Pushed to the fringe: Vaccine hesitancy in parents and pregnant women

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Glossary of terms

Vaccine and vaccine related terms

Adverse event	This term also referred to adverse effect or vaccine side effects following immunisation is any unexpected side effect following administration of a vaccine.
Conspiracy theory	A conspiracy theory is a belief that some secret but influential organization is responsible for an event or phenomena. For example, the mistaken belief that COVID19 is a plot by the Freemasons to depopulate the world.
False Narrative	A false narrative is any story that isn't real but is portrayed as if it is. For example, online participants presented inaccurate information suggesting that immunisation in pregnancy was dangerous, with many deaths occurring in infants.
Immunisation schedule	An immunisation schedule is a series of vaccinations including the timing and dosage that is recommended to people.
Herd immunity	Herd immunity occurs when a large percentage of the community becomes immune to a disease, often through immunisation, thus providing protection to those who are not immune.
Model of care	A model of care broadly defines the way health services are delivered. It outlines the best practice care and services for a person, population group or patient cohort.
Multivalent	This term refers to the inclusion of multiple antigens in one vaccine. An example of this is the Infanrix Hexa vaccine which includes six different antigens in one vaccine.
Therapeutic Goods Administration	The Therapeutic Goods Administration is Australia's medicine and therapeutic regulatory agency, which is responsible for regulating the quality and supply of medicines as well as adverse event monitoring.
Vaccines	This term is used regularly and in this thesis includes all vaccines, including child, adult, pregnancy specific and COVID19 vaccines unless otherwise stipulated.
Vaccine Hesitancy	Vaccine hesitancy has been described by the World Health Organisation as any delay or refusal to accept immunisation despite the availability of vaccines.
Vaccine decision-making	This term refers to the decision to accept or reject vaccines.

Vaccination In Australia	This term refers to all vaccines offered on any national or state schedule.

Social Media related terms

Facebook	Facebook, run by Meta, is a free social networking website that allows registered users to create profiles, take out ads, upload photos, videos, and messages.
Followers	A follower is someone who has opted to follow your profile page. Followers will receive updates in their timeline.
Like	Clicking “like” below a post on Meta (Facebook) is a way to show other users that you enjoy it or agree with the comments, pictures or memes without writing a comment. Meta (Facebook) also offers the option of reacting to a post in different ways: a heart, care face, laughing face, surprised face, sad face, or angry face. These emoji also allow users to express their reactions without making comment.
Posts	Facebook posts are public messages posted to a Facebook user’s entire audience. In the case of Business Pages, such as the “Vaccine Hesitancy in Pregnancy and Early Childhood” page, this is done to provide a presence to their audience and attract new followers or gain reactions or commentary. This can take the form of videos, images, memes or texts.
Sharing	Sharing is when a user elects to share a specific post on their own account.
Social networking site	A social networking site is an online platform that people can use to build relationships, share information or seek information.
Status	A Facebook status is an update feature that allows users to discuss their thoughts and location and express their feelings or “check in” to a location.
Thread	A thread is a sequence of responses to am message. It is possible to follow or join the discussion.

Glossary of abbreviations

CAM	complementary and alternative medicine
CAQDAS	computer-assisted qualitative data analysis software
CASP	Critical Appraisal Skills Programme
DTP	diphtheria, tetanus and bordetella pertussis
Hep B	hepatitis B
HPV	human papillomavirus
MMR	measles-mumps-rubella vaccine
mRNA	messenger ribonucleic acid
NHMRC	National Health and Medical Research Council
PPE	Personal protective equipment
PRISMA	Preferred reporting items for systematic reviews and meta-analyses
SEIFA	Socio-Economic Index for Areas
TGA	Therapeutic Goods Administration
UK	United Kingdom
USA	United States of America

Works arising from this thesis

Conference proceedings

Presented at the Virtual International Day of the Midwife, 05/05/2022, “Weighing up the risks – Vaccine hesitancy in parents and pregnant women”.

Poster presentation at the Maternal, Child and Family Health Conference 02/09/22, “Ten tips for communicating with vaccine-hesitant parents”.

Other presentations

Vaccine hesitancy in parents and pregnant women. Third year midwifery students April 2021.

Vaccine hesitancy in parents and pregnant women. Third year midwifery students April 2022.

Media

Radio Interview	2GB Radio 15/02/2022
Radio Interview	ABC Radio 16/02/2022
Radio Interview	2CC Radio 18/02/2022

Podcast

My research was included in the podcast “Thru the pinard”, a conversational podcast with @Academic_Liz. The podcast discusses the research projects of midwives and other birth professionals. The aim of the podcast is to ensure safe and up-to-date birthing practices globally.

Publications

Smith, S. E., Sivertsen, N., Lines, L., & De Bellis, A. (2022). Decision-making in vaccine hesitant parents and pregnant women – An integrative review. *International Journal of Nursing Studies Advances*, *4*, 100062. https://doi.org/10.1016/j.ijnsa.2022.100062

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Smith, S. E., Sivertsen, N., Lines, L., and De Bellis, A. (2022). A discussion paper on how to communicate with vaccine hesitant parents: top 10 tips for effective communication. *Journal of Children and Young People’s Health*, *3*(1), 4-7. https://doi.org/https://doi.org/10.33235/jcyph.3.1.4-7

Awards

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Abstract

Background

Immunisation is universally accepted as one of the most significant public health initiatives in recent times. However, vaccine hesitancy is an increasing problem in middle- to high-income countries and has overtaken vaccine access as the primary barrier to uptake. Vaccine hesitancy has been identified as one of the top threats to global health by the World Health Organisation. Pregnant women and children are some of the most at risk of serious sequelae from acquiring vaccine preventable diseases. Hence, pregnant women and parents of young children are the focus of this thesis.

Aim

The aim of this study was to explore the values, beliefs and choices made by pregnant women and parents regarding their hesitation or decision not to vaccinate their child or children, to determine the factors that influence this decision-making and to give a voice to vaccine-hesitant parents. Additionally, this thesis sought to explore when vaccine-hesitant parents and pregnant women make immunisation decisions, to discover from whom vaccine-hesitant parents and pregnant women obtain the bulk of their immunisation information and education, to explore the factors that influence vaccine choices, and to gain an understanding of the experiences of vaccine-hesitant parents and pregnant women.

Methods

This research consisted of three predominantly qualitative elements and data sources combined in the same study, underpinned by Durkheim's deviance theory, and informed by an ethnographic and netnographic methodology. Netnography is an extension of the ethnographic studies, however, it is not interchangeable. Data collection included an exploratory online survey, in-depth semi-structured interviews and a netnographic study of the discourses on a purpose-designed social media platform. The studies were undertaken to obtain a deeper understanding of the decision-making underpinning vaccine hesitancy and to give a voice to vaccine-hesitant parents and pregnant women.

Main findings

The main findings of this thesis include the negative impact of vaccine safety concerns on vaccine uptake. Additionally, vaccine-hesitant parents reported feeling socially isolated, marginalised,

bullied and pushed to the fringe of society. The online environment, specifically social media, subjected vaccine-hesitant parents to cyberbullying and false narratives (See Glossary), which had a negative impact on vaccine decision-making. Most importantly, this research identified the critical timing for healthcare professionals to provide accurate and timely immunisation information that was reliable, thereby potentially preventing the need for seeking information from less reliable spaces.

Conclusion

The problem of vaccine hesitancy was investigated using three elements in the one research project, each designed to address the research objectives in the most appropriate way and provide triangulation of the results. The findings of this research make a significant and original contribution to knowledge about the sociocultural influences on vaccine-hesitant parents. The use of multiple methodologies explored this problem from differing perspectives, and by adopting netnography as methodology investigated the problem in a novel way. Similarly, the use of deviance as the theoretical underpinning for this research provided a unique perspective on vaccine hesitancy. The implications of these findings are multifactorial but include the need for improved undergraduate immunisation education in nursing, midwifery and medicine. The significance of this research is that it provides a unique understanding of vaccine hesitancy with the potential to improve vaccine confidence among parents and pregnant women.

Declaration

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Susan E. Smith

Date 14th April 2023

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I wish to acknowledge the support received from Flinders University, and the Research Training program provided by the Australian Government. I would also like to acknowledge and thank Healthy Development Adelaide and Channel Seven for supporting me academically and financially throughout my candidature. I am most indebted to the parents and pregnant women who shared their experiences as well as their willingness to participate in this study. Without their consent and openness, this research would not have been possible. I have learnt so much from you and despite our beliefs being diametrically opposed, I value your thoughts and admire your convictions. I also hope that in some small way, this research will improve the way the world views you and above all else, the way that healthcare providers respond to you.

I would also like to thank my PhD colleagues for coming on this journey with me. Your emotional and practical support has been amazing and will not be forgotten. I would also like to mention my

furry research assistants, Tilly and Maggie, who sat with me constantly whilst I worked on this thesis. I promise there will be more walks soon. I would also like to thank my close friends who have been wonderful companions over the years and have taken on extra entertaining whilst I was otherwise occupied. I look forward to travelling with you now that this and the pandemic-related social-distancing restrictions are done. Thank you all.

Finally, I acknowledge professional editor, Rosemary Purcell, who provided copyediting and proofreading services according to the guidelines laid out in the university-endorsed national *Guidelines for Editing Research Theses.*

Dedication

This thesis is dedicated to my beautiful son Timothy William Smith, who passed away on the 27th of August 2022. He was a beloved son, husband, father, brother, favourite uncle, friend and “kid whisperer” who could turn any day into a party. He was also an amazing nurse and work colleague, admired and missed by the staff at Calvary Adelaide anaesthetics department, and was dedicated to the safe and holistic care of all. I would also like to dedicate this thesis to my six beautiful grandchildren who are the hope for the future.

My precious son and my six beautiful grandchildren.

Preface: Researchers reflexivity and positionality

> You must learn to use your life experience in your intellectual work: continually to examine and interpret it. In this sense craftsmanship is the centre of yourself and you are personally involved in every intellectual product upon which you work. To say that you can 'have experience', means, for one thing, that your past plays into and affects your present, and that it defines your capacity for future experience. As a social scientist, you have to control this rather elaborate interplay, to capture what you experience and sort it out; only in this way can you hope to use it to guide and test your reflection, and in the process shape yourself as an intellectual craftsman [sic]. (Wright Mills, 2000, p. 196)

When I began a PhD in February 2020, the choice of topic was not initially clear to me, although my passion for immunisation underpinned the decision-making. A suggestion from my primary supervisor for a suitable topic resulted in a period of reflection on my life influences and experiences. The topic choice, combined with the need to critically analyse the influences on their research, including under what conditions it was written, focused the need for self-awareness.

When I am asked why I chose this topic for my research, the "why now" is often not a consideration. It is often assumed that the study of vaccine hesitancy evolved in response to the COVID 19 pandemic. The reality is that this project began long before the arrival of COVID-19 in Australia. It could be argued that this project began when my brother acquired poliomyelitis when I was two years old. Since then, my knowledge and beliefs have developed subject to various life influences. Immunisation has become both a career choice and a passion for me. However, when deciding on a PhD project, vaccine hesitancy was far from my first choice of topic. Reflexivity is central to ethnographic and netnographic research; it has been argued that it is not just a problem to be managed. It can also be a productive force that drives a deep desire to improve understanding and to make a difference. To ensure reflexivity, and to position the author of this thesis, the following paragraphs, some of which were written as part of a research journal provide a background to my life experiences, influences and biases.

> *My passion for immunisation began as a small child as I watched my older brother suffer from the debilitating effects of poliomyelitis. The impact of this disease on both him and my parents was immense, although at the time I could not have understood this. Some of my earliest memories are of a neighbourhood child, recently weaned off the need for an iron lung, and my brother in splints squatting around an early model Astor television watching cartoons in our loungeroom. I did not fully grasp the significance of this at the time as I was*

only an infant. However, time and life experience provided knowledge and insight into both the nature of the disease and its impact on families. We have learnt subsequently that this disease is not merely a mild childhood illness but a life-threatening, whole-of-life condition with post-polio syndrome once again affecting the lives and wellbeing of those who suffered as children. Sometime later, as a 12-year-old, I became the primary carer for my mother and was required to administer injections day and night when she was unwell. Learning this skill at a young age provided me with the knowledge and experience to become a passionate immunisation advocate and provider later in life.

