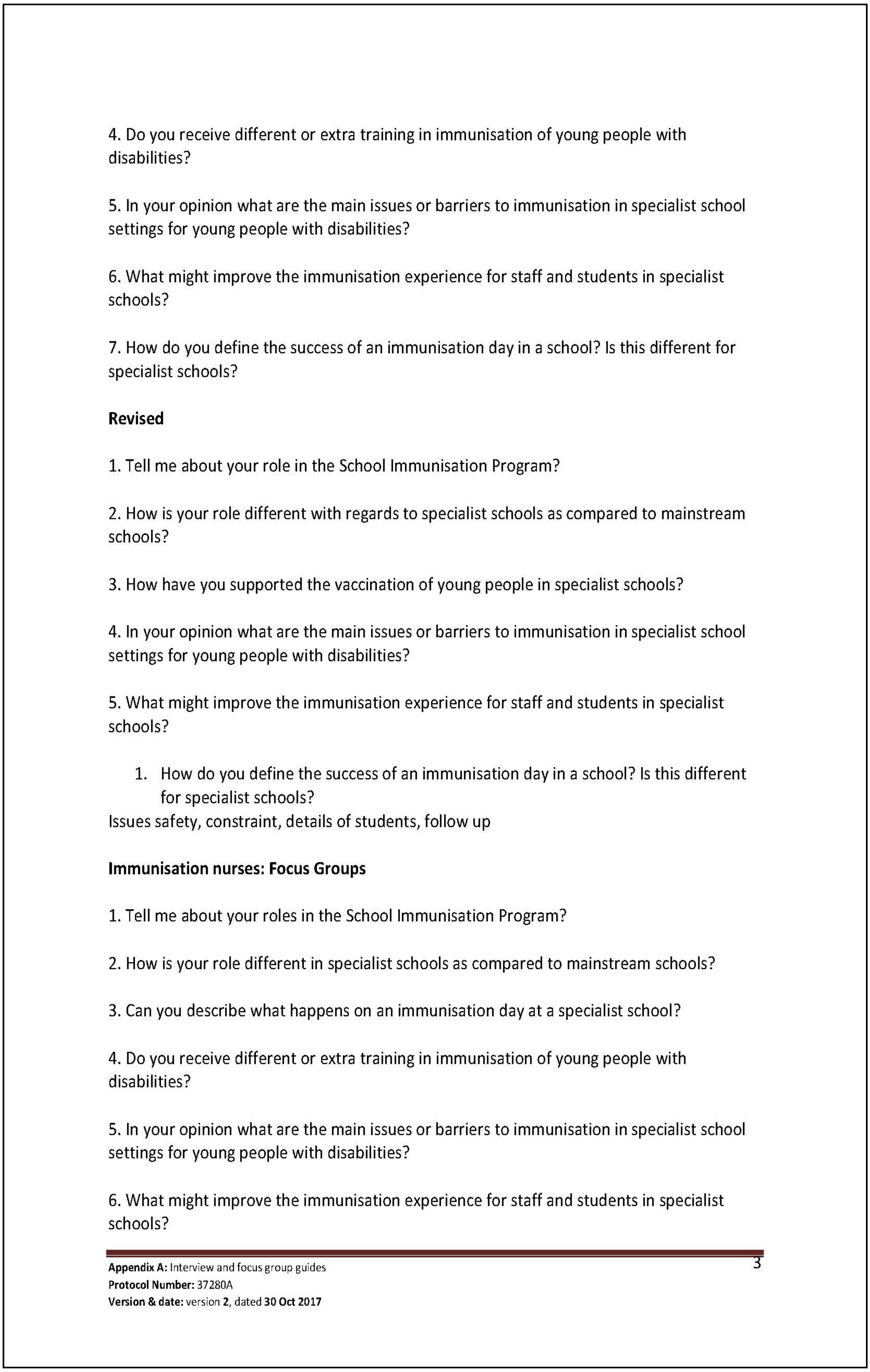
Issues safety, constraint, details of students, follow up

Immunisation nurses: Focus Groups

1. Tell me about your roles in the School Immunisation Program?

2. How is your role different in specialist schools as compared to mainstream schools?

3. Can you describe what happens on an immunisation day at a specialist school?



4. Do you receive different or extra training in immunisation of young people with disabilities?

5. In your opinion what are the main issues or barriers to immunisation in specialist school settings for young people with disabilities?

6. What might improve the immunisation experience for staff and students in specialist schools?

7. How do you define the success of an immunisation day in a school? Is this different for specialist schools?

Revised

1. Tell me about your role in the School Immunisation Program?

2. How is your role different with regards to specialist schools as compared to mainstream schools?

3. How have you supported the vaccination of young people in specialist schools?

4. In your opinion what are the main issues or barriers to immunisation in specialist school settings for young people with disabilities?

5. What might improve the immunisation experience for staff and students in specialist schools?

    1. How do you define the success of an immunisation day in a school? Is this different for specialist schools?

Issues safety, constraint, details of students, follow up

Immunisation nurses: Focus Groups

1. Tell me about your roles in the School Immunisation Program?

2. How is your role different in specialist schools as compared to mainstream schools?

3. Can you describe what happens on an immunisation day at a specialist school?

4. Do you receive different or extra training in immunisation of young people with disabilities?

5. In your opinion what are the main issues or barriers to immunisation in specialist school settings for young people with disabilities?

6. What might improve the immunisation experience for staff and students in specialist schools?

7. How do you define the success of an immunisation day in a school? Is this different for specialist schools?

Schools:
Immunisation Co-ordinator: Key informant interviews

1. Tell me about your role in the School Immunisation Program?

2. How do you prepare students for Immunisation day? What information or education do they receive?

3. Can you describe what happens on Immunisation day?

4. In your opinion what are the main issues or barriers to immunisation in specialist school settings for young people with disabilities?

5. What might improve the immunisation experience for staff and students in specialist schools?

6. How do you define the success of an immunisation day?

Families:
Parent/Carer: Interviews

1. If your child received immunisations in the last year, how do you think the immunisation experience was for your child? Was there anything that could have been done to improve this experience?

2. How do you feel about immunisations being given at school rather than the doctor or a community setting?

3. How did you make the decision whether or not to consent to your child having their adolescent immunisations?

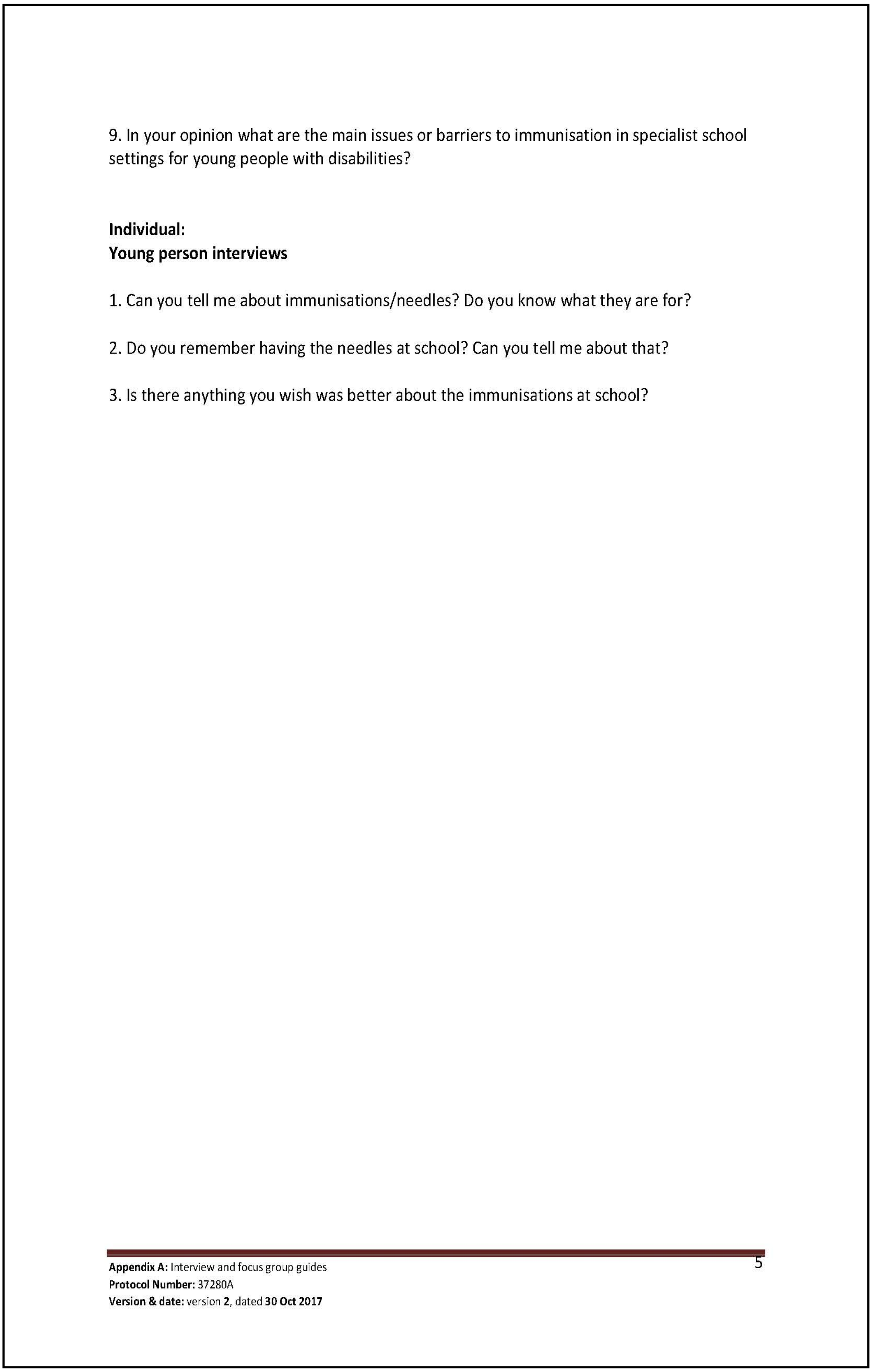
4. What information did you receive about the adolescent immunisations? Who was this from?

5. Did you feel the information you received was relevant and appropriate?

6. Did you seek out other information about immunisations?

7. Did you have any unanswered questions or concerns about the immunisations?

8. How did you prepare your child for immunisations?



9. In your opinion what are the main issues or barriers to immunisation in specialist school settings for young people with disabilities?

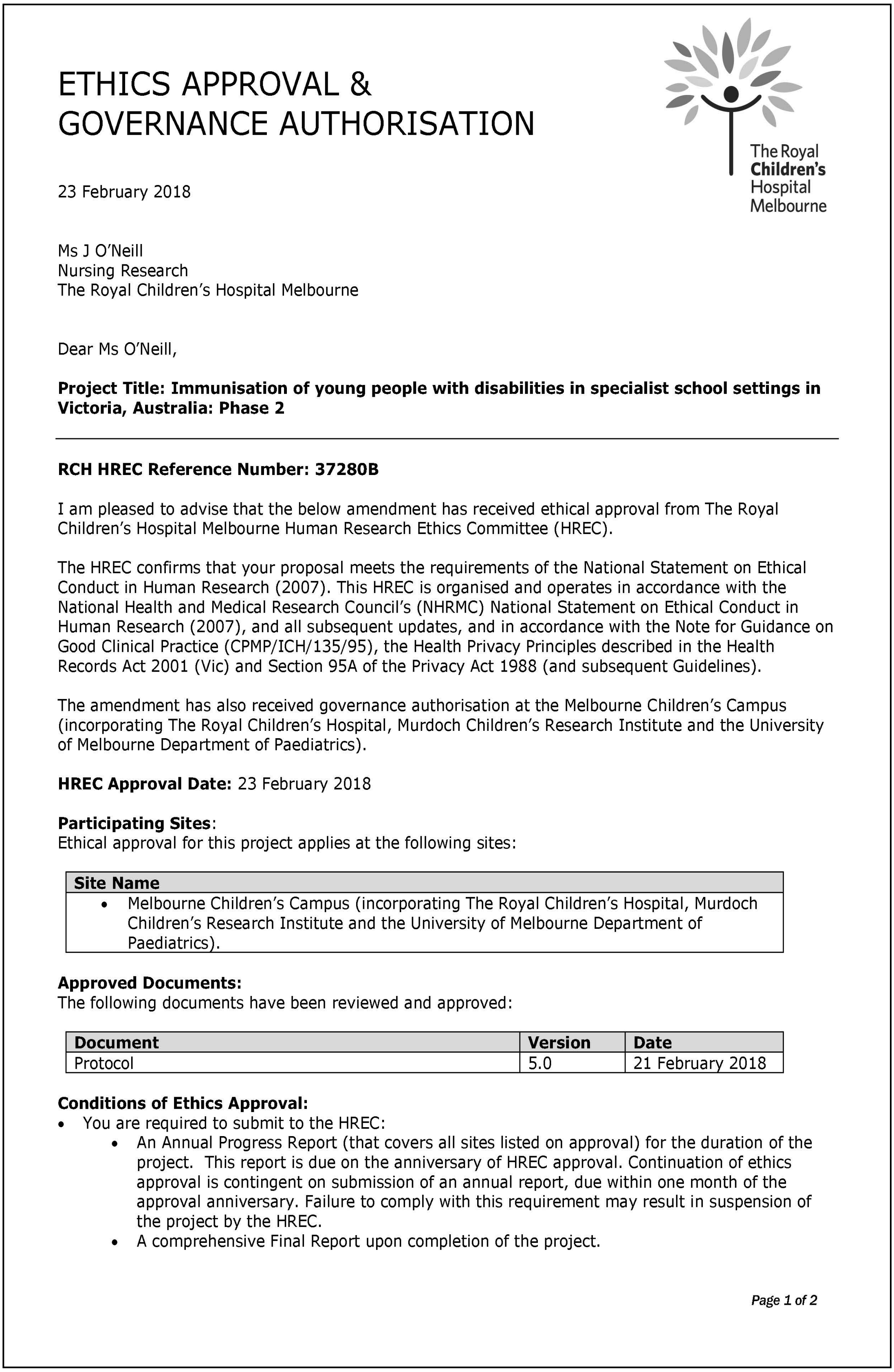
Individual:
Young person interviews

1. Can you tell me about immunisations/needles? Do you know what they are for?

2. Do you remember having the needles at school? Can you tell me about that?

3. Is there anything you wish was better about the immunisations at school?

APPENDIX U: PHASE TWO HREC APPROVAL AND AMENDMENT APPROVAL



ETHICS APPROVAL & GOVERNANCE AUTHORISATION

The Royal
Children's
Hospital
Melbourne

23 February 2018

Ms J O'Neill
Nursing Research
The Royal Children's Hospital Melbourne

Dear Ms O'Neill,

Project Title: Immunisation of young people with disabilities in specialist school settings in Victoria, Australia: Phase 2

RCH HREC Reference Number: 37280B

I am pleased to advise that the below amendment has received ethical approval from The Royal Children's Hospital Melbourne Human Research Ethics Committee (HREC).

The HREC confirms that your proposal meets the requirements of the National Statement on Ethical Conduct in Human Research (2007). This HREC is organised and operates in accordance with the National Health and Medical Research Council's (NHRMC) National Statement on Ethical Conduct in Human Research (2007), and all subsequent updates, and in accordance with the Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95), the Health Privacy Principles described in the Health Records Act 2001 (Vic) and Section 95A of the Privacy Act 1988 (and subsequent Guidelines).

The amendment has also received governance authorisation at the Melbourne Children's Campus (incorporating The Royal Children's Hospital, Murdoch Children's Research Institute and the University of Melbourne Department of Paediatrics).

HREC Approval Date: 23 February 2018

Participating Sites:
Ethical approval for this project applies at the following sites:

Site Name
• Melbourne Children's Campus (incorporating The Royal Children's Hospital, Murdoch Children's Research Institute and the University of Melbourne Department of Paediatrics).

Approved Documents:
The following documents have been reviewed and approved:

Document	Version	Date
Protocol	5.0	21 February 2018

Conditions of Ethics Approval:

- You are required to submit to the HREC:
    - An Annual Progress Report (that covers all sites listed on approval) for the duration of the project. This report is due on the anniversary of HREC approval. Continuation of ethics approval is contingent on submission of an annual report, due within one month of the approval anniversary. Failure to comply with this requirement may result in suspension of the project by the HREC.
    - A comprehensive Final Report upon completion of the project.

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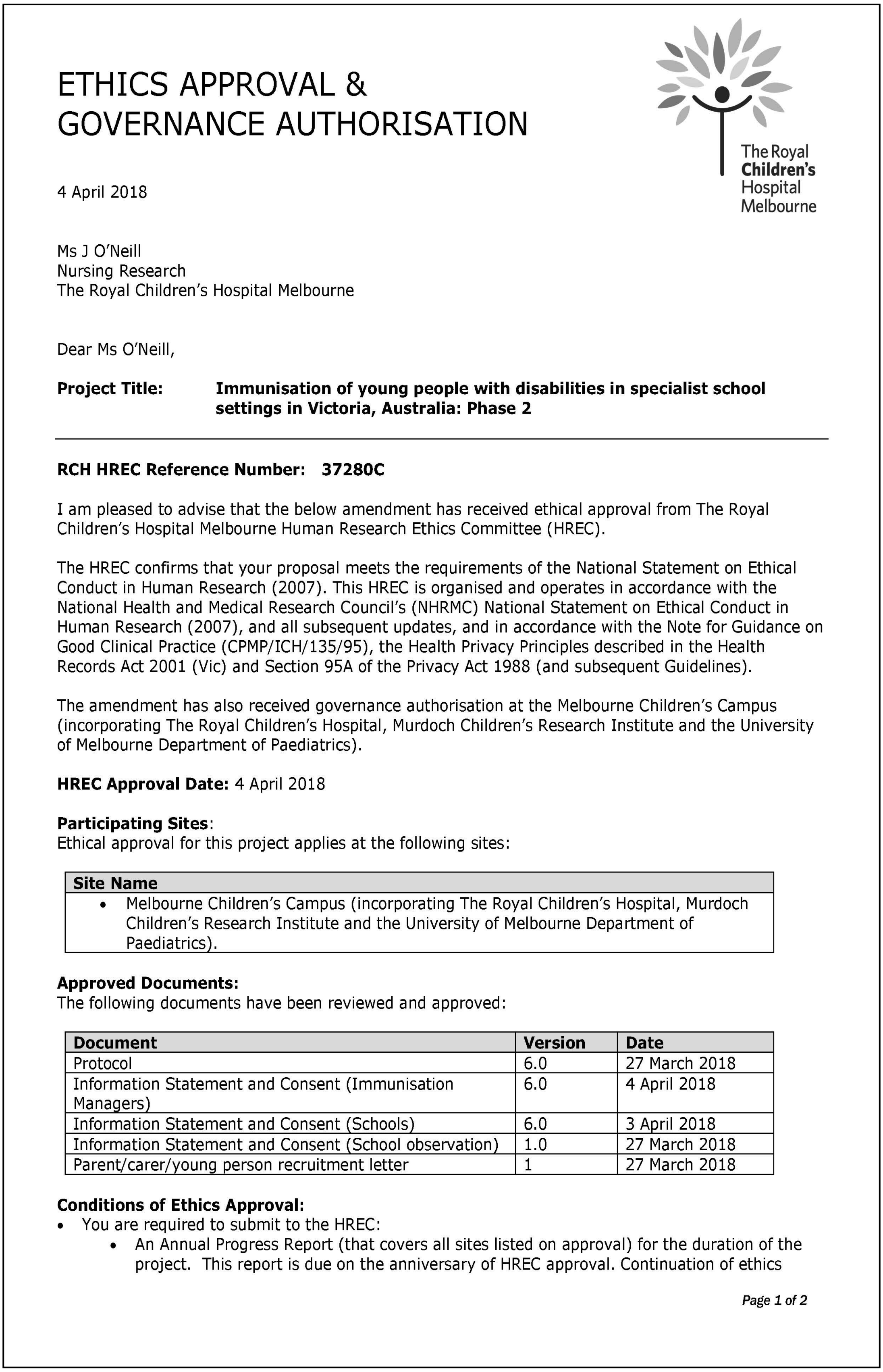
- Submit to the reviewing HREC for approval any proposed amendments to the project including any proposed changes to the Protocol, Participant Information and Consent Form/s and the Investigator Brochure.
- Notify the reviewing HREC of any adverse events that have a material impact on the conduct of the research in accordance with the NHMRC Position Statement: *Monitoring and reporting of safety for clinical trials involving therapeutic products May 2009*.
- Notify the reviewing HREC of your inability to continue as Coordinating Principal Investigator.
- Notify the reviewing HREC of the failure to commence the study within 12 months of the HREC approval date or if a decision is taken to end the study at any of the sites prior to the expected date of completion.
- Notify the reviewing HREC of any matters which may impact the conduct of the project.
- If your project involves radiation, you are legally obliged to conduct your research in accordance with the Australian Radiation Protection and Nuclear Safety Agency Code of Practice 'Exposure of Humans to Ionizing Radiation for Research Purposes' Radiation Protection series Publication No.8 (May 2005)(ARPANSA Code).
- The HREC, authorising institution and/or their delegate/s may conduct an audit of the project at any time.

Yours sincerely,

Deeptika Chauhan
Research Ethics and Governance Officer
Research Ethics and Governance
The Royal Children's Hospital Melbourne
Phone : (03) 9345 5044
Email : rch.ethics@rch.org.au
Web : www.rch.org.au



ETHICS APPROVAL & GOVERNANCE AUTHORISATION

The Royal
Children's
Hospital
Melbourne

4 April 2018

Ms J O'Neill
Nursing Research
The Royal Children's Hospital Melbourne

Dear Ms O'Neill,

Project Title: **Immunisation of young people with disabilities in specialist school settings in Victoria, Australia: Phase 2**

RCH HREC Reference Number: 37280C

I am pleased to advise that the below amendment has received ethical approval from The Royal Children's Hospital Melbourne Human Research Ethics Committee (HREC).

The HREC confirms that your proposal meets the requirements of the National Statement on Ethical Conduct in Human Research (2007). This HREC is organised and operates in accordance with the National Health and Medical Research Council's (NHRMC) National Statement on Ethical Conduct in Human Research (2007), and all subsequent updates, and in accordance with the Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95), the Health Privacy Principles described in the Health Records Act 2001 (Vic) and Section 95A of the Privacy Act 1988 (and subsequent Guidelines).