Nursing became an obvious career choice, and midwifery and maternal child health seemed like the best fit for me. Unsurprisingly, my passion for immunisation led me to a long career in childhood immunisation provision and promotion. During this time, I encountered many vaccine-hesitant parents, but was never fully able to address their concerns or as a result, meet their needs. These experiences have shown me that both undergraduate and postgraduate education in communicating with vaccine-hesitant parents is at the best suboptimal and at the worst non-existent.

One case that influenced me as both a healthcare professional and as a parent involved a woman and her three beautiful pre-teen girls. This extract from my research journal discusses an episode where I felt my skills as a healthcare professionals were lacking.

The woman had been a vaccine refuser in the early years of the girls' lives and when she presented at the immunisation clinic, only the oldest child had received any vaccines at all. She requested that I bring all the girls up to date with all vaccines. This was a stressful situation for the both the family and for me as the immuniser, as all girls required regular visits with multiple injections on each occasion. The mother never shared what had influenced either her decision to refuse vaccines or her subsequent decision to immunise her girls, and on reflection this was a missed opportunity to gain an understanding and insight into her decision-making process.

I realised from this and similar experiences that I held a different perspective to the people who became the focus of this investigation. My life experiences differ, and my opinions are grounded in science. As a mother of three adult children and a grandmother of six beautiful grandchildren, who are all fully immunised and protected against vaccine preventable diseases, there can be no better choice than to protect children by immunising them against vaccine preventable diseases. This statement alone indicates a degree of bias towards immunisation that is not entirely unexpected

in a registered nurse from a white middle-class upbringing. Combined with my experiences of childhood diseases, it is not entirely unreasonable or unexpected. However, through acknowledging this bias and recognising that my childhood experiences are likely to be unusual, an open and accepting approach can be taken to participants with differing life experiences.

Not all people feel confidence in immunisation and, like 50% of the population, I have experienced some anxiety with the introduction of new vaccines, but predominantly from a vaccine provider's point of view. There is always a degree of concern when administering a new vaccine and reactions, whilst rare, are by no means unheard of. However, I would be less than truthful if I did not admit to a degree of anxiety about the side effects of the new COVID-19 vaccines (AstraZeneca) with its history of clotting disorders and on occasions, death. Whilst as an immuniser, I know these events are rare, I hope I can now understand and relate to vaccine-hesitant parents on some level. This extract from my research journal discussed my frustration at being unable to communicate with vaccine-hesitant parents.

> *On reflection, my greatest disappointment as an immunisation provider was being unable to effectively communicate with vaccine-hesitant parents and as a result, children were left unprotected and vulnerable, and in some cases therapeutic relationships were strained. The therapeutic relationship between healthcare provider and client is a vitally important one if both the mother and child are to receive timely and appropriate health care. It was this feeling of inadequacy and inability to communicate effectively with vaccine-hesitant parents that ultimately focused my studies in this area.*

Throughout this research journey I experienced moments when I began to doubt my beliefs. The beliefs of the participants were strong and whilst mostly based on misinformation there were times when I wondered if in fact, I was the one who was too trusting. Below is an example of this from my research journal.

> *Several of the interview participants have expressed such genuine fear about the contents of vaccines and the inefficiency of the scientific processes that I am beginning to have doubts. Am I the one who has it wrong? Many of the participant are highly educated and all are informed and articulate. Their knowledge is different to mine and their beliefs are strong.*

Throughout this research process I was surprised at my ability to actively listen and respond kindly to the conspiracy theories and misinformation that the participants so obviously accepted as fact. I believe that through the process of reflexivity, I have gained the ability to listen without judgement and or frustration, a skill which as a healthcare professional would have been valuable. Through reflexivity I have gained the ability to reflect an emic view by enabling the voices of vaccine-hesitant parents and pregnant women whilst also adopting an etic view that adopts an outsider viewpoint (Madison, 2005).

At the beginning of this PhD journey, I spent a great deal of time in reflection, both on my career as an immuniser and my life experiences in general. Throughout this process it became clear that my life experiences may have conspired to create biases that could impact the quality of this research. However, despite these influences, or perhaps because of them, I hope that through researcher reflexivity this research was undertaken with an open mind, and a sincere desire to gain a deeper understanding of vaccine hesitancy, with a view to improving immunisation uptake in two at-risk groups, pregnant women and children, and to make a difference.

Chapter 1- Background

> While the vaccine discovery was progressive, the joy I felt at the prospect before me of being the instrument destined to take away from the world one of its greatest calamities [smallpox], blended with the fond hope of enjoying independence and domestic peace and happiness, was often so excessive that, in pursuing my favourite subject among the meadows, I have sometimes found myself in a kind of reverie. Edward Jenner (n.d.)

Chapter 1 introduces this thesis and acts as a background to the research. It highlights the conditions under which this research was conducted, specifically during the COVID-19 pandemic. This chapter introduces the aim, research question and research objectives as well as providing an outline of the purpose and significance of the study. Throughout this thesis, terms are frequently used such as vaccines, vaccine hesitancy, vaccine decision-making, herd immunity, vaccine side effects and adverse events. These are explained in the Glossary. This chapter also provides an overview of the thesis.

Immunisation is an important and cost-effective health initiative and in Australia, the federal government provides free access to vaccines for Medicare Card holders (Department of Health, 2018). This includes children, adolescents, pregnant women, adults and seniors, as well as Aboriginal people and people with medical conditions which puts them at risk of acquiring certain diseases (Department of Health and Aged Care, 2023b). These vaccines are offered across Australia, with some additional vaccines offered at a state and territory level. The aim of immunisation programs is to limit the impact of vaccine preventable diseases which vary according to the specific needs of the population. For example, Aboriginal people have a higher disease burden than non-Aboriginal people and additional vaccines are recommended to provide greater protection (Department of Health and Aged Care, 2023b). For this reason, vaccines offered vary between states and territories and immunisation schedules change regularly to meet the changing needs of the population. The current National Immunisation schedule as well as links to the state specific schedules are included at Appendix 19. Whilst immunisation is one of the most cost-effective ways of preventing disease, vaccine hesitancy remains a problem (WHO, 2019d).

Vaccine hesitancy is a growing problem in middle-to high-income countries and was listed in the top 10 threats to global health by the World Health Organisation (WHO) in 2019 (WHO, 2019b, 2019d). Both pregnant women and children are affected by vaccine hesitancy, and these at-risk

groups were the primary focus of this research along with the influences on vaccine decision-making. Additionally, burgeoning national and international research indicate increasing evidence of vaccine hesitancy in Australia as well as considerable animosity towards this minority group (Wiley et al., 2021). This research explored the decision-making of vaccine-hesitant pregnant women and parents to gain a deep understanding of the emotions surrounding it and the influences upon it. Some parents struggle to decide between the dangers of vaccine preventable diseases and the risks associated with vaccines (Ward et al., 2017). Others are influenced by conspiracy theories or misinformation gained through social media and other influences (Bradshaw et al., 2021). However, some parents are certain that the risks associated with vaccines are too great and experience no hesitancy in their decision-making (Helps et al., 2019). This research describes some of the issues at play in vaccine decision-making and provides recommendations to improve outcomes for children and pregnant women.

Conducting research during a global pandemic, in this case SARS-CoV–2 or Corona Virus (COVID-19) has the capacity to affect the overall outcome (Omary et al., 2020). The COVID-19 pandemic has acted as a significant backdrop to this research, and by its nature, has emphasised its importance. However, whilst an understandable influence on this research, it is by no means the prime focus of this thesis. Rather, it could be described as a backdrop to the research and an unavoidable accompaniment to it. The state-imposed restrictions of social distancing and recommendations to work from home where possible, as well as the recommendations to use personal protective equipment (PPE), affected not only the supervision of this project by restricting face-to-face access to the supervisory team, but also the methods of data collection (Government of South Australia, 2020). In any primarily qualitative study, data collection relies upon the gathering of not only rich data in the form of the spoken word, but also facial expressions, body language and other nuanced communication (Bossers et al., 2021). Being restricted to online data collection or via telephone or teleconference, meant this important data could not be collected and subsequently was lost to the project.

Anxiety regarding COVID-19 and the subsequent vaccines, became apparent during the progress of this research (Peteet, 2020). Whilst several vaccines were registered for use in Australia, significant anxiety about the speed of production and potential side effects have resulted in increased vaccine anxiety in the wider population (Cornwall, 2020). This vaccine hesitancy has the potential to result in vaccine hesitancy with potentially fatal results. The chances of eliminating the COVID-19 virus depends upon a strong well-supported vaccine campaign (Anderson et al.,

2020). With many refusing to be immunised, the long-term eradication of this virus is in doubt (Kaufman, Tuckerman, et al., 2022). This situation, combined with the presence of multiple strains of the COVID-19 virus, specifically the Delta and Omicron strains, have not only emphasised the importance of this project but has also acted to make this research even more significant.

A version of this chapter was published in the *International Journal of Nursing Studies Advances* and the first page is included at Appendix 5 under Creative Commons agreement. Whilst changes were made for the purpose of publication, there is still direct overlap in content and phrasing. Co-author agreements are attached at Appendix 16.

1.1 Background

Immunisation is universally accepted as one of the most significant health initiatives in recent times (WHO, 2019a). Childhood immunisation alone is responsible for saving 2–3 million lives each year. However, more deaths could be avoided with greater immunisation coverage (WHO, 2019b). Globally, one in five children are inadequately immunised, and an estimated 1.5 million children still die each year of vaccine preventable diseases (WHO, 2019b). Immunisation is a simple, safe and effective way of reducing disease burden throughout populations by inducing an immune response in individuals as well as protecting communities indirectly through herd immunity (WHO, 2019b). Immunisation levels in low- to middle-income countries are improving and in 2018, 86% of children worldwide had received at least three doses of diphtheria, tetanus and bordetella pertussis (DTP), and 129 countries had achieved 90% coverage. However, there are many more diseases that achieved far less coverage and many countries with poor vaccine uptake (WHO, 2019b, 2019d).

Vaccine hesitancy has recently overtaken vaccine access as the primary barrier to immunisation uptake (Larson, 2018b). Vaccine hesitancy is of such concern that it was included in the top 10 threats to global health by the WHO (WHO, 2019d). Whilst Australia has a high level of vaccine confidence, there are pockets of resistance to immunisation. These pockets of resistance are often gathered in semi-rural areas and have the capacity to affect herd immunity, resulting in the resurgence of diseases (Department of health, 2020b). The USA Department of Health and Human Services (2019) describes vaccine confidence as the trust parents have in vaccines, the providers who administer the vaccines, and the policies and processes that lead to vaccine development. Vaccine confidence is dynamic and volatile, and affected by the viral spread of misinformation (Larson, 2018a, 2018b).

In Australia, childhood immunisation is provided free for all children, adolescents and some adults. The National Immunisation Program includes schedules for both non-Indigenous and Indigenous children as well as medically at-risk children, adolescents and adults, and is attached at Appendix 19. In addition, an annual influenza schedule is also in place and is provided free to children, adolescents, healthcare workers and people aged over 65 years (Department of Health, 2020c). The success of this and previous programs are represented in the current statistics, which stand above 91% coverage for all Australian states and territories However, the immunisation rates vary significantly according to the age of the child, the state, and the Primary Health Network in which they live. However, at age five years the overall national childhood coverage stands at 95.09% (Department of Health, 2020c).

Whilst childhood immunisation against vaccine preventable diseases is high, in Australia there is significant variance and serious uptake shortfall in some communities. For example, the immunisation rate across Australia in 2020 varied between a very high uptake rate of 99.02% in the Perth North Primary Health Network area of Western Australia, to as low as 91.22% in the North Coast area of New South Wales (AIHW, 2018b). Additionally, areas with a high coverage overall, can conceal pockets of under-immunisation and vaccine hesitancy. This can result in outbreaks of vaccine preventable diseases such as measles. An example is the outbreak that occurred in Western Sydney in 2012 resulting in 168 identified cases of measles (Dawson & Apte, 2015). This shortfall in uptake in some Primary Health Network areas suggests a degree of vaccine hesitancy.