The amendment has also received governance authorisation at the Melbourne Children's Campus (incorporating The Royal Children's Hospital, Murdoch Children's Research Institute and the University of Melbourne Department of Paediatrics).

HREC Approval Date: 4 April 2018

Participating Sites:
Ethical approval for this project applies at the following sites:

Site Name
• Melbourne Children's Campus (incorporating The Royal Children's Hospital, Murdoch Children's Research Institute and the University of Melbourne Department of Paediatrics).

Approved Documents:
The following documents have been reviewed and approved:

Document	Version	Date
Protocol	6.0	27 March 2018
Information Statement and Consent (Immunisation Managers)	6.0	4 April 2018
Information Statement and Consent (Schools)	6.0	3 April 2018
Information Statement and Consent (School observation)	1.0	27 March 2018
Parent/carer/young person recruitment letter	1	27 March 2018

Conditions of Ethics Approval:

- You are required to submit to the HREC:
    - An Annual Progress Report (that covers all sites listed on approval) for the duration of the project. This report is due on the anniversary of HREC approval. Continuation of ethics

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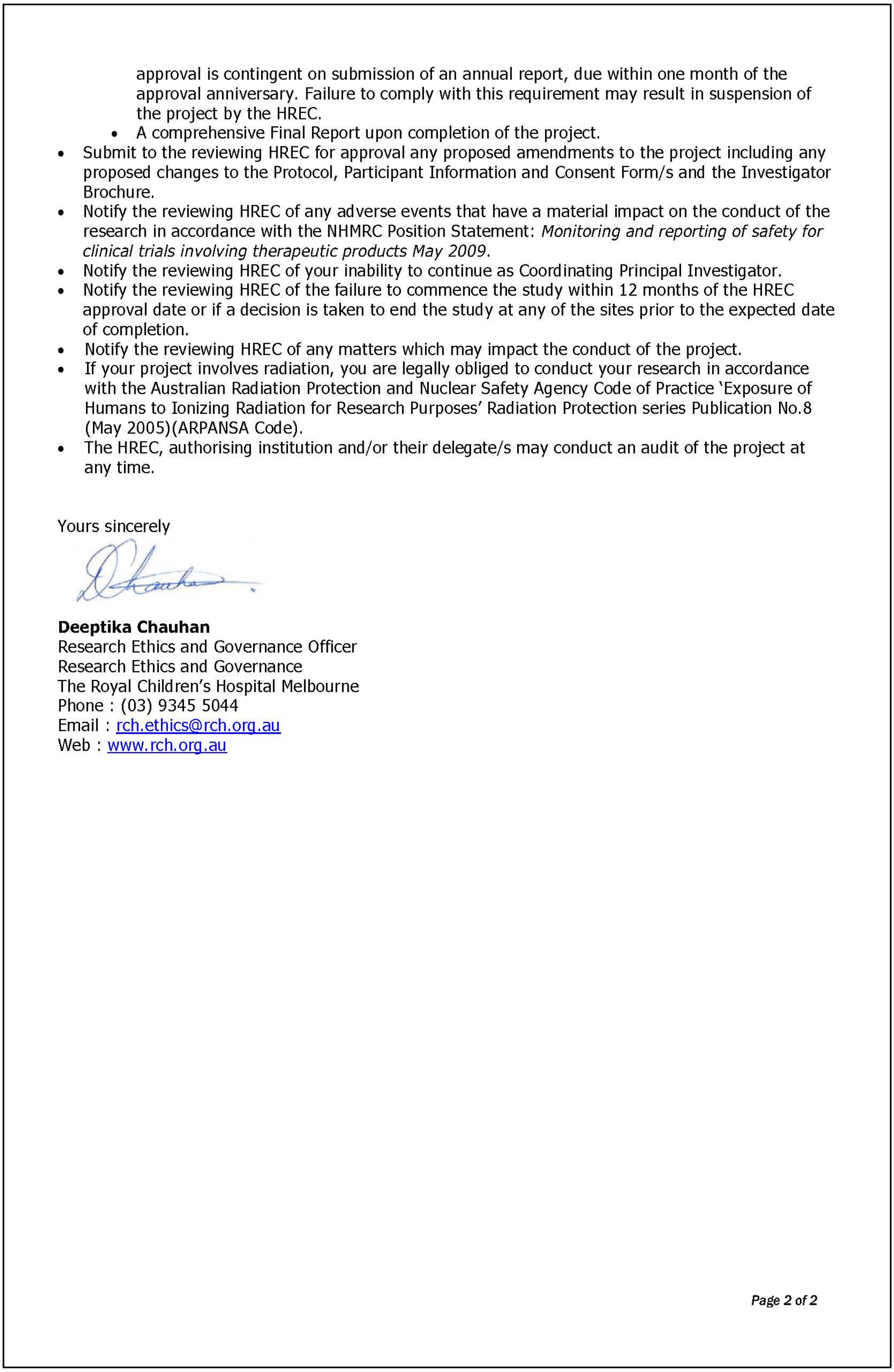

  approval is contingent on submission of an annual report, due within one month of the approval anniversary. Failure to comply with this requirement may result in suspension of the project by the HREC.
  - A comprehensive Final Report upon completion of the project.
- Submit to the reviewing HREC for approval any proposed amendments to the project including any proposed changes to the Protocol, Participant Information and Consent Form/s and the Investigator Brochure.
- Notify the reviewing HREC of any adverse events that have a material impact on the conduct of the research in accordance with the NHMRC Position Statement: *Monitoring and reporting of safety for clinical trials involving therapeutic products May 2009*.
- Notify the reviewing HREC of your inability to continue as Coordinating Principal Investigator.
- Notify the reviewing HREC of the failure to commence the study within 12 months of the HREC approval date or if a decision is taken to end the study at any of the sites prior to the expected date of completion.
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- If your project involves radiation, you are legally obliged to conduct your research in accordance with the Australian Radiation Protection and Nuclear Safety Agency Code of Practice 'Exposure of Humans to Ionizing Radiation for Research Purposes' Radiation Protection series Publication No.8 (May 2005)(ARPANSA Code).
- The HREC, authorising institution and/or their delegate/s may conduct an audit of the project at any time.

Yours sincerely

Deeptika Chauhan
Research Ethics and Governance Officer
Research Ethics and Governance
The Royal Children's Hospital Melbourne
Phone : (03) 9345 5044
Email : rch.ethics@rch.org.au
Web : www.rch.org.au

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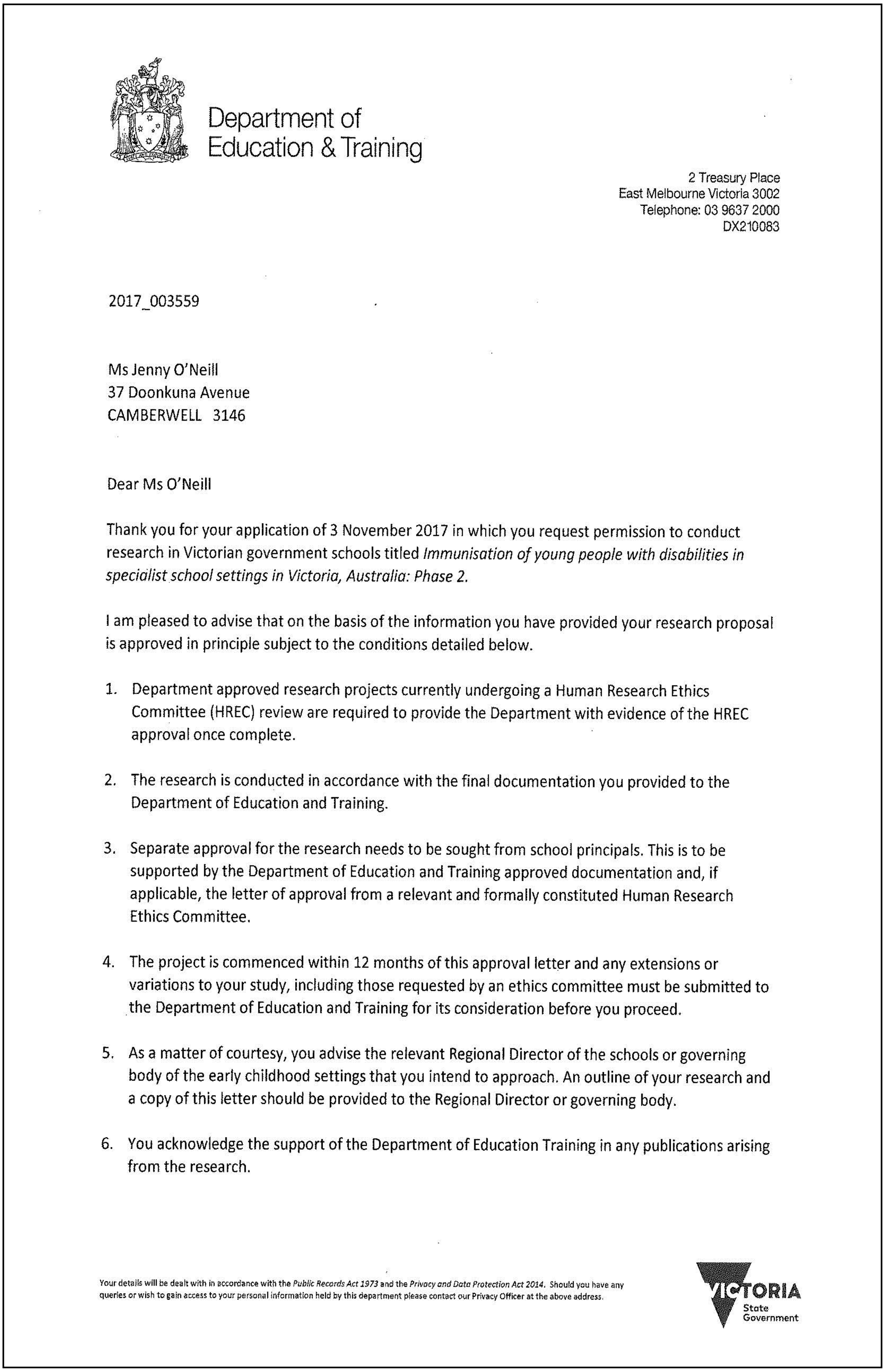
APPENDIX V: PHASE TWO DET APPROVAL



Department of
Education & Training

2 Treasury Place
East Melbourne Victoria 3002
Telephone: 03 9637 2000
DX210083

2017_003559

Ms Jenny O'Neill
37 Doonkuna Avenue
CAMBERWELL 3146

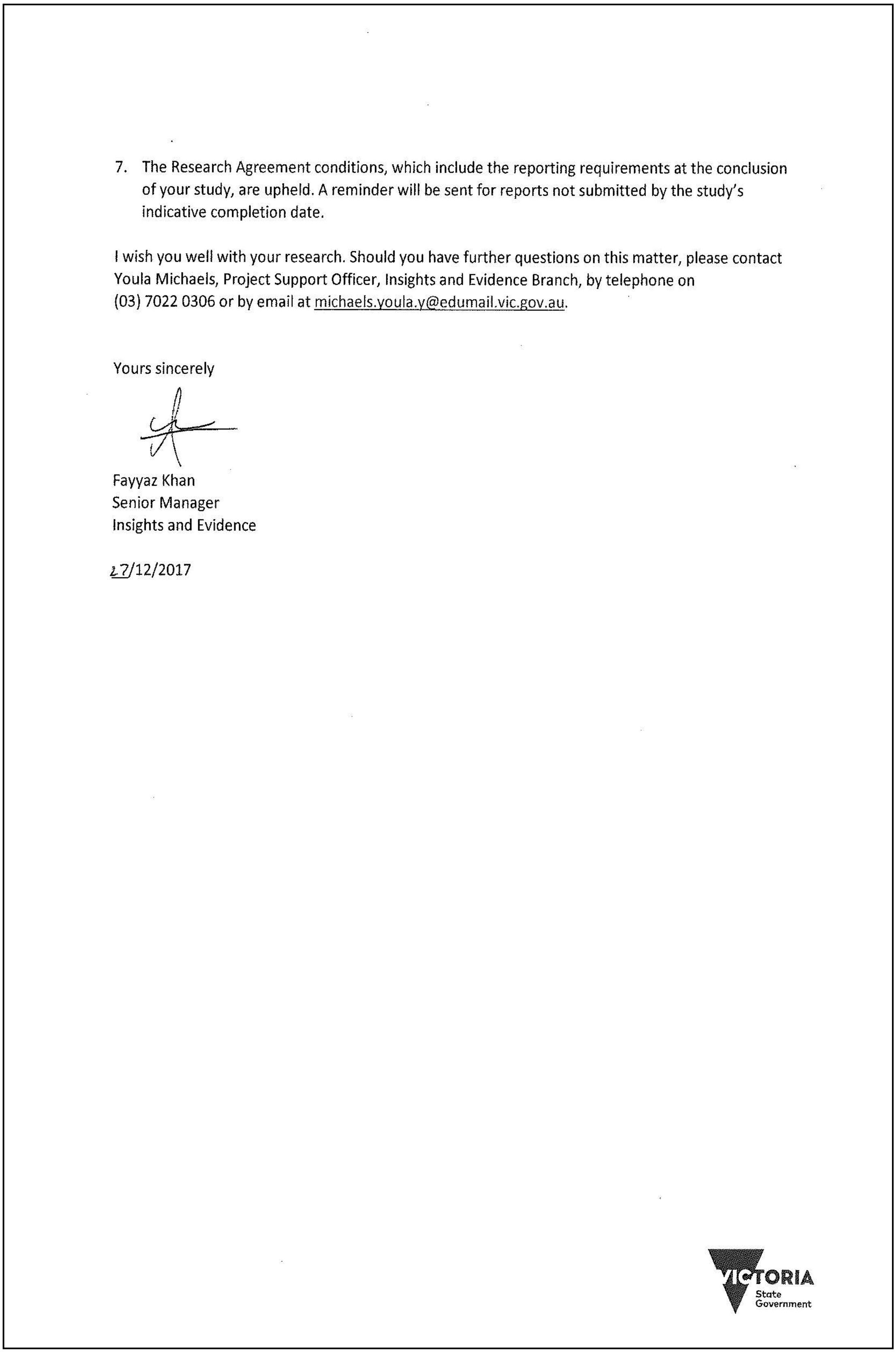
Dear Ms O'Neill

Thank you for your application of 3 November 2017 in which you request permission to conduct research in Victorian government schools titled *Immunisation of young people with disabilities in specialist school settings in Victoria, Australia: Phase 2.*

I am pleased to advise that on the basis of the information you have provided your research proposal is approved in principle subject to the conditions detailed below.

1. Department approved research projects currently undergoing a Human Research Ethics Committee (HREC) review are required to provide the Department with evidence of the HREC approval once complete.
2. The research is conducted in accordance with the final documentation you provided to the Department of Education and Training.
3. Separate approval for the research needs to be sought from school principals. This is to be supported by the Department of Education and Training approved documentation and, if applicable, the letter of approval from a relevant and formally constituted Human Research Ethics Committee.
4. The project is commenced within 12 months of this approval letter and any extensions or variations to your study, including those requested by an ethics committee must be submitted to the Department of Education and Training for its consideration before you proceed.
5. As a matter of courtesy, you advise the relevant Regional Director of the schools or governing body of the early childhood settings that you intend to approach. An outline of your research and a copy of this letter should be provided to the Regional Director or governing body.
6. You acknowledge the support of the Department of Education Training in any publications arising from the research.

VICTORIA
State
Government



7. The Research Agreement conditions, which include the reporting requirements at the conclusion of your study, are upheld. A reminder will be sent for reports not submitted by the study's indicative completion date.

I wish you well with your research. Should you have further questions on this matter, please contact Youla Michaels, Project Support Officer, Insights and Evidence Branch, by telephone on (03) 7022 0306 or by email at michaels.youla.y@edumail.vic.gov.au.

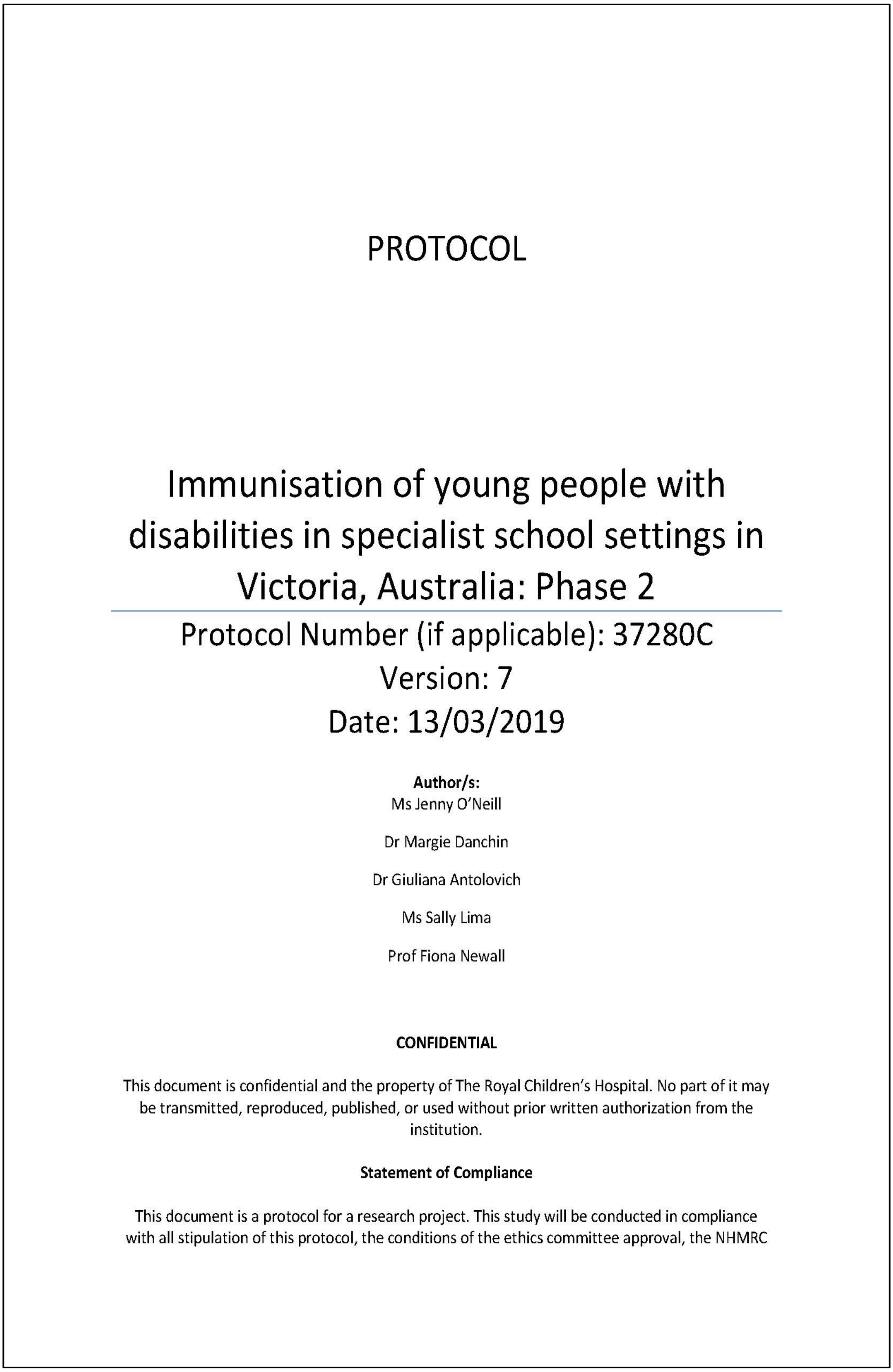
Yours sincerely

Fayyaz Khan
Senior Manager
Insights and Evidence

27/12/2017

VICTORIA
State
Government

APPENDIX W: PHASE TWO HREC AMENDMENT AND APPROVAL TO APPROACH FAMILIES



PROTOCOL

Immunisation of young people with disabilities in specialist school settings in Victoria, Australia: Phase 2