Evidence also suggests that antenatal immunisation uptake is suboptimal in Australia, despite its proven safety and efficacy in protecting women and their unborn and newborn infants (Marshall et al., 2016). This is also the case in developing countries like Kenya where maternal vaccine rates are partly due to gender disparities (Dutta et al., 2021). Antenatal vaccines include influenza and DTP, which have been shown to provide protection against severe morbidity and mortality (Blanchard-Rohner & Siegrist, 2011; Reuman et al., 1987; Zaman et al., 2008). More recently, the COVID-19 vaccine has been included in the schedule for pregnant women (Australian Government Department of Health, 2021a). In 2021 the Comirnaty/Pfizer COVID-19 vaccine was added to the schedule for pregnant women (Australian Government Department of Health, 2021b). These vaccines are recommended to all pregnant women in Australia; however, there is currently no reliable method of measuring the uptake of these vaccines in pregnancy. A recent South Australian study reported uptake at 51.7% for influenza and 80.5% for DTP in one large metropolitan birthing

hospital (Mohammed et al., 2020). However, no accurate statistics are currently available for the COVID-19 vaccine in pregnancy.

The current COVID-19 pandemic was announced by the Director-General of the WHO in March 2020 (WHO, 2020a). COVID-19 is a potentially life-threatening virus caused by infection with a novel β-coronavirus. Symptoms of the virus vary from respiratory disease to gastrointestinal and other symptoms (Hajifathalian et al., 2020). The severity of this disease varies, and deaths attributed to this pandemic stand at 6.6 million at the time of publication (World Health Organisation, 2022). This virus can have systemic effects including lung function, hypertension, kidney and liver disease, as well as long-term implications. Knowledge of the full effects of the virus on pregnant women and infants is still developing (Arthurs et al., 2021). However, early indications suggest that there is an increased risk of stillbirth, in-utero death, maternal death and poorer maternal mental health (Ceulemans et al., 2021; Delahoy et al., 2020; Juan et al., 2020; Wenling, 2020). There are also reports of newborn infants with COVID-19 symptoms ranging from minimal to severe respiratory distress, thrombocytopenia and impaired liver function (Zhu et al., 2020). Whilst it is currently unknown whether vertical transmission can take place in utero, maternal COVID-19 infection has been shown to have serious sequelae on neonatal health (Delahoy et al., 2020).

Historically, deaths of pregnant women from influenza have been high in pandemics. Up to 50% of women of childbearing age who have died in pandemics were either pregnant or immediately postpartum (McHugh et al., 2017). Prior to the COVID-19 pandemic, deaths of pregnant women in pandemics had been between 20 and 27% of the affected population (Jamieson et al., 2009; Rasmussen et al., 2008). The H1N1 influenza pandemic of 2009 greatly affected pregnant women in New South Wales, resulting in 28% of admissions to Intensive Care Units being pregnant women (Carlson et al., 2010). Similarly, the COVID-19 pandemic has adversely affected pregnant women and infants (Khoury et al., 2020). A study by Gonçalves et al. (2021) reports that pregnant women had a higher risk of needing intensive care support and requiring intubation. Additionally, this study concluded that pregnancy and the postpartum period was an important risk factor for acquiring severe COVID-19.

The Comirnaty/Pfizer COVID-19 vaccine is a recent addition to the Australian schedule for pregnant women; however, resistance to the vaccine and issues of access has resulted in hospital admissions and deaths of pregnant women (Taylor, 2021) . A recent newspaper report suggested

increased numbers of hospital admissions in Melbourne with the outbreak of the Delta variant of COVID-19 in September 2021 (Taylor, 2021). The poor uptake of antenatal vaccines combined with the increased risks associated with acquiring vaccine preventable diseases in pregnancy and infancy has the potential to adversely affect outcomes of women and children (Adegbola et al., 2012).

A recent Australian study suggests that vaccine decision-making begins in pregnancy (Danchin et al., 2018). This study reports that nearly half of Australian parents had some concerns about childhood vaccinations. Additionally, parents who refuse or delay immunisations were more likely to have considered their options prenatally (Danchin et al., 2018). This study reports that parents want simple balanced information on all vaccines, including antenatal, postnatal and childhood immunisations, and during pregnancy, and the primary source of this information is midwives (66%) and general practitioners (58%) (Danchin et al., 2018). However, not all parents are convinced of the safety of vaccines or the severity of vaccine preventable diseases and some choose to delay or refuse routine immunisations. This presents a challenge to both herd immunity as well as maternal and child outcomes. Additionally, health professionals have reported feeling challenged by encounters with vaccine-hesitant parents and few believe they are adequately prepared for these discussions (Berry et al., 2018; Berry et al., 2017; Smith et al., 2021).

Infants are at increased risk of disease due to their immature immune system (Adegbola et al., 2012; Yuen & Tarrant, 2014; Zaman et al., 2008). Herd immunity is a form of community protection provided to members of a population where most individuals are immunised. This form of immunity is particularly useful to some members of a population who are either too young (infants under six weeks of age) or medically unable to be immunised (Fine et al., 2011; Logan et al., 2018). However, its effectiveness depends on several factors, including the transmissibility of the pathogen, the effectiveness of the vaccine in use and the percentage of the population who are immunised. By achieving high levels of immunisation in a population, outbreaks of disease can be reduced, thereby offering protection to the entire community. There is evidence to suggest that when vaccine hesitancy clusters occur in communities, there is the potential to rapidly undermine vaccine coverage and herd immunity (WHO, 2019c). These clusters have contributed to outbreaks of disease previously considered eradicated or controlled (Rossen et al., 2019). Other factors that influence the effectiveness of herd immunity include the closeness of the population and the frequency of contacts. School-aged children for example, are in frequent and close contact

with others, and may benefit less from herd immunity (Fine et al., 2011; Kawano & Kakehashi, 2015).

Historically, the Australian Government has strongly promoted childhood immunisation and provides funding for 17 diseases (AIHW, 2018a). Parents are now required to demonstrate that their child is fully immunised to access family assistance payments (Berry et al., 2017). The rate of conscientious objectors was recorded between 1999 and 2015 and rose to 2% of the population in 2013 (Beard et al., 2016). More recently, the introduction of initiatives such as No Jab No Pay and No Jab No Play, which is designed to ensure that all children are fully immunised, as well as the removal of the "conscientious objection" caveat in 2015, has increased the uptake of immunisation to its current level (Berry et al., 2017). However, a small but concerning proportion of parents continue to be vaccine hesitant (Beard et al., 2016). There is also evidence to suggest that immunisation decision-making induces considerable anxiety in some parents, with recent studies reporting that up to 40% of parents experience some degree of vaccine hesitancy (Costa-Pinto et al., 2018; Danchin et al., 2018).

Vaccine hesitancy is not a new phenomenon, with evidence of hesitancy in existence as early as 1885 in Montreal where a physician known as Dr Alexander Ross circulated pamphlets urging the people to reconsider immunisation against smallpox (Gavi-The Vaccine Alliance, 2021). However, the source of this information is also surrounded by some controversy having been linked to the pharmaceutical industry. In modern times, a significant factor in vaccine hesitancy is thought to be the viral spread of misinformation by a small but active anti-vaccination movement that uses the internet and social media, amongst other media, to influence vaccine-hesitant parents (*n* = 296) (Larson, 2018b; Rossen et al., 2019). Misinformation such as the report of neurological damage to children caused by the DTP vaccine in the mid-1970s and allegation of autism resulting from the measles-mumps-rubella vaccine (MMR) in the 1990s has caused significant parental anxiety (College of Physicians, 2020). Despite the study by Andrew Wakefield being retracted by Lancet and Wakefield being deregistered, it continues to be cited as a credible source by anti-vaccination activists (Kmietowicz, 2010). Articles such as this provide credibility for vaccine hesitancy and have contributed to vaccine hesitancy overtaking vaccine access as the primary barrier to immunisation (Jimenez et al., 2018).

1.2 Aim of the study

The aim of this study is to explore the values, beliefs and choices made by pregnant women and parents regarding their decision not to vaccinate their child or children, to determine the factors that influence this decision-making and to give a voice to vaccine-hesitant parents.

1.3 Significance of the study

This research will gain a new perspective on the impact of vaccine hesitancy on the uptake of immunisation. The significance of this study is based on four key aspects:

(i) Vaccine hesitancy was listed in the top 10 threats to global health by the WHO in 2019.

(ii) There is a need to gain a better understanding of vaccine hesitancy, and the decision-making that impacts it, to enable healthcare professionals to better meet the needs of vaccine-hesitant parents.

(iii) There is a need to increase vaccine uptake to ensure greater herd immunity and to provide better protection to the very young and those who are medically unable to be immunised.

(iv) Most significantly, there is a need to improve vaccine confidence and uptake to better protect the population in general. This research is particularly relevant as it has taken place during a global pandemic, specifically COVID-19.

1.3.1 World Health Organisation top 10 threats to global health

Vaccine hesitancy is a high priority area for research and was listed in the top 10 threats to global health by the (WHO, 2019d). One in five children continue to be under or unvaccinated and 1.5 million die each year from vaccine preventable diseases. Vaccine hesitancy has overtaken vaccine access as the main reason for under-immunisation and continues to be an important area for research as it is neither understood nor appropriately managed by healthcare professionals (Smith et al., 2021).

1.3.2 Vaccine decision-making

Vaccine hesitancy is placing increasing pressure on immunisation programs and understanding the drivers behind vaccine hesitancy and the decision-making process may assist healthcare

professionals to better meet the needs of vaccine-hesitant parents. Healthcare professionals have reported finding conversations with vaccine-hesitant parents challenging and feeling inadequately prepared for their role (Smith et al., 2021). Through gaining a deeper understanding of vaccine hesitancy and the decision-making that impacts it, healthcare professionals may be better able to meet the needs of vaccine-hesitant parents. This could be achieved through more focused education of healthcare professionals (Kaufman, Bagot, et al., 2022; Leask et al., 2012).

1.3.3 Herd immunity

There is a need to increase vaccine uptake to ensure greater herd immunity to provide protection to the very young and those who are medically unable to be immunised (Logan et al., 2018). Herd immunity is a vitally important factor in immunisation. Whilst immunisation provides direct protection to the population who can be immunised, herd immunity has the potential to protect those who are either too young or medically unable to be immunised (Logan et al., 2018). By maintaining high levels of immunisation in a population, herd immunity can prevent outbreaks of preventable disease by means of indirect protection (Logan et al., 2018). Studies have shown that between 1 and 6% of parents who choose to immunise their children consider the benefit to others as an important motivator to immunise (Logan et al., 2018). Increasing herd immunity is a significant motivation for improving vaccine uptake and gaining a deeper understanding of the choices parents make may assist to achieve this.

1.3.4 Australian literature

There is a large amount of literature, both global and Australian, which addresses vaccine hesitancy. However, vaccine decision-making is less well investigated (Helps et al., 2019; WHO, 2019a). Few papers were located that investigated the process whereby pregnant women and parents become vaccine hesitant or gained an understanding of the influences upon the decision-making process (Danchin et al., 2018). Additionally, papers that do exist focus on the influence of CAM (complementary and alternative medicine) or the impact of recent legislation (Attwell, Ward, et al., 2018). Other studies focused on categorising parents into groups, measuring the impact of becoming a parent on vaccine choices or assessed the prevalence of vaccine hesitancy (Rossen et al., 2019). Whilst all are important factors and excellent papers, few studies were located that fully investigated the decision-making process or the influences upon pregnant women and parents of

young children. This research will provide vital information and aims to close the knowledge gap and add to the existing body of knowledge.

1.3.5 Immunisation uptake

Most significantly, there is a need to improve vaccine confidence and uptake to better protect the population in general. This research is particularly relevant as it took place during a global pandemic, specifically COVID-19, where the threat to under-immunised pregnant women and children is high. The impact of immunisation on outcomes in pregnancy and childhood is well documented (Arthurs et al., 2021; Taylor, 2021; Zaman et al., 2008). During a global pandemic, any vaccine hesitancy among pregnant women and parents of young children has the potential to seriously impact the health, wellbeing, and overall outcomes of these two at-risk groups. Vaccine hesitancy is an issue of concern and considered a high priority by the (WHO, 2019d). The persistence of vaccine hesitancy also has the capacity to adversely affect the uptake of a COVID-19 vaccine, which may lead to vaccine hesitancy with potentially fatal consequences.