Protocol Number (if applicable): 37280C
Version: 7
Date: 13/03/2019

Author/s:
Ms Jenny O'Neill

Dr Margie Danchin

Dr Giuliana Antolovich

Ms Sally Lima

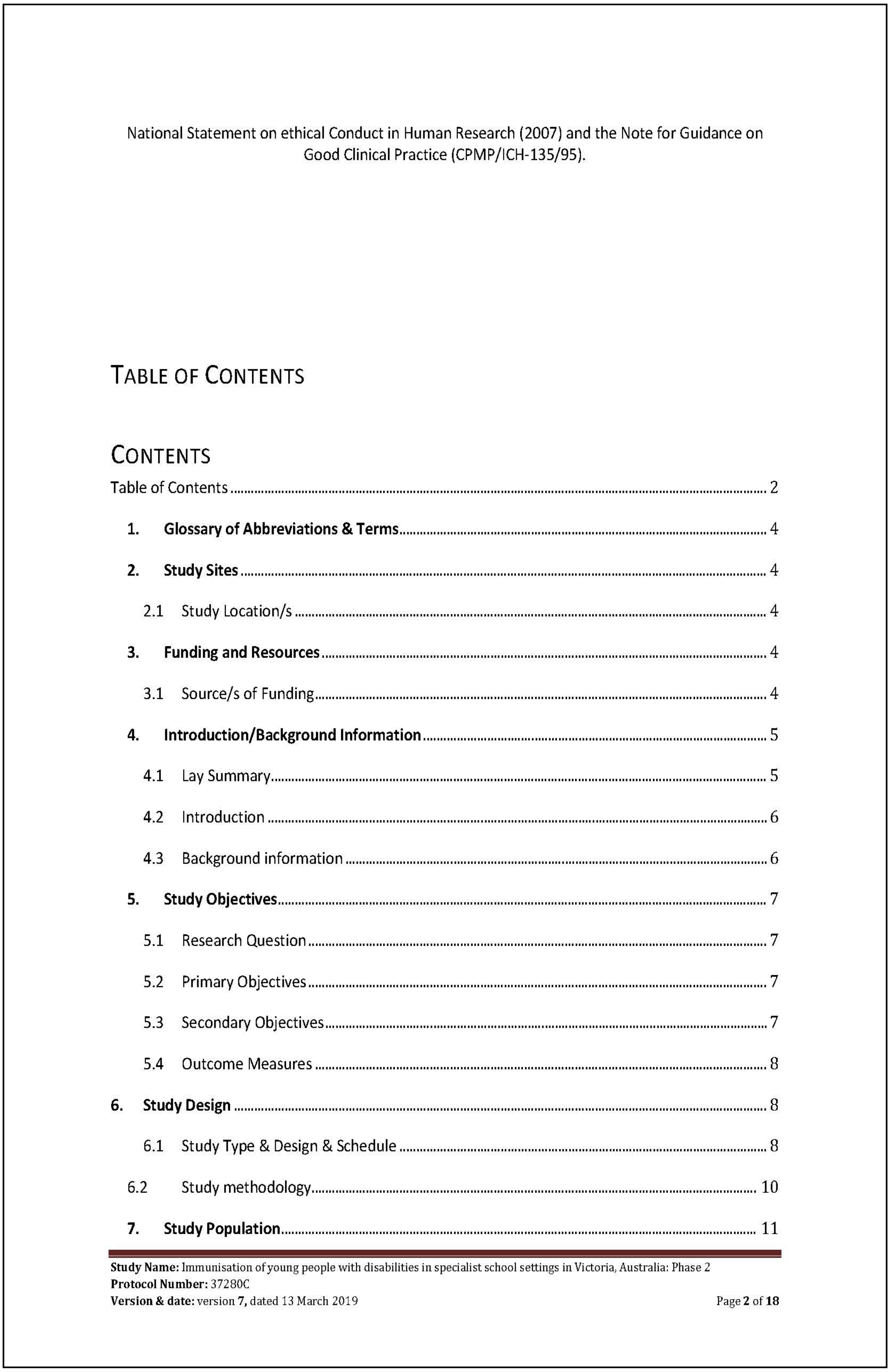
Prof Fiona Newall

CONFIDENTIAL

This document is confidential and the property of The Royal Children's Hospital. No part of it may be transmitted, reproduced, published, or used without prior written authorization from the institution.

Statement of Compliance

This document is a protocol for a research project. This study will be conducted in compliance with all stipulation of this protocol, the conditions of the ethics committee approval, the NHMRC



National Statement on ethical Conduct in Human Research (2007) and the Note for Guidance on Good Clinical Practice (CPMP/ICH-135/95).

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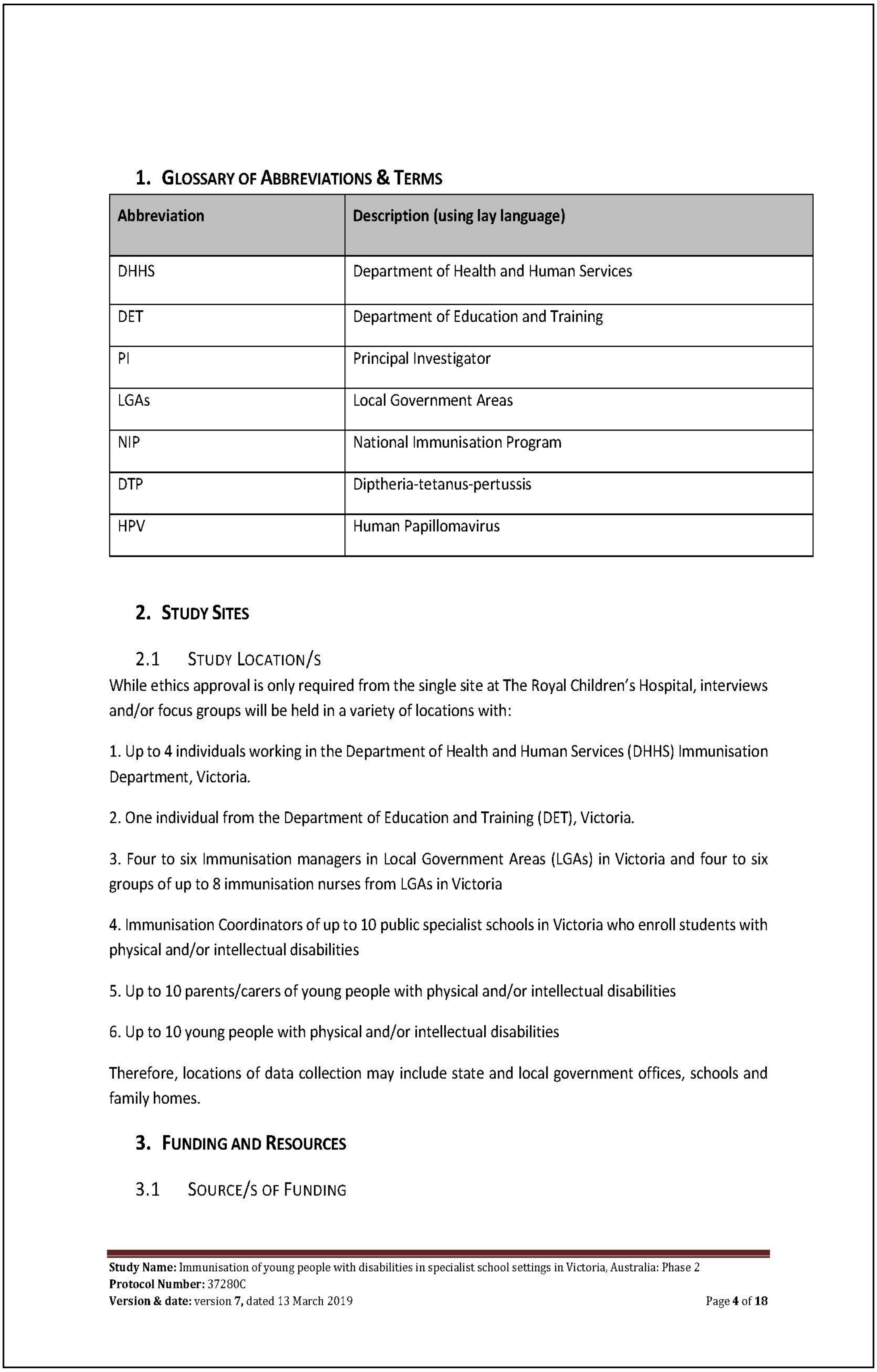


1. Glossary of Abbreviations & Terms

Abbreviation	Description (using lay language)
DHHS	Department of Health and Human Services
DET	Department of Education and Training
PI	Principal Investigator
LGAs	Local Government Areas
NIP	National Immunisation Program
DTP	Diptheria-tetanus-pertussis
HPV	Human Papillomavirus

2. Study Sites

2.1 Study Location/s

While ethics approval is only required from the single site at The Royal Children's Hospital, interviews and/or focus groups will be held in a variety of locations with:

1. Up to 4 individuals working in the Department of Health and Human Services (DHHS) Immunisation Department, Victoria.

2. One individual from the Department of Education and Training (DET), Victoria.

3. Four to six Immunisation managers in Local Government Areas (LGAs) in Victoria and four to six groups of up to 8 immunisation nurses from LGAs in Victoria

4. Immunisation Coordinators of up to 10 public specialist schools in Victoria who enroll students with physical and/or intellectual disabilities

5. Up to 10 parents/carers of young people with physical and/or intellectual disabilities

6. Up to 10 young people with physical and/or intellectual disabilities

Therefore, locations of data collection may include state and local government offices, schools and family homes.

3. Funding and Resources

3.1 Source/s of Funding

The Principal Investigator (PI) is supported by a Research and Training Stipend from the University of Melbourne and a top-up scholarship from the Developmental Disability and Rehabilitation Research Group Gallie Trust, The Murdoch Childrens Research Institute. In addition, the PI has received a grant from DHHS Immunisation Victoria to assist with any costs of data collection and analysis.

4. INTRODUCTION/BACKGROUND INFORMATION

4.1 LAY SUMMARY

Victoria has a program of scheduled vaccinations, which are included in the National Immunisation Program (NIP) schedule and are paid for by the Australian government. Included in the NIP schedule is the school-based immunisation program, which offers all young people aged 12 to 13 years:

- the Diphtheria/tetanus/pertussis (DTP) vaccine;
- the varicella (chickenpox) vaccine if they have not already received one dose (<= 14 years old) or have a clear history of prior varicella infection; and
- the Human Papillomavirus (HPV) vaccine, which is currently given as three doses within 6 months.

In Victoria these vaccinations are given in Year 7, administered in schools by immunisation nurses arranged by the Local Government Areas (LGAs).

This school-based immunisation program is successful with high rates of young people being vaccinated. However, it is not clear if this is different for young people with disabilities in specialist school settings as there is very little information in Australia, or indeed internationally, about vaccination in children with disabilities. The limited studies that have been conducted suggest vaccination rates are lower in children with disabilities than for children in mainstream schools but they have not examined the reasons why this might be. The first phase of this research (HREC 36326B) is currently being undertaken, collecting information about young people's vaccination status in specialist schools in Victoria, in order to understand the size of the problem, and what factors are contributing to these young people remaining un-vaccinated. This second phase aims to understand the experiences of, concerns with, barriers and facilitators of acceptance and delivery immunisation for young people with disabilities, their parents, teachers and immunisation nurses and managers who deliver immunisation as well as policy makers. This ensures the viewpoint of all key stakeholders in the school-based immunisation program are included.

This information will be collected by in-depth interviews and focus groups. Participants will provide informed consent prior to taking part in interviews or focus groups. Focus groups will be undertaken at the participant's workplace, in the case of immunisation nurses, or at The Royal Children's Hospital, in the case of parents. Interview will be undertaken at a location that is mutually convenient. It is expected that the time commitment from adult participants will be 30 to 60 mins. For young people the time commitment will be 5 to 20 mins. The main consideration for participants taking part will be one of inconvenience and time commitment. No identifying information from this data will be published or presented.

This type of information about immunisations in specialist schools has not been collected previously and with this information, we hope to inform tailored interventions to ensure that young people with disabilities are able to have the same access, and optimal experiences in adolescent immunisation. This is essential to ensure that young people with disabilities are protected against infectious diseases that can be prevented by immunisation.

4.2 INTRODUCTION

As part of the government-funded immunisation program in Australia, all young people aged 12 and 13 years are eligible to receive DTP, HPV and varicella immunisations through the school-based immunisaion program. In Victoria this is given in the first year of secondary school (Year 7), with DTP and varicella given as one dose each, and HPV given as three doses within six months (0, 1 and 6 months). Uptake of these vaccinations is recorded by the DHHS Immunisation in Victoria and through the HPV register. In 2015, 89.6% of eligible students received the adolescent dose of DTP and 77.4% of girls and 66.4% of boys received all three doses of HPV. Varicella is only necessary if the young person has not received one dose in childhood (<= 14 years) or does not have natural immunity or a strong clinical history of infection.

This study represents the second phase of a larger study aiming to explore the issues relation to school-based vaccination for young people with disabilities in specialist schools using the socio-ecological framework. The first phase focuses on collecting data on immunisation uptake in specialist schools. This second phase aims to answer the question: what are the experiences of, concerns with, barriers and facilitators to acceptance and delivery of school-based immunisation for young people with disabilities in specialist schools in Victoria, Australia?

The importance of understanding concerns, experiences, barriers and facilitators to immunisation delivery in the specialist school setting at all levels cannot be underestimated. In 2008, Australia ratified the United Nation Convention on the Rights of Persons with Disabilities, which recognises the need to provide health care for those with disabilities "in the same range, quality and standard of free or affordable health care and programs as provided to other persons" (United Nations, 2006, sec. 25). Without having accurate data to assess the delivery of the school-based immunisation program in non-mainstream schools, nor understanding the potential reasons for missed immunisations, and the concerns, barriers and enablers of the school-based immunisation program for this population, it is difficult to be certain that young people with disabilities are receiving equitable and acceptable preventative health care.

4.3 BACKGROUND INFORMATION

There is very little research in Australia or internationally, on immunisation in children and adolescents with a disability. When considering children of all ages, most studies suggest children with disabilities are at risk for under or non-immunisation. Lower rates of immunisation are recorded for children with disabilities in early childhood (Greenwood, Crawford, Walstab & Reddihough, 2013; Raddish, Goldmann, Lawrence, Kaplan & Perrin, 1993; Tillmann, Tillmann, Heininger, Lutschg & Weber, 2005), and for the seasonal influenza vaccine (Pandolfi et al., 2012; Yen et al., 2012). Of these studies only Greenwood et al. (2013) is Australian, with the focus on children with cerebral palsy under 7 years. Only one study in the USA (O'Connor & Bramlett, 2008), found that children with special health care needs, broadly defined to include children with developmental issues, emotional issues or needing any specialist care or medication, had immunisation rates similar to typically developing children. This was a data linkage study in the USA, which relied on parent report of vaccination coverage as opposed to data obtained from an immunisation register.

In terms of adolescent immunisation specifically, two studies from the USA and Canada found that only 17% of children with special health care needs were immunised against HPV, and that having Down syndrome or ASD was significantly associated with missing HPV immunisation (Cody & Lerand, 2013; Remes et al., 2014). Tuffrey and Finlay (2001) reported that only 59% of children from special schools in Bath, United Kingdom were fully immunised compared to 83% of matched controls. There is no published data on adolescent immunisation for young people in special schools in Australia. Crucially, also missing from the research is qualitative information on the experiences of immunisation for young people with a disability and exploration of the reasons for the difference in the uptake of adolescent vaccinations in populations of young people with disabilities. Uptake only illustrates the potential scope of the issue, and this in isolation does not help identify or understand the factors that influence whether a young person with a disability receives an immunisation. Quantitative data does not provide comprehensive information about the drivers of vaccine acceptance. There is a need for qualitative data exploring individual and family decision making about immunisation and the policies and processes in the education and health system available to support this.

Therefore, there is a significant gap in the literature with respect to understanding school-based adolescent immunisation for young people with disabilities in Australia. If indeed the bulk of the international data regarding immunisation uptake rates for this group is similar in Australia, there is much work to be done to ensure that this already vulnerable group has increased access to and promotion around the importance of immunisation. This research has the potential for considerable impact on immunisation policy. Most importantly interventions, which could be developed as a result of this research, have the potential to affect the morbidity and mortality of children with disabilities and are congruent with the principles of equity in health care and the rights of persons with disabilities.

5. STUDY OBJECTIVES

5.1 RESEARCH QUESTION

What are the experiences, concerns with, barriers and facilitators of acceptance and delivery of school-based immunisation for young people with disabilities in specialist schools in Victoria, Australia?

5.2 PRIMARY OBJECTIVES

The primary objective is to explore and establish the specific socio-ecological determinants that prevent or enable immunisation for young people with disabilities in specialist schools in Australia.

5.3 SECONDARY OBJECTIVES

Secondary objectives of this study include:

1. Exploration of implementation of the school-based immunisation program in specialist schools

2. Development of an understanding of the role of teachers, nurses, managers and policy makers in the school-based immunisation Program in specialist schools

3. Exploration of decision-making about consent to immunisation and administering immunisation to young people in specialist schools

4. Development of an understanding of the experience of young people with disability undergoing immunisation in specialist schools

5.4 OUTCOME MEASURES

Consistent with the methodology of qualitative inquiry outcome measures will not be objective measures, but will be the prevailing themes from the interviews and focus groups which will make up the qualitative data collection. The primary outcome measure will be a description of the understanding of specific socio-ecological determinants that prevent or enable immunisation for young people in specialist schools.

Secondary outcome measures with be a description of the themes relating to other aspects of the school-based immunisation program in specialist schools raised by participants.

6. STUDY DESIGN

6.1 STUDY TYPE & DESIGN & SCHEDULE

This is an exploratory qualitative study utlising a socio-ecological model adapted from Bronfenbrenner's Ecological Systems Theory. Bronfenbrenner's Ecological Systems Theory describes layers of influence from micro to macro levels. An adaptation of this, shown in Figure 1, is the socio-ecological model which has been widely used in health promotion to examine a range of factors which can affect health promotion or preventative health actions. This encompasses the individual's beliefs, attitudes and behaviours, the social influences of their immediate community, the organisational influences or arrangements, the broader community and structures and systems guiding policy. Most importantly the socio-ecological model emphasises the need to analyse the way these layers interact. Figure 1 illustrates the layers of the socio-ecological model. In this study, the stakeholders in each of the five layers of the socio-ecological model have been identified as:

Structures and systems: DHHS Immunisation and DET policy makers

Community: LGA Immunisation managers and nurses

Institutions: School immunisation co-ordinators

Interpersonal: Parents and family

Individual: Student

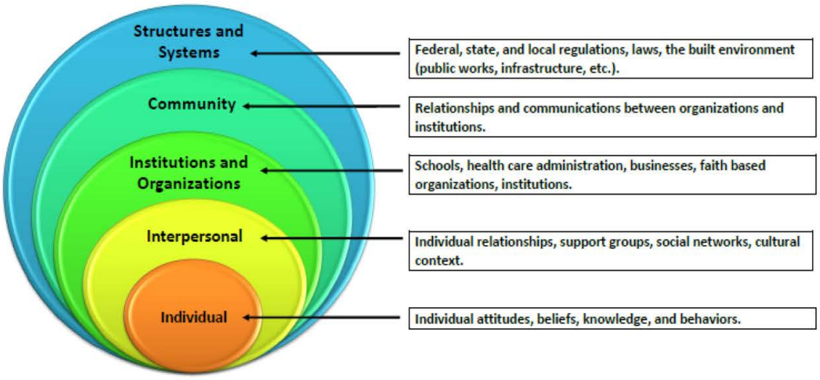


Figure 1: The socio-ecological model

Recruitment for this phase of the study will commence in October 2017 and will be continue until all interviews and focus groups are completed which is expected to be by September 2018. All participants will only have basic demographic data collected including: position in the socio-ecological model and job description relevant to school-based immunisation program, gender and age range. Participants will be provided with an alias and all data collected will be re-identifiable.

Only interviews will be offered for the policy, immunisation managers and immunisation schools co-ordinators as at these levels these stakeholders are key informants in immunisation for the state government, local government or school respectively. Key informants act as expert spokespeople for their group or population, therefore in-depth interviews are an appropriate method of gaining a comprehensive understanding of their perspective.

Key informants have been identified within Phase 1 of the study, through contact with government, LGAs and schools. The PI will approach key informant participants via email or phone to explain the research and invite participation. Contact details have been identified in Phase 1 of the research. If the participant agrees, the Information Statement and consent form will be sent electronically to the participant, and a time and location will be mutually agreed. The PI expects to most commonly travel to participant's place of work to conduct interviews. If there is no response to the initial invitation to participate a maximum of two follow up emails and/or phone calls to the key informant participants will be undertaken.

The rationale of using focus groups for immunisation nurses is because their job in the school immunisation program is within their team of immunisation nurses, which is different than the other stakeholders. Therefore, there is value in hearing their views within a team. However, for nurses who wish to participate outside the focus group and interview will be offered.

The rationale for including a focus group as well as interviews for parents as the group dynamic of parent discussion may both serve to add depth to the discussion, and will also enable more parent voices to be heard. However, for parents who prefer to be participate outside the focus group, interviews will be offered. Young people with a disability will be offered an interview and can participate with parental consent. Interviews with young people will take place after the interview with their parent/carer. The parent/carer can be present as a support person but will be asked not to take part in the young person's interview. This will be agreed upon by the young person and parent. These interviews will be held at the family home.

When undertaking interviews at the family home, the research team will adhere to the RCH Safety at Home Policy and Procedure. This will include

1. The interviewer having their car key and mobile on them at all times.
2. The interviewer assessing for any signs of violence or danger upon entering the home and exiting immediately if these are present.
3. The interviewer texting a nominated member of the research team on arrival to the family home and on departure.
4. The allocated member of the research team will have details of the time of arrival and expected departure and if the interviewer has not checked in within 15 minutes of these times, the member of the research team will text the interviewer. If there is no response in 10 minutes the member of the research team will call the interviewer. If there is no response the interviewer will escalate to the other members of the research team and the police.
5. All members of the research team will have access to a password protected spreadsheet with scheduled home interviews and addresses.

For all interviews and focus groups consent will be verbally re-visited in person prior to commencement of the discussion, and signed consent forms will be collected at that time. Interviews and focus groups will be recorded and transcribed. Transcription will be undertaken by a transcription service who will receive be required to sign a confidentiality agreement. Voice recordings will be destroyed once they are transcribed. Data will be coded and themed by the PI with consultation from the research team and the assistance of NVivo software.

To triangulate data from interviews and focus groups, the Principal investigator will also approach Immunisation Managers of local government areas to attend immunisation days at specialist schools during 2018, to collect data through observation. Notes and reflections from this observation will be journaled by the Principal Investigator and used to supplement information from interviews and focus groups.

Data analysis of this stage is expected to be completed by November 2018. Phase 2 is the second part of a PhD study undertaken through the Department of Paediatrics at the Royal Children's Hospital which is due for completion in May 2019.