1.4 COVID-19 pandemic

In late 2019 a novel β coronavirus (SARS-CoV-2) was identified in the city of Wuhan in Hubei province China, which had infected humans, causing severe acute respiratory symptoms. This virus was originally believed to have originated in bats; however, subsequent research confirmed that the Huanan seafood market was the pandemic epicentre with unknown live wildlife the likely source of the virus (Worobey et al., 2022). The SARS-CoV-2 virus is the seventh coronavirus to infect humans, and is by far the most contagious (Liu et al., 2020). By January 2020, the β coronavirus, now named COVID-19, had spread throughout China, and begun its spread across the world. The WHO declared the COVID-19 outbreak a "Public Health Emergency of International Concern" on January 30, 2020, and the epidemic was escalated to a pandemic on March 11, 2020 (WHO, 2020b). This highly contagious virus became the fifth pandemic since the 1918 Spanish flu (Liu et al., 2020).

Person-to-person contact, surface and airborne transmission combined with international air travel, resulted in rapid global spread of this virus (Dubey et al., 2021). The spread of the virus was accompanied by a surge of social, economic, political and epidemiological chaos across the globe. In response to the pandemic, Australia, and many other countries, enforced a variety of public health measures to limit transmission of the virus. These included restrictions on international

travel, closure of non-essential businesses, and the lock-down of state borders among other measures. Further restrictions included the implementation of strict public health infection control measures to prevent further spread, such as social distancing, the requirement to wear face masks, and quarantining of infected areas and people (Sturman et al., 2021).

By the end of 2020 there were over 28,408 cases of COVID-19 in Australia with 909 deaths (Department of Health, 2020a). On the 31st of March 2021, there were over 128,776,839 cases of coronavirus and 2,814,822 deaths, globally (Johns Hopkins University (JHU), n.d.). This number continued to increase with 331 million cases reported and 5.55 million deaths as at 31st December 2021, and on submission of this thesis stands at 15,508 (World Health Organisation, 2022). However, despite the devastation caused by this pandemic, a small proportion of people continued to propose conspiracy theories to explain the situation. A conspiracy theory is a belief that some secret but influential organisation is responsible for an event or phenomena (Merrium Webster.com Dictionary, n.d.). Whilst it was initially unknown how many people do not believe the disease exists or how many would refuse a vaccine, recent research has shown that approximately 20% were unwilling to receive the vaccine (Kaufman, Tuckerman, et al., 2022). This is of significance to this study given the nature of vaccine hesitancy and the impact of conducting research during a global pandemic. For this reason, a further objective of this study was to gain an understanding of the vaccine decisions people made surrounding a COVID-19 vaccine.

COVID-19 vaccines first became available in late 2020 and, despite the limited time from development to release to the public, have played a major part in the fight against the disease (Department of Health and Aged Care, 2023a). However, vaccine hesitancy continues to influence vaccine uptake with concerns about the speed of vaccine development, media reports of side effects and other concerns. Provider and community confidence in a COVID-19 vaccine is vital to achieve adequate vaccine uptake. Additionally, evidence suggests that high levels of immunisation with a highly effective COVID-19 vaccine will be required to prevent outbreaks. In Australia, as in many other countries such as the United States of America (USA), vaccine hesitancy continues to have an impact on COVID-19 vaccine uptake. Despite targeted COVID-19 immunisation programs, uptake of the vaccines was reported as suboptimal in 2021 in Australia and other countries (Blyth et al., 2021; Geana et al., 2021; Tuckerman et al., 2021). An Australian study reported that only around 59% of older Australians would get a COVID-19 vaccine, however a more recent statistics suggest that this figure is much higher (Department of Health and Aged Care, 2023a; Edwards et

al., 2021; Kaufman, Bagot, et al., 2022). Similarly, an American study reported vaccine hesitancy of around 30–40% (Geana et al., 2021).

1.5 Research question

The research question is: What factors influence pregnant women and parents to become vaccine hesitant?

1.6 Research objectives

Beyond providing answers to the research question, the following objectives were also explored in this study:

i) To explore when vaccine-hesitant parents and pregnant women make immunisation decisions.
ii) To discover from whom vaccine-hesitant parents and pregnant women obtain the bulk of their immunisation information and education.
iii) To explore the factors that influence the vaccine choices that vaccine-hesitant parents and pregnant women make.
iv) To gain an understanding of the experiences of vaccine-hesitant pregnant women and parents.

1.7 Thesis summary

This thesis consists of nine chapters and a preface. The preface provides a description of “why this topic” and “why now” as well as researcher reflexivity and positionality. Chapter 1 acts as an introduction to the thesis and provides a background to the research problem. This chapter provided the aim, research question and research objectives as well as an outline of the purpose and significance of this study. Additionally, this chapter discussed the circumstances in which this research was undertaken, during a global pandemic, as well as the impact this pandemic had on the completion of the project. Vaccine hesitancy has been shown to be a global problem that has the potential to undermine vaccine coverage and impact the health and wellbeing of pregnant women and children.

Chapter 2 presents the results of an integrative literature review that was undertaken to explore and investigate the global literature on the decision-making of vaccine-hesitant parents and pregnant women. The results of 31 studies were thematically analysed to gain a deeper

understanding of the decision-making process, the influences at play and to gain an understanding about why some parents are vaccine hesitant.

Chapter 3 presents the theoretical underpinning for this research and discusses the role of Émile Durkheim's deviance theory in society's reaction to vaccine-hesitant parents. This chapter also explores the concept of moral panic and positive deviance in contemporary healthcare and acts as an introduction to the methodology.

Chapter 4 explores both the methodologies and methods used throughout this research and Chapters 5–7 present the findings of data collected in the exploratory survey, in-depth interviews and the netnographic study respectively. This research used a combination of ethnography and netnography as methodology, and survey, interview and netnographic studies as method. Chapter 5 presents the results of the online survey, which used a combination of open- and closed-ended questions to gather data from vaccine-hesitant parents. Chapter 6 presents the results of the interview phase of this research, revealing insights into the life and experiences of vaccine-hesitant parents and pregnant women. Chapter 7 presents the results of the netnographic phase of this research, which used a purpose-designed Facebook page to gather data and to experience the online world of vaccine-hesitant parents.

Chapter 8 presents and critically examines the key findings from this research with consideration given to Durkheim's deviance theory as well as the cultural aspects of the vaccine-hesitant cohort, develops meaning and understanding and compares this body of research with current literature. Chapter 9 presents the conclusions from this research. This chapter makes meaning of the data by developing deeper understanding and further exploring the implications of their experiences. Additionally, this chapter makes recommendations based on this body of research.

1.8 Chapter summary

Chapter 1 introduced the thesis and provided background to the study. It highlighted the conditions under which this research was conducted. Most importantly, this chapter described the impact of vaccine hesitancy with a specific focus on the effects of vaccine hesitancy on pregnant women and children and provided an overview of the thesis. The next chapter presents the results of the integrated literature review that drove the study design.

Chapter 2 Integrative Literature Review

> Research is to see what everybody else has seen and think what nobody else has thought.
>
> Albert Szent-Gyorgyi (1957)

Chapter 1 introduced the thesis, whilst this chapter presents a review of the current literature in the form of an integrative literature review. The review explored and analysed the literature that was available online, describing the vaccine decision-making of pregnant women and parents of preschool-aged children, contributed to the identification of a gap in the literature and the subsequent development of the research question and objectives. This chapter describes the review process, the critical appraisal of selected literature and finally the data synthesis. The initial review took place in June 2020, and a subsequent literature search incorporated new literature into the thesis in June 2022. The initial review presented the results of 31 independent studies that were thematically analysed using the framework of Coughlan (2017) (Appendix 1). The secondary search, which utilised the same search protocols, took place in June 2022, and acted as a supplement to the initial search. Prior to submission, further recent publications which were undertaken concurrently with this research, were also cited. The data synthesis of both reviews is presented in this chapter.

The aim of the integrative review was to explore and critically analyse the literature describing vaccine decision-making of pregnant women and parents of preschool-aged children. The initial results of 31 independent studies were synthesised to gain a deeper understanding of the decision-making process, the influences at play and to improve our knowledge about why some become vaccine hesitant. A modified version of this review was published in the *International Journal of Nursing Studies Advances* and is included in Appendix 8 under Creative Commons License (Smith et al., 2022). Co-author agreements and individual contributions are at Appendix 16.

2.1 Integrative review framework

The framework developed by Coughlan (2017) was adopted to guide this integrative literature review. Additionally, the use of the Critical Appraisal Skills Programme (CASP) appraisal tools has ensured the inclusion of quality articles (CASP, 2018; Whittemore & Knafl, 2005) (Appendices 2–4). The review also includes a variety of recent articles, using a combination of qualitative and quantitative approaches, chosen from 13 countries, which gave the review a broad focus. The

purpose of an integrative review is to provide clarity on health issues and to gain a new perspective of a topic (Coughlan, 2017). Integrative reviews have been described as the broadest type of review, which allows for the inclusion of experimental, non-experimental, conceptual, theoretical and grey literature, thereby allowing a deeper understanding of the research problem (Whittemore & Knafl, 2005). This form of literature review supports evidence-based practice for nursing, midwifery and healthcare professionals in general, and has the capacity to re-frame thinking on a specific phenomenon of interest. By using explicit and systematic methods and incorporating multiple sources of evidence, rigour is enhanced, resulting in a greater understanding of the research problem with the potential to develop a knowledge base, identify a research gap and inform practice, policy and research (Whittemore & Knafl, 2005, pp. 546-553).

2.2 Search strategy

Upon definition of the research problem, a comprehensive search strategy was designed in collaboration between the researcher and a research librarian. The aim was to locate primary source articles with the inclusion/exclusion criteria identified in Table 2.1, presented in Section 2.6. To achieve a comprehensive search strategy both a purposive approach and a comprehensive search of multiple databases were used. The following databases were identified as most appropriate as they are important sources of medical, nursing and immunisation literature: Medline, CINAHL, ProQuest, Scopus and Web of Science, and these databases were searched throughout June 2020. Articles located included primary research studies, including qualitative, quantitative and mixed methods studies, which addressed the issue of vaccine decision-making, vaccine hesitancy, vaccine refusal or schedule manipulation published between 2015 and 2020. English language was also an inclusion criterion. Reference lists were searched to ensure all pertinent papers were included. Studies with a focus on vaccines given in later childhood, such as human papillomavirus (HPV) were excluded, as were papers focusing on vaccines such as oral polio vaccine, Japanese encephalitis, or other vaccines not included in the Australian schedule (Department of Health, 2020c). This was done to ensure that the integrative review presented both Australian and international research, as well as a focus on pregnancy and early childhood vaccine decision-making. The database searches were conducted electronically, and results were uploaded to Covidence for initial title and abstract screening by the primary researcher (Veritas health Innovation, n.d.). Covidence is an online tool that streamlines the systematic review process. It achieves this by providing ease of access to both title and abstract and full text articles

to multiple users. In this way the article selection process is visible to all users and the decisions made in the inclusion/exclusion process collaborative (Veritas health Innovation, n.d.).

2.3 Key search terms

The following key words and phrases formed the basis of the literature search: # Vaccine refusal # vaccine hesitancy # anti-vaccination movement # anti-vax # pregnant women # mother # father # parent. These keywords were systematically searched across all selected databases. The search of the selected databases identified a total of 827 articles, including 12 articles located by a manual search of reference lists.

2.4 Inclusion/exclusion criteria

The inclusion/exclusion criteria applied to the literature search is presented in Table 2.1.

Table 2.1 Inclusion and exclusion criteria

Inclusion Criteria	Exclusion Criteria
Primary research studies and literature reviews	Non-primary research papers
English language	Languages other than English
2015–2020	Studies conducted prior to 2015
Addressed the issue of decision-making, vaccine hesitancy, schedule manipulation or refusal in pregnancy or early childhood	Studies with a focus outside pregnancy or early childhood immunisation, specifically (HPV) human papillomavirus or other vaccines provided to school-aged children or adults
	Papers with a focus on oral polio or other vaccines not included in the Australian Immunisation Schedule

The inclusion criteria (Table 2.1) were decided upon based on the most recent and appropriate articles available. For this reason, the papers included were all primary research articles or literature reviews published in 2015 or after. Only English language papers were considered as the primary researcher only speaks English; however, no papers were located that were published in languages other than English. A further selection criterion was that the articles addressed the issue of vaccine decision-making, schedule manipulation or vaccine refusal in pregnancy or early childhood. Other exclusion criteria were adopted by this integrative review, which whilst taking a

global view, needed to maintain relevance to the Australian population. For this reason, papers with a focus on vaccines not included in the Australian Immunisation Schedule, were not included. This criterion eliminated articles with a focus on oral polio and Japanese encephalitis. Additionally, papers with a focus on HPV vaccine were excluded from this study as this vaccine is given in late childhood. This vaccine is also relatively new and continues to attract significant negative responses. Thus, it was excluded from the review so as not to skew the results.

2.5 Search outcomes

The initial search of the selected databases and Google Scholar yielded a total of 827 papers, which were exported to Endnote X9 (The EndNote Team, 2013). This search was repeated in 2022 to ensure that all relevant literature were included (see Section 2.10). EndNote is a commercial reference management software package that is used to manage bibliographies and references (The EndNote Team, 2013). In this instance EndNote X9 was used as a storage system for the selected articles prior to uploading to Covidence, the software of choice for bibliographic management (The EndNote Team, 2013; Veritas health Innovation, n.d.).

Subsequently, 161 duplicates were removed. A total of 673 potentially relevant papers were accepted for title and abstract screening and these were uploaded to Covidence in June 2020. Six further duplicates were then removed resulting in a total of 667 papers selected for title and abstract screening. After initial title and abstract screening by two researchers (SS and NS), 556 papers were deemed to be irrelevant, and 111 papers were subject to full screening. Papers were deemed irrelevant if the study did not meet the inclusion/exclusion criteria. Most exclusions were because vaccine decision-making, schedule manipulation or vaccine refusal were not addressed in the research. A further 80 papers were excluded after full text screening, subject to the search criteria. Consensus was sought between both reviewers and in the event of disagreement, the non-reviewing author's vote resolved the issue. Finally, 31 papers were selected for inclusion in the review. These papers were checked by all authors for relevance. The decision to include or exclude data was informed by both the research question and the selection criteria and maintained a strong focus on the decision-making processes of pregnant women and parents regarding their decision to not vaccinate their children. The 1 (Preferred reporting items for systematic reviews and meta-analyses) flow chart, a visual representation of the search outcomes, can be located at Figure 2.1.

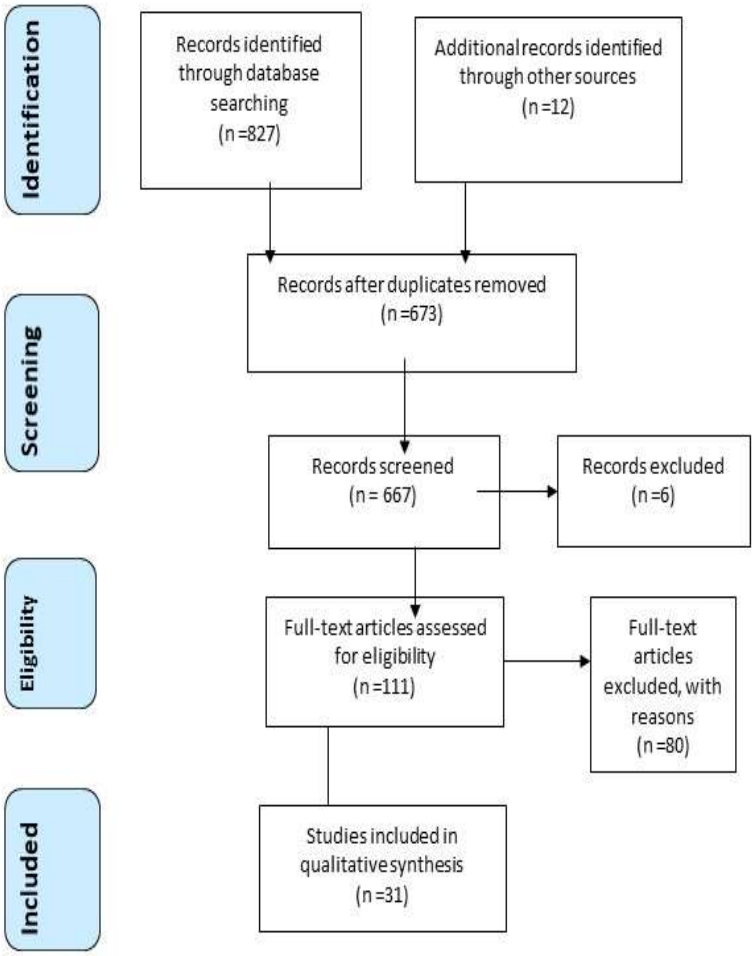


Figure 2.1 PRISMA flow chart

2.6 Quality appraisal

Evaluating the quality of the primary source articles is a complex process and in an integrative review this may incorporate grey literature, historical papers and other sources not usually included in a systematic review. However, in this case only primary source articles and reviews were located, and all were included in the review. Each article was evaluated for methodological integrity using the CASP(Critical appraisal skills programme) tool appropriate to the study design (CASP, 2018). The CASP tools were designed as a method of appraising different types of evidence (CASP, 2018). The included studies scored 8 or higher on the appropriate CASP tool in terms of planning, data collection, analysis and reporting, thereby proving their value for inclusion in the integrative review. Appendix 1 provides a summary of the literature review and Appendices 2 and 3 itemise the studies according to CASP.

2.7 Data extraction and thematic analysis

This review included 31 primary source articles, three systematic reviews and three content analyses of Facebook parenting blogs and testimonials of the movie *Vaxxed*, published between 2015 and 2020. No grey literature was included in this paper. Data synthesis was achieved using descriptive coding to further organise data and to systematically compare the findings of all studies. These codes were discussed among all authors and the final themes were agreed upon.

2.8 Study settings

Thirty-one papers from 13 predominantly high-income countries were included in this integrative review. Articles were also included from medium- and low-income countries such as Malaysia and Indonesia, to provide a thorough understanding of global vaccine hesitancy from both the developed and developing world. Nine papers were included with an Australian focus including five qualitative papers and three quantitative papers. Seven papers from the USA were included: three content analyses, one systematic review, two qualitative and one quantitative paper. Three papers from Canada were selected: two qualitative papers and one quantitative paper. Three papers from Italy were also included: two systematic reviews and one quantitative article. Papers were also reviewed from Israel, the United Kingdom (UK), Germany, France, the Netherlands, Malaysia, Indonesia, Croatia and Finland. The design features and main findings of the included papers were then separated into subject groups including pregnant women, both pregnant women and parents, and parents alone. These results are listed at Appendices 1–4.

2.9 Follow-up search

The literature search was repeated in June 2022 to ensure all relevant literature was included in this research. In the subsequent search a further 805 studies were located. This is possibly due to an increased interest in the topic, arguably because of the COVID-19 pandemic influence. Papers were deemed irrelevant if the study did not meet the inclusion/exclusion criteria. Most exclusions were because vaccine decision-making, schedule manipulation or vaccine refusal was not addressed in the research. The inclusion and exclusion criteria used in the initial search were adopted with two subsequent additions. The decision was taken to exclude papers with a COVID-19 focus as well as review papers that reported on many of the articles previously included in the integrative review. This decision was driven by the primary aim and objectives of this research, which focused on the influences on decision-making in vaccine-hesitant parents and pregnant

women. Whilst the COVID-19 pandemic is a significant backdrop and an unavoidable accompaniment to this research, it is not the primary focus.

The new inclusion and exclusion criteria are listed below in Table 2.2. A total of 102 duplicates were removed and 703 articles were subject to title and abstract screening. A total of 523 were removed as not relevant. Most of the 523 articles removed were COVID-19 specific studies and were removed according to the new exclusion criteria. A total of 108 studies were subject to full text and quality appraisal and assessed for eligibility. Twelve new studies were subsequently incorporated into this thesis to ensure currency and accuracy of the data. Table 2.3 includes the additional papers, methodology and country of origin.

Table 2.2 Secondary search inclusion/exclusion criteria

Inclusion Criteria	**Exclusion Criteria**
Primary research studies	Non-primary research papers
English Language	Languages other than English
2015 – current	Studies conducted prior to 2015
Addressed the issue of decision-making, vaccine hesitancy, schedule manipulation or refusal in pregnancy or early childhood	Studies with a focus outside pregnancy or early childhood immunisation, specifically human papillomavirus or other vaccine provided to school-aged children or adults
	Papers with a focus on oral polio or other vaccines not included in the Australian Immunisation Schedule
	Papers with a primary focus on COVID-19 decision-making
	Literature review papers that focused on studies previously assessed and/or included in the integrative review

Table 2.3 Articles included from second search.

Source Country	Quantitative	Qualitative
Australia	(Attwell et al., 2020; Gilmartin et al., 2020)	(Court et al., 2021; Thomas et al., 2022; Wiley et al., 2021; Wiley et al., 2020)
Canada		(Mossey et al., 2019)
France	(Charron et al., 2020)	
India		(Nair et al., 2021)
Saudi Arabia	(Al-Regaiey et al., 2022)	
Turkey		(Celik et al., 2021)
USA		(Reich, 2020)

2.10 Thematic analysis

Thematic analysis is a widely used method of identifying, classifying and interpreting data (Clarke & Braun, 2018). For this chapter, thematic analysis was used to organise and provide a rich description of the data that was obtained from the 31 research articles included in this integrative review. Presented later in this thesis, thematic analysis was also used to organise, describe and interpret data obtained from interviews with vaccine-hesitant parents. Prior to conducting the thematic analysis, the decision was taken to undertake an inductive analysis as opposed to a theoretical thematic analysis. Inductive analyses code data without trying to fit the data into a pre-existing pattern, whereas theoretical coding is driven by a desire to make the data fit a theoretical or analytical interest (Braun & Clarke, 2006). This decision was taken based on a strong desire to accurately reflect the content of the data, as opposed to fitting it into a pre-existing coding framework. Therefore, this thematic analysis was driven by the data and attempted to faithfully reproduce the intentions of each author in line with the analytical framework of Braun and Clarke (2006). It is also important to note that researchers cannot code or analyse data in an epistemological vacuum, therefore for reflexivity the reader is referred to the introductory chapter to position the author within this thesis.

The framework used in this thematic analysis incorporates six phases as defined by Braun and Clark (2006). These phases include familiarising yourself with the data. This means repeated reading of the articles and note taking, which will subsequently lead to coding. In the case of recorded data this includes transcription. The next step is to generate initial codes. In this case the analysis was purely data driven. The codes were then focused into themes. Visual representations of this process are shown at Figure 2.2. The themes were then reviewed. Some were reworked at this point; others were recoded. The themes were subsequently defined and named. In this integrative review four main themes were identified. The final step is report production (Braun & Clarke, 2006).