6.2 STUDY METHODOLOGY

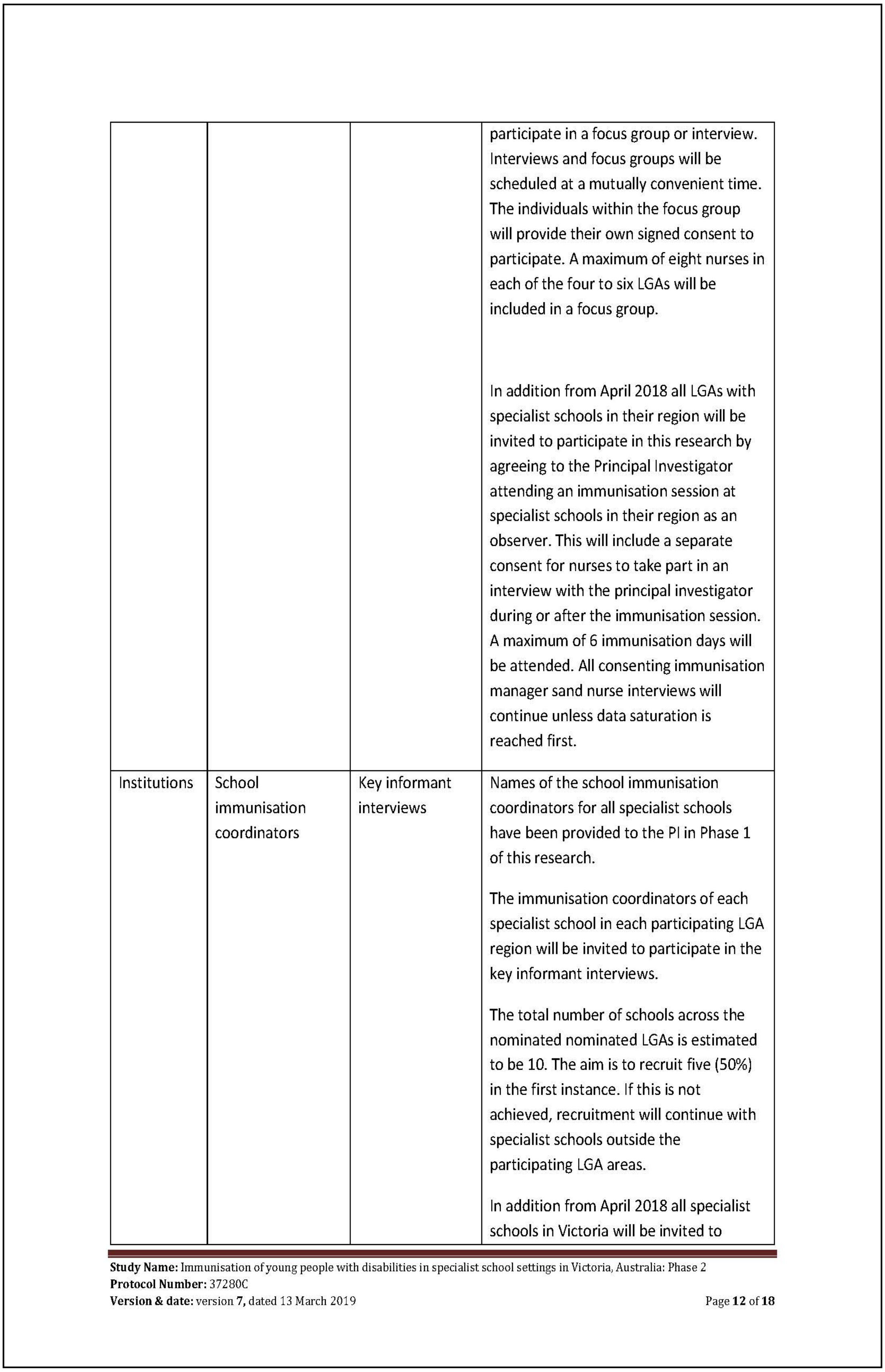
Data collection with be by in-depth semi-structured interviews, focus groups and observation of immunisation days at specialist schools. Interview guides have been developed to ensure consistency in data collection. This will allow broad themes to be covered, including: the experience of the participant's role in the school-based immunisation program in specialist schools, the perceived barriers and enablers to immunisation in specialist schools and particular concerns of the participants about immunisation in specialist schools. The semi-structured nature also allows for themes and topics to be initiated by participants, therefore ensuring the discussion is participant driven and not reliant on preconceived themes. Interview guides for each interview/focus group can be found in Appendix A.

7. STUDY POPULATION

7.1 RECRUITMENT PROCEDURE

Recruitment will be purposeful with the aim to capture key informants and diversity of experience. Recruitment strategy is set out below:

SEM level	Stakeholders	Data collection method	Recruitment strategy
Policy	DHHS Immunisation and DET	Key Informant interviews	Four individuals in DHHS Immunisation and one individual at DET have been identified as key informants in Phase 1 of the study. All of these individuals will be contacted and invited to participate in an in-depth interview. In addition any other key informants in policy suggested during the recruitment or interview process will be invited to participate in an interview
Community	LGA immunisation managers LGA immunisation nurses	Key informant interviews Focus groups	Six Victorian LGAs with specialist schools identified by the research team based on maximum diversity sampling. This includes consideration of diversity of: location (metropolitan, regional, and where applicable rural); population; a range of immunisation uptake levels (as recorded for mainstream schools); socioeconomic levels (as measured by index of relative economic advantage and disadvantage); and type of specialist schools. If less than 4 LGAs agree to participate the research team will nominate a mix of other LGAs that are representative of diversity to ensure a minimum of four LGAs. Immunisation managers of all LGAs with specialist schools have been identified in Phase 1 of the research. They will be the contact for LGAs and will be asked to participate in an in-depth interview. At the same time, they will be asked to invite their immunisation nurses to



			participate in a focus group or interview. Interviews and focus groups will be scheduled at a mutually convenient time. The individuals within the focus group will provide their own signed consent to participate. A maximum of eight nurses in each of the four to six LGAs will be included in a focus group. In addition from April 2018 all LGAs with specialist schools in their region will be invited to participate in this research by agreeing to the Principal Investigator attending an immunisation session at specialist schools in their region as an observer. This will include a separate consent for nurses to take part in an interview with the principal investigator during or after the immunisation session. A maximum of 6 immunisation days will be attended. All consenting immunisation manager sand nurse interviews will continue unless data saturation is reached first.
Institutions	School immunisation coordinators	Key informant interviews	Names of the school immunisation coordinators for all specialist schools have been provided to the PI in Phase 1 of this research. The immunisation coordinators of each specialist school in each participating LGA region will be invited to participate in the key informant interviews. The total number of schools across the nominated nominated LGAs is estimated to be 10. The aim is to recruit five (50%) in the first instance. If this is not achieved, recruitment will continue with specialist schools outside the participating LGA areas. In addition from April 2018 all specialist schools in Victoria will be invited to

			participate in this research by agreeing to an interview with the Immunisation Coordinator. This could occur by phone or in person. If the Principal Investigator is attending an immunisation session as an observer this interview could occur before or after this session. All consenting immunisation coordinators will be interviewed unless data saturation is reached first.
Family	Parent/carer	Interviews	The PI will approach participating schools to advertise for parent and young person participants through the school newsletters. In addition, the Cerebral Palsy Support Network, Association for Children with a Disability and Amaze will be approached to advertise in their newsletters and through their social media for parent participation. Advertisements will also be place in local Leader newspapers where appropriate. Advertising will also take place through Neurodevelopment and Disability outpatient clinics and through the Rehabilitation and Complex Care departments and on the website at The Royal Children's Hospital. Where parents are approached at The Royal Children's Hospital in person, this will be done by the PI in her role as a Clinical Nurse Consultant for Neurodevelopment and Disability or the child's paediatrician or other RCH health professional. Where an RCH health professional has identified a family who is appropriate to approach but is not in the hospital at the time the PI is, the PI will call the family to invite them to participate in the study. In all cases, a contact number and email will be advertised on the flyer, or printed advertisement for parents to self-

			nominate to participate in a focus group or interview. Parents will be eligible if they have had a child attending a specialist school who has been eligible for the adolescent immunisations in the last 12 months, whether or not they received them. The aim is to recruit up to 10 parents/carers or parent/carer pairs and 10 young people for interviews and one focus group of up to eight parents. In addition all schools where the Principal Investigator attends an immunisation session as an observer and/or interviews the Immunsiation Co-ordinator will receive hard copy letters to send home with the students to invite parent/carers and/or young people to participate in an interview at a time and location convenient to them. This could include phone or in-person interview. Recruitment of parent/carers and young people may also be undertaken by approaching developmental paediatricians through the state to alert them of the study and pass on the recruitment flyer to appropriate families. A list of developmental paediatricians is available to the Principal Investigator through her work as a nurse in the Neurodevelopmental and Disability department at The Royal Children's Hospital. A maximum of 10 parent/carer and young person interviews will be undertaken.

7.2 INCLUSION AND EXCLUSION CRITERIA

Exclusion criteria for all participants will include: need for an interpreter to participate, as interpreters will not be available for interviews or focus groups.

Exclusion criteria for young people with a disability will include: non-verbal communication system as the interviewer will require verbal answers to questions.

Inclusion criteria: For parents: inclusion criteria will include primary carers (including biological parents, adoptive or foster parents or grandparents) of young adolescents attending a specialist school in Victoria and eligible for the adolescent immunisations given at 12-14 years old in the last 12 months, whether or not they received them.

For young people: inclusion criteria will include any young person who attends a specialist school and was eligible to receive their adolescent immunisations in the last 12 months, whether or not they received them.

7.3 CONSENT

Signed consent will be obtained from all participants prior to the interview or focus group commencing.

Signed consent will be obtained from the Immunisation Manager of LGAs for the Principal Investigator to attend an immunisation session at a specialist school with the immunisation team. The principal of each school involved will be informed of this and receive an Information Statement with a copy of DET approval for the research via email. Verbal consent to enter the school and observe the immunisation session will be obtained at the start of each immunisation session from the principal of the school or proxy.

8. PARTICIPANT SAFETY AND WITHDRAWAL

8.1 RISK MANAGEMENT AND SAFETY

There are minimal risks to participants involved in this study. The risk of psychological distress when recounting thoughts and experiences of immunisations of young people however must be considered. If this should occur the PI will stop the interview/focus group and allow the individual to have a break. The choice will be given to the participant whether to continue the interview or focus group. If the participant continues and appears to recover further support will be offered by way of a follow up phone call by the PI within the next week.

If the participant declines to continue or continues to appear distressed, the PI will encourage follow up by the individual's general practitioner or employee wellbeing scheme (for professionals). For parents, if the discussion provokes uncertainty about the choice they have made to vaccinate or not vaccinate their children, details of the Immunisation Service at The Royal Children's Hospital will be given to the parent in order for them to access the clinic in which they can review these decisions with an paediatrician or a senior nurse specialised in immunisation.

For the PI, safety will be ensured when travelling to different locations by:

1. Notifying the research team of all interviews and focus group, including time, date and locations

2. Having a charged mobile phone on person at all times

3. Organizing to notify a member of the research team via text message when entering an interview and on leaving

8.2 ADVERSE EVENT REPORTING

There are no foreseeable serious adverse events for this study.

Distress of any individuals taking part will be discussed with the research team and, if referral to supports is required the Research and Ethics department at The Royal Children's Hospital will also be notified and advice sought as to whether any further action is needed.

8.3 HANDLING OF WITHDRAWALS

At any time, participants may withdraw from the study. Any such participants will then be asked for verbal permission to include their response to any interview or focus group questions already recorded. If verbal permission is not given, any recordings of interviews will be destroyed, or in the case of focus groups, any responses they have given will not be transcribed or used.

9. DATA SECURITY & HANDLING

9.1 DETAILS OF WHERE RECORDS WILL BE KEPT & HOW LONG WILL THEY BE STORED

Audio-recordings, transcriptions and demographic data will be stored electronically on a password protected computer with locked cloud back-up, only accessible to the research team and the transcription service who will be asked to sign a confidentiality agreement. Transcriptions will be kept for 7 years after completion of the study. This computer will be in the possession of the PI who works between the Royal Children's Hospital and her home.

9.2 CONFIDENTIALITY AND SECURITY

Participants will be given an alias which will be assumed on all transcriptions and analyses of data. A spreadsheet will be maintained with allocation of alias in order the data is re-identifiable for the purposes of rechecking of data and meaning with participants if necessary. This spreadsheet will be password protected. No identifiable data will be included in any publications or presentations. This includes identifying individuals, schools or LGAs.

10 APPENDIX

Please see Appendix A attached for interview and focus group guides.