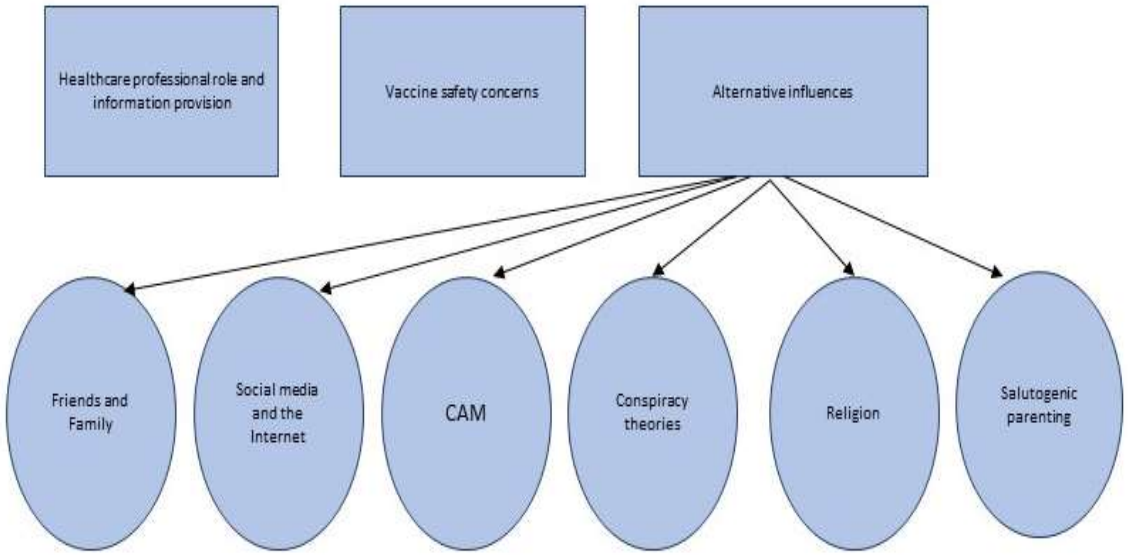


Figure 2.1 Thematic analysis map

Prior to the identification of themes, 9 initial codes were generated including the role of healthcare professionals, allied health practitioners, the internet, religion, social media, and friends and family. Additionally, a significant impact on vaccine refusal was conspiracy theories and the risk-versus-benefits debate of vaccines. It also became evident that parents placed a great deal of protective importance on the employment of salutogenic practices, and this became the final code. Salutogenic parenting is an approach focusing on health and wellbeing rather than on factors that cause disease (pathogenesis) and is concerned with the relationship between health, stress and coping. It often includes long-term breastfeeding, organic eating, avoiding toxins, reduced screen time, exercise and fresh air. These 9 codes were then reviewed, and themes were defined and named. By following the guidelines of Braun and Clarke (2006) three main themes were identified: 1) healthcare professionals – role and information provision 2) vaccine safety

concerns and 3) alternative influences including, friends and family, CAM; social media; conspiracy theories; religious beliefs and salutogenic parenting.

2.11 Healthcare professionals – role and information seeking.

This theme shows the important role of healthcare professionals as the primary immunisation information source to pregnant women and parents of young children. The role of the healthcare professional in the promotion and provision of immunisation is well established (Facciola et al., 2019; Kennedy, 2020). The recommendation of a healthcare professional is a predictor for immunisation uptake (Van Buynder et al., 2019). This concept is supported by many studies in this review (Ben Natan et al., 2017; Costa-Pinto et al., 2018; Danchin et al., 2018; Giambi et al., 2018; Lama et al., 2020). Reports of between 62% and 67% of parents in the UK and USA respectively, chose to accept vaccines because of the information they received from a healthcare professional (Clarke, Sirota, et al., 2019; Lama et al., 2020). A recent Italian study, a country with high levels of vaccine safety scepticism, reported that healthcare professionals play a key role in informing parents about vaccines (Giambi et al., 2018). In terms of timing for this information, it was reported in the literature that pregnancy was an optimal time to provide childhood vaccination education (Betsch et al., 2018; Clarke, Sirota, et al., 2019; Danchin et al., 2018). Evidence suggests that parents and pregnant women placed trust in healthcare professionals to provide timely accurate and in-depth immunisation information (Krishnaswamy et al., 2018). However, this information was not always provided (Costa-Pinto et al., 2018; Peretti-Watel et al., 2019; Romijnders et al., 2019; Rozbroj et al., 2020; Saada et al., 2015). Parents reported having their information needs ignored by healthcare providers and their concerns dismissed (Ben Natan et al., 2017; Helps et al., 2019). The importance of healthcare professionals in information provision and education of pregnant women and parents of young children was well supported in the literature.

Similarly, a lack of trust in healthcare professionals was also identified in several studies. (Diaz Crescitelli et al., 2020; Duchsherer et al., 2020; Gidengil et al., 2019; Rumetta et al., 2020). A common criticism of healthcare professionals was their perceived dismissal of concerns, thereby, undermining trust in both the healthcare professional and the healthcare system in general (Helps et al., 2019; Rumetta et al., 2020). Parents also felt that healthcare professionals were influenced by vaccine manufacturers and therefore could not be trusted (Rumetta et al., 2020). Studies conducted in the USA reported the use of many alternative vaccine schedules, some with manipulated timing and others with vaccines excluded completely (Saada et al., 2015). One study

identified five alternative schedules in use across one health-maintenance organisation in Northern California. This accepted use of alternative schedules, whilst potentially designed to meet the needs of vaccine-hesitant parents, may also be interpreted as justification of vaccine hesitancy and ultimately lead to loss of confidence in immunisation (Wang, 2015). The lack of trust in healthcare professionals and their perceived dismissal of vaccine concerns demonstrates a need for focused education in dealing with vaccine-hesitant parents.

Healthcare professionals have reported finding conversations with vaccine-hesitant parents challenging and have also reported feeling inadequately prepared to promote and provide antenatal immunisation (Berry et al., 2017; Facciola et al., 2019; Glanz et al., 2013; Leask et al., 2012; Smith et al., 2021). There is evidence to suggest a need for additional education of healthcare professionals to promote effective communication with vaccine-hesitant parents. Several studies in this review report that healthcare professionals may need additional training to assist parents with vaccine decision-making (Giambi et al., 2018; Helps et al., 2019; Rosso et al., 2020; Rumetta et al., 2020). This review demonstrates a knowledge gap in the ability of healthcare professionals to effectively communicate with vaccine-hesitant parents. Additionally, recent research has demonstrated that parents need to be involved in the decision-making process (Berry et al., 2018)

Vaccine decision-making has been reported to begin in pregnancy. Several studies report that parents want more information on the risks and benefits of both pregnancy and childhood immunisation during pregnancy (Ben Natan et al., 2017; Betsch et al., 2018; Danchin et al., 2018). Additionally, one large German study (*n* = 1299) reported that the vaccination experiences during the first year of a child's life and the information acquired in the first year of life, are crucial to long-term vaccine decision-making (Betsch et al., 2018). Several studies describe the important role of midwives in antenatal immunisation education and provision (Danchin et al., 2018; Rosso et al., 2020). Pregnancy is a time when effective communication of the risks and benefits of immunisation are vital. This is also an opportunity to demonstrate understanding of the concerns of vaccine-hesitant parents whilst addressing each concern calmly and respectfully, thereby building the therapeutic relationship.

Parental lack of awareness about vaccination has been cited as a reason for vaccine hesitancy (Dube et al., 2018). This is supported by an Italian review of the literature, which claims that it is the main reason for vaccine hesitancy (Rosso et al., 2020). Additionally, a UK study reported that

perceived susceptibility to, and severity of, a disease combined with lower levels of vaccine confidence, were associated with spending more time searching for information which may result in misinformation and adversely affect decision-making (Clarke, Sirota, et al., 2019). Low levels of vaccine confidence combined with decreased concerns about vaccine preventable diseases are issues best addressed by a well-informed healthcare professional; however, this cannot happen when therapeutic relationships are affected by poor education and communication.

In summary, this review has demonstrated the important role of healthcare professionals and their need to receive education on the beliefs, decision-making processes and influences on vaccine-hesitant parents. Evidence suggests that lack of knowledge and sensitivity of healthcare professionals has seriously, and in some cases irretrievably, affected the therapeutic relationship (Costa-Pinto et al., 2018; Saada et al., 2015). Once this has broken down, parents seek information elsewhere. Meeting the needs of vaccine-hesitant parents can be both confronting and challenging for healthcare professionals, and with inadequate education it is unsurprising that parents report unsatisfactory therapeutic relationships. Immunisation education must become a core focus in all healthcare-related undergraduate degrees to fully inform healthcare professionals prior to entry to the workforce (Attwell, Wiley, et al., 2018; Smith et al., 2021).

2.11.1 Vaccine safety concerns

This theme highlights the influence of vaccine safety concerns on vaccine decision-making in the target population. Evidence exists that high immunisation levels do not always imply high levels of vaccine confidence (Mendel-Van Alstyne et al., 2018; Wang, 2015). Many factors influence the decision to accept or reject vaccines and concerns about vaccine safety, which are present in both high- and middle-income countries, is one of the most cited reason for vaccine refusal (Kennedy, 2020; Kumar et al., 2016). These include the perceived safety of the vaccine, and the perceived low risks associated with diseases (Ben Natan et al., 2017; Clarke, Sirota, et al., 2019; Diaz Crescitelli et al., 2020; Gidengil et al., 2019). A meta-analysis conducted in Italy reports that parents often focused more substantially on the risks associated with vaccines. This is supported by studies in many other countries including Germany, Canada and the Netherlands, amongst others (Betsch et al., 2018; Costa-Pinto et al., 2018; Danchin et al., 2018; Jenkins & Moreno, 2020; Romijnders et al., 2019). Vaccine concerns are also cited in an Australian study of high-income parents, which reported low-risk perception of vaccine preventable diseases and a disproportionately high perceived risk associated with vaccines (Helps et al., 2019; Swaney &

Burns, 2019; Tustin et al., 2018). Additionally, there was a higher level of vaccine concern associated with new vaccines such as pneumococcal and rota-virus vaccines reported (Gidengil et al., 2019). A recent study into hepatitis B (Hep B) vaccine uptake in newborn infants in Australia also cites safety concerns as one of the reasons for refusing this vaccine (Gilmartin et al., 2020). Safety concerns associated with vaccines have been shown to adversely affect vaccine choices. This, associated with the perception of low risk associated with vaccine preventable diseases, makes this a major theme in the review.

Vaccine safety concerns are one of the main reasons that parents become hesitant about immunisation. It is an area of global concern in high-, medium- and low-income countries (Celik et al., 2021; Rumetta et al., 2020; Syiroj et al., 2019). Additionally, high immunisation levels do not always imply high levels of vaccine confidence. There is evidence that nearly half of Australian parents have some concerns about vaccines yet still ultimately immunise their children (Danchin et al., 2018). A recent Australian study by Ward et al. (2017) argues that vaccine-hesitant parents consider conducting risk assessments as being their personal responsibility, and questioning vaccines is part of that.

The vaccine decision-making process is complex and often takes place over time and for many parents continues throughout their child's early years. Multiple factors influence the decision to accept or reject vaccines on perceived safety concerns, including false reports of autism links in the case of measles. Despite significant evidence to debunk this concern, fears persist (Dawson & Apte, 2015). Educating parents about the risks associated with vaccine preventable diseases can also present a challenge to healthcare professionals with both minimal immunisation education and limited experience of the diseases themselves. In comparison, the evidence presented by anti-vaccination groups are both emotive and convincing.

2.11.2 Alternative influences on vaccine decision-making

This theme introduces some of the alternative influences on vaccine decision-making of parents and pregnant women that were identified in the literature. These include the role of friends and family, CAM practitioners, social media and the internet, conspiracy theories, religion and salutogenic parenting.

2.11.3 Friends and family

Conflicting information exists about the influence of friends and family members on vaccine choices (Costa-Pinto et al., 2018; Peretti-Watel et al., 2019; Rumetta et al., 2020). One UK study reports that 68% of parents reported their input did not influence their vaccine choices (Clarke, Sirota, et al., 2019). Additionally, the important influence of family and friends was reported in a French study (Peretti-Watel et al., 2019). However, other studies report the important influence of peers and significant others on vaccination attitudes and decision-making. One Malaysian-based study linked the lack of trust in healthcare professionals with increasing reliance on significant others to assist their decision-making (Peretti-Watel et al., 2019; Rumetta et al., 2020). Despite conflicting evidence about the influence of friends and family across the globe, it is apparent that when healthcare professionals are not considered a valued and trusted source of information, other sources take on a more significant and valued role. This role is dependent upon what is most accessible and valued in each country. Additionally, the quality of information obtained from friends and family may vary according to the knowledge, education and biases of the source. Whilst this was presented as a minor theme, it has the potential to influence vaccine decision-making, and was included for that reason.

2.11.4 Complementary and alternative medicine

CAM consists of a diverse group of practitioners that includes chiropractic, naturopathy and other modalities not usually offered by traditional medicine. Alternative influences on vaccine decision-making were identified as a theme in this review. This theme included three minor themes. The influence of CAM practitioners on vaccine decision-making was a minor theme in the studies included in this review. The use of CAM amongst pregnant women and parents of preschool children was evident in recent studies. However, whilst CAM is associated with vaccine decision-making, evidence suggests that it is not the cause of vaccine hesitancy (Attwell, Ward, et al., 2018; Costa-Pinto et al., 2018; Dube, Gagnon, Ouakki, et al., 2016; Helps et al., 2019; Swaney & Burns, 2019; Syiroj et al., 2019). Parents included in the study by Attwell and colleagues (2018), reported using CAM as a method of supporting health and wellbeing in children and was identified as complementary to salutogenic parenting. Whilst included as a minor theme in this review, in an Australian setting the use of CAM was not considered to have an adverse influence on vaccine uptake. This theme was included for completeness and to demonstrate that previously held beliefs about the negative effects of CAM appear to be no longer relevant.

2.11.5 Social media and the internet

Social media has become a trusted source of information; however, exposure has been associated with an increased risk of parents rejecting immunisation. Studies included in this review confirm that parents who elected to delay immunisation, often did so because of influences within their social media network (Costa-Pinto et al., 2018; Dube et al., 2016; Duchsherer et al., 2020; Tustin et al., 2018). An Italian study reports social media was a factor that influenced vaccine-related decisions (Diaz Crescitelli et al., 2020). Similarly, two Canadian studies report higher odds of perceiving vaccines as unsafe after searching social media sites (Tustin et al., 2018). In France, considerable mistrust of healthcare professionals and official vaccine information, has been associated with an increased reliance on unofficial internet sites, thereby increasing exposure to inaccurate information (Diaz Crescitelli et al., 2020). This finding was supported by a content analysis of social media groups conducted in the USA. Vaccine-hesitant parents who posted on these pages cited their main sources of information as social media, anti-vaccination documentaries and anti-vaccination websites (Bradshaw et al., 2021; Jenkins & Moreno, 2020). A recent study from the USA also found that social media had a greater influence on mothers with higher social privilege. In contrast, a study by Giambi (2018) conducted in Italy, reports that only 33% of participants considered the internet to be reliable and, therefore, it was not generally considered to be a reliable source of immunisation information. However, in the UK, it has been reported that information obtained by parents from the internet generally supported vaccination on most occasions (57%), therefore it was not considered to have a negative impact on vaccine decision-making (Clarke et al., 2019). A recent study from Turkey found no significant association between social media exposure and vaccine hesitancy (Al-Regaiey et al., 2022).

Overall, it is evident that social media is influential in most parental vaccine decision-making, and in most cases, this influence heightens parental vaccine hesitancy. In a digital world, little can be done to discourage parents seeking information online; however, more should be done to ensure the accuracy of data in this space. This is of particular importance during the COVID-19 pandemic, when anxiety associated with vaccines appears to be increasing.

2.11.6 Conspiracy theories

Conspiracy theories are a minor theme in this review, although they are a global phenomenon with the potential to have severe effects on vaccine hesitancy. Conspiracy theories have existed

for as long as immunisation, and studies included in this review have reported multiple belief systems and demonstrated significant distrust in both vaccine content and pharmaceutical companies in general (Diaz Crescitelli et al., 2020; Dube, Gagnon, Ouakki, et al., 2016; Dube et al., 2018; Gidengil et al., 2019; Helps et al., 2019; Koski & Holst, 2017; Rossen et al., 2019; Rumetta et al., 2020; Swaney & Burns, 2019). Belief in debunked studies persist throughout the literature, as do inaccurate theories on vaccine content (Helps et al., 2019). Several studies report that parents want more information on vaccine content and greater clarity on the rationale and timing of vaccine schedules (Rozbroj et al., 2020; Tomljenovic et al., 2020). However, conspiracy theories and false narratives may still prevail despite the provision of this information. (See Glossary for description and examples of these terms) (; Merrium-Webster.com Dictionary, n.d.; Merrium Webster.com Dictionary, n.d.). This is arguably because a conspiracy theory is not based on fact per se but is based on a strongly held belief by a small group of people who have difficulty accepting scientifically proven facts (Pertwee et al., 2022). In an Australian setting, conspiracy theories abound and conspiracy theorists, though a minority of the population, are extremely vocal (Pertwee et al., 2022). Whilst this is considered a minor theme it is one with a wide impact across the globe.

2.11.7 Religion

Religion was identified as a minor theme in this review, however, whilst it may still be a reason for vaccine refusal in Australia, religious beliefs ceased to be a valid reason for vaccine exemption in Australia in 2015; however, they continue to be a reason for vaccine refusal in several other countries including the USA, Malaysia and Indonesia (Rumetta et al., 2020; Syiroj et al., 2019). Religious beliefs are cited as a reason for vaccine refusal in Malaysia and Indonesia; however, this is largely based on misinformation. Studies by Rumetta (2020) and Syiroj (2019) cite beliefs by the Islamic community that vaccines contain pork products, which are haram or forbidden. Whilst vaccines have been approved by Islamic scholars and the WHO, and been given the certification of halal status, mistrust persists. This combined with a deep belief in natural immunity, concerns of safety and distrust in vaccines account for a large percentage of vaccine hesitancy in predominantly Islamic countries. Additionally, 18 states in the USA still allow non-medical reasons, including religious and philosophical reasons for vaccine exemptions (Olive et al., 2018).

2.11.8 Salutogenic parenting

Salutogenic parenting is a theme identified across many studies. Salutogenic parenting is an approach to parenting that focuses on health and wellbeing rather than on factors that cause disease (pathogenesis) (Salutogenesis (n.d) In Merriam-Webster's Collegiate Dictionary, 1999). Whilst there is no agreed definition of this parenting style, it is generally thought to be concerned with the relationship between health, stress and coping and often includes long-term breastfeeding, organic eating, avoiding toxins, reduced screen time, exercise and fresh air (Ward et al., 2017). Many studies report parents using this form of parenting were encouraged by a desire for natural living, healthy eating and reduced exposure to chemicals (Bradshaw et al., 2021; Danchin et al., 2018; Diaz Crescitelli et al., 2020; Dube, Gagnon, Ouakki, et al., 2016; Gidengil et al., 2019; Helps et al., 2018; Helps et al., 2019; Koski & Holst, 2017; Peretti-Watel et al., 2019; Rumetta et al., 2020; Swaney & Burns, 2019). However, not all vaccine-hesitant parents meet the alternative lifestyle stereotype (Wiley et al., 2020). Several studies state that the use of salutogenic parenting was complementary to living; however, it was also associated with a significant fear of vaccine content, vaccine side effects and a disregard for the risks associated with vaccine preventable diseases (Swaney & Burns, 2019). This is also reported in the study by Koski and Holst (2017), which reveals that some parents did not fear disease but felt that something would be gained from travelling through it, that it would make the child healthier as a result. Whilst there is evidence to suggest that salutogenic parenting coexists with vaccine hesitancy, there is no indication to suggest that it is a direct cause of it. This is a major theme identified in this review and one that may have a negative impact on vaccine uptake.

Alternative influences vary across countries with friends, family and religion having a greater impact on parents and pregnant women from Malaysia and Indonesia, whereas the influence of CAM was cited mainly in the Australian and Canadian literature and may be more specific to high-income countries. However, conspiracy theories and the impact of social media and the internet, seem to be almost universal and a subsequent influence on vaccine decision-making. Hence the impact should not be underestimated. Similarly, the adoption of salutogenic practices are cited in many studies across a broad geographical location and whilst on face value may appear a harmless practice, were also associated with significant fear of vaccines.

2.12 Discussion

This review explored and synthesised the literature describing vaccine decision-making in pregnancy and early childhood. The findings reveal that healthcare professionals have a critical role to play in information provision, education and promotion of immunisation. Whilst healthcare professionals are an important source of information, they often find conversations with vaccine-hesitant parents challenging, and healthcare professionals have reported feeling inadequately prepared to promote and provide antenatal and childhood immunisation (Clarke, Sirota, et al., 2019; Facciola et al., 2019; Kennedy, 2020; Lama et al., 2020; Smith et al., 2021; Van Buynder et al., 2019). This review has also revealed that education and support in vaccine decision-making is best provided in pregnancy, and midwives are well placed to provide this (Danchin et al., 2018; Rosso et al., 2020). However, recent studies have identified a knowledge deficit in this area (Berry et al., 2017; Facciola et al., 2019; Giambi et al., 2018; Glanz et al., 2013; Krishnaswamy et al., 2018; Leask et al., 2012; Smith et al., 2021). Midwives are both under-educated and under-prepared for the role and have identified a need for further education at an undergraduate level (Attwell, Wiley, et al., 2018). Analysis of the literature suggests that the information seeking behaviour of pregnant women and parents is a significant factor in vaccine hesitancy.

Vaccine safety is one of the main concerns cited by parents who are hesitant about immunisation. It is a global area of concern in both high- and medium-income countries (Kennedy, 2020; Kumar et al., 2016). Additionally, high immunisation levels do not always imply high levels of vaccine confidence (Mendel-Van Alstyne et al., 2018). There is evidence that nearly half of Australian parents have some concerns about vaccines (Danchin et al., 2018). A recent Australian study argues that vaccine-hesitant parents consider conducting risk assessments as being their personal responsibility, and question vaccines a part of that (Ward et al., 2018). This integrative review of the literature has identified vaccine safety concerns as an influence on vaccine decision-making in Europe, the USA, Canada, Israel, Australia and other countries. In combination with a low-risk perception of vaccine preventable diseases, vaccine safety concerns have been identified as having a strong influence on vaccine decision-making. A further factor identified with the potential to influence both social and public health is social media. Whilst some studies investigated social media and identified that it may impact vaccine decision-making, this was not fully investigated. Therefore, the role of social media was identified as a gap in the literature (Bradshaw, 2020; Jenkins, 2020).

Addressing the perception of relative risk is difficult when therapeutic relationships with vaccine-hesitant parents are strained (Omer et al., 2019). Additionally, it could be argued that few parents have firsthand experience of vaccine preventable diseases. Polio is unknown in most developed countries, as are diphtheria and tetanus (WHO, 2021). Measles has resurfaced recently in both Australia and Samoa largely due to pockets of low immunisation uptake (Ninan & Evans, 2019). Despite the potential morbidity and mortality associated with measles, it is often considered by parents to be a minor childhood illness (Craig, et al., 2020; Swaney & Burns, 2019). Multiple factors influence the decision to accept or reject vaccines based on perceived safety concerns, including false reports of autism links in the case of measles. Despite significant evidence to debunk this concern, fears persist (Dawson & Apte, 2015). Literature included in this review demonstrate that a lack of knowledge about vaccine preventable diseases exists among some vaccine-hesitant parents. This knowledge deficit suggests inadequate information and education provision about the risks and benefits of vaccines, a role ideally undertaken by healthcare professionals.

Literature included in this review suggests that alternative influences, such as CAM and religion, have limited influence in an Australian setting (Attwell, Ward, et al., 2018; Rumetta et al., 2020; Syiroj et al., 2019). The CAM group of practitioners have previously been associated with having a negative impact on immunisation uptake (Chow et al., 2017; Wardle et al., 2016). However, there is conflicting evidence about the influence of friends and family internationally. Few studies exist within an Australian setting that have evaluated its impact on vaccine uptake. However, friends and family members remain a significant influence in countries such as Malaysia and Indonesia (Rumetta et al., 2020; Syiroj et al., 2019).

Other factors that continue to influence vaccine decision-making include social media, which has become a trusted source of information for many parents (Clarke, Sirota, et al., 2019). Exposure to this medium has been associated with an increased risk of parents questioning the safety of immunisation (Atkinson et al., 2015). Additionally, social media sites have been the subject of recent research and their role in supporting vaccine hesitancy is becoming evident (Bradshaw et al., 2021; Duchsherer et al., 2020; Jenkins & Moreno, 2020). However, the role of the internet and social media whilst forceful, is not fully understood, and this is an area in need of further research.