List of Attachments included:

Document Name	**Version Number**	**Date (e.g., 18 January 2012)**
Appendix A: Interview and focus group guides	2	30 Oct 2017
Budget	1	8 May 2017
Information Statement and Consent (Policy)	3	30 Oct 2017
Information Statement and Consent (Immunisation Managers)	4	27 Mar 2018
Information Statement and Consent (Immunisation Nurses)	3	30 Oct 2017
Information Statement and Consent (Schools)	4	27 Mar 2018
Information Statement (Schools observation)	1	27 Mar 2018
Information Statement and Consent (Family)	3	30 Oct 2017
Parent/ young person recruitment advertisement	3	30 Oct 2017
Parent/ young person recruitment letter	1	27 Mar 2018
Department of Education and Training Research Approval Application	1	6 Nov 2017

11. REFERENC

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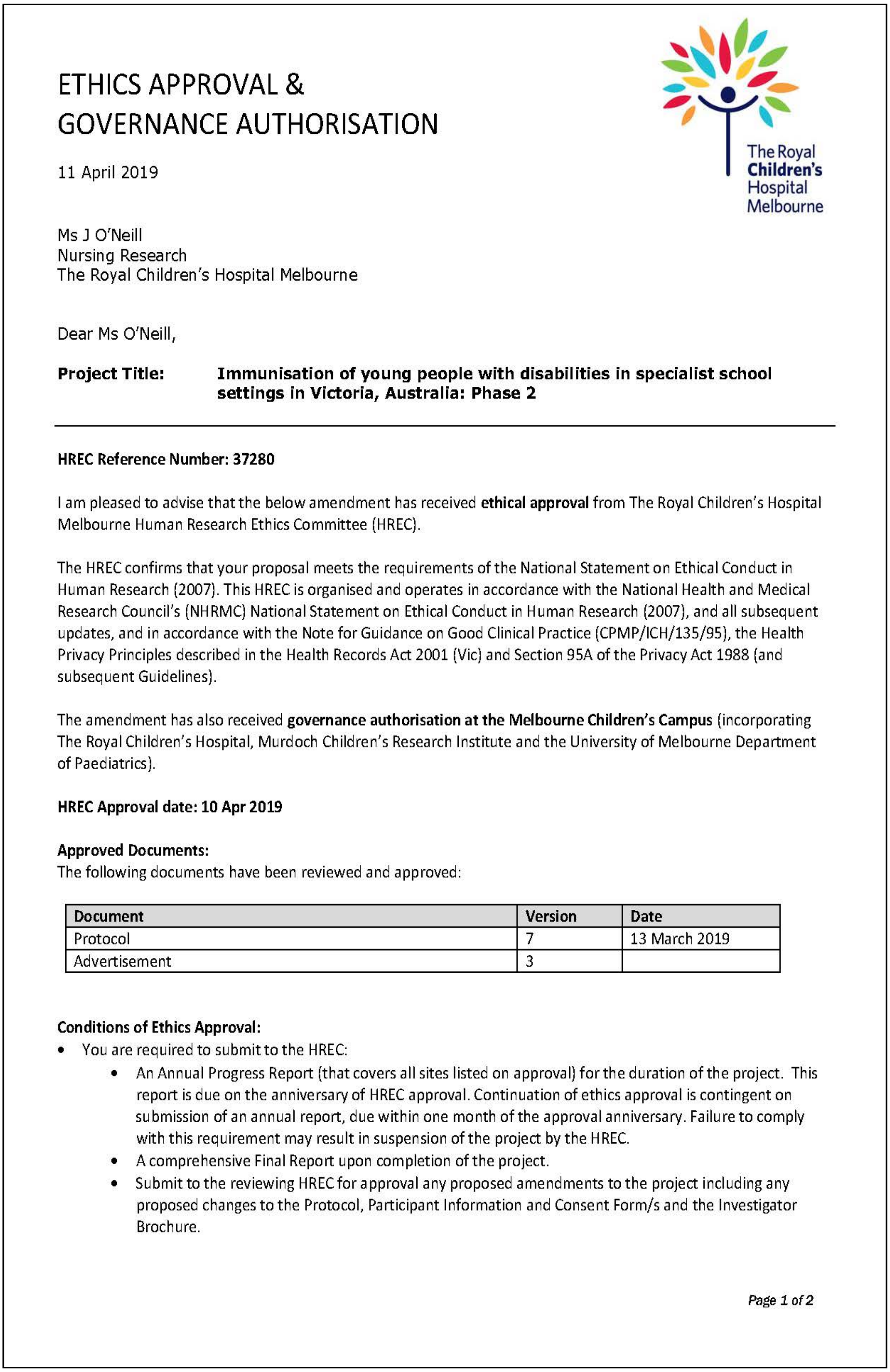

ETHICS APPROVAL & GOVERNANCE AUTHORISATION

The Royal
Children's
Hospital
Melbourne

11 April 2019

Ms J O'Neill
Nursing Research
The Royal Children's Hospital Melbourne

Dear Ms O'Neill,

Project Title: **Immunisation of young people with disabilities in specialist school settings in Victoria, Australia: Phase 2**

HREC Reference Number: 37280

I am pleased to advise that the below amendment has received **ethical approval** from The Royal Children's Hospital Melbourne Human Research Ethics Committee (HREC).

The HREC confirms that your proposal meets the requirements of the National Statement on Ethical Conduct in Human Research (2007). This HREC is organised and operates in accordance with the National Health and Medical Research Council's (NHRMC) National Statement on Ethical Conduct in Human Research (2007), and all subsequent updates, and in accordance with the Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95), the Health Privacy Principles described in the Health Records Act 2001 (Vic) and Section 95A of the Privacy Act 1988 (and subsequent Guidelines).

The amendment has also received **governance authorisation at the Melbourne Children's Campus** (incorporating The Royal Children's Hospital, Murdoch Children's Research Institute and the University of Melbourne Department of Paediatrics).

HREC Approval date: 10 Apr 2019

Approved Documents:
The following documents have been reviewed and approved:

Document	Version	Date
Protocol	7	13 March 2019
Advertisement	3	

Conditions of Ethics Approval:

- You are required to submit to the HREC:
    - An Annual Progress Report (that covers all sites listed on approval) for the duration of the project. This report is due on the anniversary of HREC approval. Continuation of ethics approval is contingent on submission of an annual report, due within one month of the approval anniversary. Failure to comply with this requirement may result in suspension of the project by the HREC.
    - A comprehensive Final Report upon completion of the project.
    - Submit to the reviewing HREC for approval any proposed amendments to the project including any proposed changes to the Protocol, Participant Information and Consent Form/s and the Investigator Brochure.

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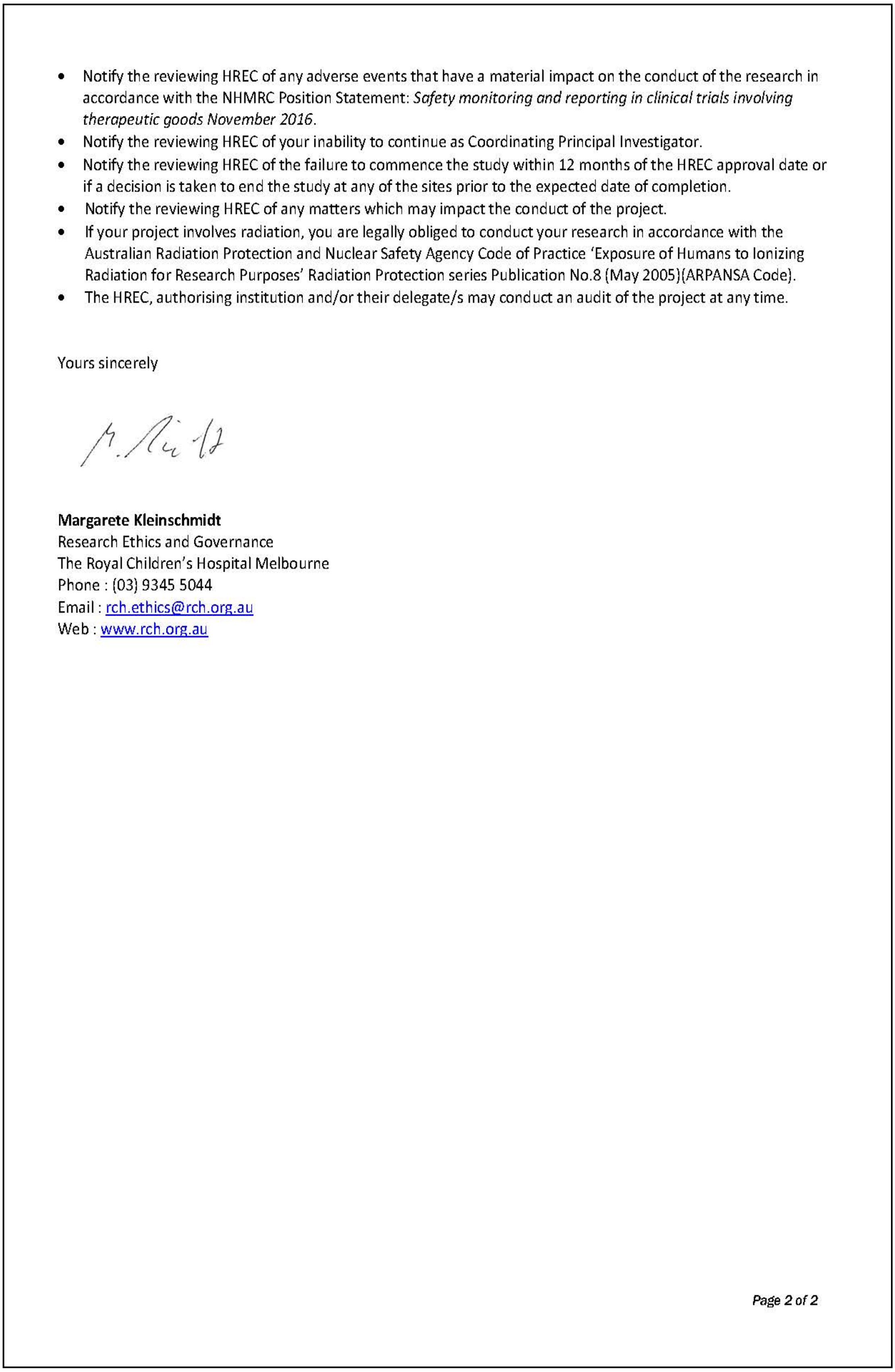

- Notify the reviewing HREC of any adverse events that have a material impact on the conduct of the research in accordance with the NHMRC Position Statement: *Safety monitoring and reporting in clinical trials involving therapeutic goods November 2016*.
- Notify the reviewing HREC of your inability to continue as Coordinating Principal Investigator.
- Notify the reviewing HREC of the failure to commence the study within 12 months of the HREC approval date or if a decision is taken to end the study at any of the sites prior to the expected date of completion.
- Notify the reviewing HREC of any matters which may impact the conduct of the project.
- If your project involves radiation, you are legally obliged to conduct your research in accordance with the Australian Radiation Protection and Nuclear Safety Agency Code of Practice 'Exposure of Humans to Ionizing Radiation for Research Purposes' Radiation Protection series Publication No.8 (May 2005)(ARPANSA Code).
- The HREC, authorising institution and/or their delegate/s may conduct an audit of the project at any time.

Yours sincerely

Margarete Kleinschmidt
Research Ethics and Governance
The Royal Children's Hospital Melbourne
Phone : (03) 9345 5044
Email : rch.ethics@rch.org.au
Web : www.rch.org.au