Conspiracy theories have existed for almost as long as immunisation and continue to exist in multiple forms (Diaz Crescitelli et al., 2020; Kennedy, 2020; Kumar et al., 2016; Mendel-Van

Alstyne et al., 2018; Rozbroj et al., 2020). Parents who hold strong beliefs influenced by misinformation are some of the most vaccine hesitant. Whilst debunking conspiracy theories is complex, improved healthcare provider education and a consistent approach may assist in addressing this. Australia has adopted a consistent approach by refusing to accept non-medical exemptions to vaccination; however, this is not the case in other countries. Eighteen states in the USA still allow non-medical reasons for exemption, including religious and philosophical reasons for vaccine exemptions (Olive et al., 2018). This is not a consistent approach, nor does it support vaccine confidence.

The desire for a more natural lifestyle, which is often described as salutogenic parenting, has been seen to coexist with vaccine hesitancy. Parents have reported using salutogenic parenting as a means of supporting the immunity of an unimmunised child (Schanfarber, 2015; Ward et al., 2018). This is an area where healthcare professionals are well placed to address concerns, correct misinformation and support decision-making based on the incorrect assumption that living a healthy lifestyle offers protection against vaccine preventable diseases. However, further research is needed to confirm a link between salutogenic parenting and vaccine refusal.

2.13 Implications

This review of the literature has identified factors that have implications for practice, education and research. It has become clear that vaccine hesitancy exists among a sizeable proportion of pregnant women and parents, even in those who elect to immunise. However, vaccine decision-making can be a fraught and ongoing situation. With a significant factor being attributed to lack of knowledge and misinformation, the role of healthcare professionals is clear. However, it has become apparent that a knowledge gap exists that would ideally be met by a healthcare professional. This is an area in need of further research to identify why this shortfall of education is not taking place. This knowledge gap was explored throughout both the online survey and the interview phase, reported in Chapters 5 and 6, with particular emphasis placed on parents' experiences.

There is evidence to suggest that vaccine decision-making begins in pregnancy, and this has been shown to be an ideal time to provide education on both pregnancy and childhood vaccinations. However, studies have revealed that pregnant women and parents of young children can be dissatisfied with their therapeutic relationships and resort to seeking their own information. This dissatisfaction with both the therapeutic relationship and a demonstrated lack of knowledge,

suggests a knowledge deficit amongst healthcare professionals. Further research is required to fully understand this and was explored at length in both the online survey and the interview phase of this research.

A poor therapeutic relationship combined with a high need for information can lead to the acquisition of misinformation, exposure to conspiracy theories and, inevitably, vaccine hesitancy. Social media is thought to be a popular source of immunisation information; however, little is known about its role in vaccine decision-making, and this is an area requiring further research. This aspect of vaccine decision-making was explored at length throughout all phases of this research with a strong focus on the netnographic phase reported in Chapter 7.

Finally, the findings of this review will assist healthcare professionals to recognise the needs of vaccine-hesitant parents. Additionally, this review will inform policymakers and educators of the current state of the literature. This review will raise awareness of the anxiety that vaccine hesitancy induces, including in those who elect to vaccinate, and of the need for education of all healthcare professionals.

2.14 Strengths and limitations

This integrative review has several strengths. These include the use of a framework to guide it (Coughlan, 2017). Additionally, the use of CASP appraisal tools has ensured the inclusion of quality articles (CASP, 2018; Whittemore & Knafl, 2005). The review also includes a variety of recent articles, using a combination of qualitative and quantitative approaches, chosen from 13 countries, giving the review the broadest possible focus. A primary limitation of this review is the nature of vaccine hesitancy itself. It has been described as a context specific phenomenon (WHO, 2022). Each country included in this review has its own immunisation guidelines, policies and legislation to promote vaccine compliance. This means that articles may not be directly comparable because of vastly differing local conditions. However, by incorporating articles from multiple countries, this review has the broadest possible focus on vaccine hesitancy, thereby informing health practice globally.

2.15 Conclusion

This integrative review synthesised data from papers published in 13 countries and included data obtained from qualitative and quantitative studies, systematic reviews and content analysis. The focus of the review was decision-making in vaccine-hesitant pregnant women and parents.

Findings suggest that vaccine decision-making is a complex process that for some continues throughout pregnancy and childhood. The levels of anxiety involved in this process can be high, with parents seeking information from multiple sources including healthcare professionals, the internet, friends and social media. Additionally, studies have reported a degree of dissatisfaction in the attitude and information provided by healthcare professionals in general and whilst the importance of healthcare professionals is recognised in some articles; this is not always reflected in commentary from parents. Concerns also persist about the adverse effects of vaccines, the influences of CAM, religion and salutogenic parenting, which continue to be prevalent in the literature. Finally, this review demonstrates that there are factors that negatively influence vaccine uptake and further research is needed to address these.

Significant gaps in the research have been revealed by this review, which became the focus of this study. There have been few studies that have actively addressed parental vaccine decision-making. Of the 31 studies located in a global search of literature published in the last five years, many had a primary focus other than vaccine decision-making. The gaps in the literature that this research addresses are from whom and when do pregnant women receive the bulk of their immunisation education, when do pregnant women make immunisation decisions and what factors influence their vaccine choices. Through gaining a deeper understanding of vaccine decision-making processes, this research has the potential to improve knowledge, enhance communication and have a positive effect on both education and policymaking.

This chapter presented the results of the integrative review, which explored and analysed the literature describing the vaccine decision-making of pregnant women and parents of preschool children. The results of 31 independent studies were thematically analysed to gain a deeper understanding of the decision-making process, the influences at play, and to gain an understanding of why some parents become vaccine hesitant. The results of this review revealed gaps in the literature as well as enablers and barriers to vaccine uptake, the investigation of which is presented in future chapters and formed the basis of the online survey and the interview questions. Chapter 3 will introduce the theoretical underpinning of this research.

Chapter 3 Theoretical Underpinning

> It is science, and not religion, which has taught men that things are complex and difficult to understand. Émile Durkheim (n.d.).

Chapter 1 introduced the thesis whilst chapter 2 presented the results of the integrative literature review., The purpose of this chapter is to introduce and discuss the theoretical underpinnings of this research and to set the scene for the research methodology which is contained in Chapter 4. Deviance theory was adopted as the theoretical underpinning of this predominantly qualitative inquiry. First conceived in the late 19th century, deviance theory is arguably as relevant today as it was when first published in 1893. This chapter will demonstrate its relevance to vaccine hesitancy in the 21st century.

3.1 Social deviance

Evidence obtained from the integrative literature review presented in Chapter 2, suggests that vaccine-hesitant parents and pregnant women are subject to negative attitudes from the pro-vaccination majority that makes up a large percentage of the population. Additionally, evidence suggests that some parents have also been subject to bullying and disrespect from healthcare professionals (Wang, 2015). Whilst only a small overall proportion of the Australian population are vaccine hesitant, their presence has the potential to impact herd immunity. Additionally, these vaccine-hesitant parents are sometimes impacted by feelings of social difference or deviance. This among other factors, impacts their vaccine decision-making. For this reason, the theoretical underpinning chosen for this research was the theory of social order and deviance, published by Émile Durkheim (1858–1917) in 1893 (Durkheim, 1964; Scott-Jones & Watt, 2010).

Durkheim's work, The Division of Labour in Society, and his later work, Suicide, published in 1893 and 1897 respectively, amongst other seminal works, introduced and expanded on the concept of deviance in society (Durkheim, 1982). These works and others helped to define and establish the field of sociology as an academic discipline, separate from philosophy, psychology and other social sciences (Fenton, 1984; Turner, 2004). In partnership with Max Weber and Karl Marx, Durkheim is commonly cited as one of the founding fathers of sociology and is well known for his work on social regulation in the context of deviance, crime, law and punishment. The development of Durkheim's deviance theory was influenced by both his background and the political circumstances of the time. Durkheim was born into a Jewish family in Épinal, France prior to World

War I. Because of the timing and location of his birth, which took place during a time of war and political turbulence, it has been postulated that Durkheim's works were a response to his own marginalisation. However, this theory has stood the test of time and remains as relevant today as at its inception. Durkheim helped to develop sociology as a formal academic discipline by establishing the department of sociology at the University of Bordeaux in 1895 (Collins et al., 2014). It is Durkheim's deviance theory that forms the theoretical underpinning of this research for several reasons. The literature review presented in Chapter 2 revealed that vaccine-refusing parents experience a degree of social isolation from the pro-vaccine majority. This, combined with the breakdown of some therapeutic relationships, places them in the deviant minority based on their choice to refuse vaccines. Hence, deviance was the most suitable theory to underpin this research.

Deviance has been described as "not a monolithic construct. Rather, it is far more nebulous with fuzzy borders and shifting parameters" (Bryant, 2011, p. 1). Bryant (2011) believes that the concept of deviance depends on the way an individual perceives it, which may vary between time, place and circumstances. What is considered normal in one society may be considered a violation in another. For example, whilst it is normal in some societies to use marijuana, it is not only considered to be deviant, but is also illegal in others (Erickson, 1976) However, deviance has been described as both a relative and ambiguous phenomenon and arguably, an inevitable aspect of all societies (Ben-Yehuda, 2019). According to Durkheim, deviance is a basis for change and innovation in a healthy society, and a way of defining social norms. Additionally, Durkheim believed that without change, society would stagnate, or cease to grow and adapt to changing circumstances (Fenton, 1984).

Some theories of deviance include the anomie-strain theories, and feminist theories (Bryant, 2011). The anomie-strain theory was first introduced by Durkheim in The Division of Labour in Society (Durkheim, 1964) in 1893. In the 1930s, Robert Merton reformulated the work of Durkheim in the seminal paper entitled Social Structure and Anomie (Merton, 1938). This theory replaced the concept of human desires with the influence of culture and socialisation and became one of the most influential contributions to the study of crime and deviance (Bryant, 2011). This theory postulated that human desires were a function of the pressures applied by culture and society and was largely used to support the study of criminology. Considerable developments and enhancements have taken place since Merton conceived his anomie-strain theory and these, arguably, act in part, to explain the perpetual interest in Durkheim's' original work (Bryant, 2011).

Other theories that may be considered relevant to this research include the feminist theories, which were developed from the 1960s to the present day. These theories are described as interdisciplinary theories with women as the central feature of the theorising and retaining a strong focus on the difference of women (Bryant, 2011). The feminist theories include works on liberal feminism, radical feminism, and Marxist feminism, among other areas of interest, all of which have been utilised in the study of deviance (Bryant, 2011; Lorber, 1994; Reed, 1970; Tong, 2009). A common argument of feminist researchers is that all that is considered to be normal, or deviant, is affected by gender (Bryant, 2011). Feminist researchers have studied many gender-related areas including sex, eating disorders, pornography and childbirth; however, drawing a link between feminism and vaccine hesitancy is more problematic. Whilst women and predominantly mothers make many health-related decisions for their children, it could be argued that equally as many men are influential in vaccine decision-making. For this reason, feminist theories were not considered the best fit for this research. However, the proliferation of theories to describe deviance including anomie-strain theory, and the feminist theories all act to ensure the continued relevance of Durkheim's original work.

Durkheim and other early sociologists were interested in the way human society functioned and aimed to discover why some people's behaviour was atypical of societal expectations (Herington & van de Fliert, 2017). Durkheim believed that crime and deviance was, to a degree, a normal function of a healthy society, but that too little or too much could be detrimental to society (Thompson, 2017). Durkheim believed it was vital that the amount of crime and deviance remain relatively stable within a society. He posited that as deviance exists in all healthy societies, it must have a role to play (Durkheim, 1984). This concept becomes clearer when viewed in the context of social change, where stagnation could arguably result in prejudice, domination and subjugation of minority groups. Whilst the concept of deviance is mostly considered to refer to criminality, it could be argued that deviance can be as simple as being left-handed in a predominantly right-handed world (Bowditch, 2017; Thompson, 2017). This concept could arguably be expanded to include being vaccine-hesitant in a pro-vaccine world. In terms of vaccine choices, in Australia approximately 95% of children are immunised, and the vaccine-refusing minority make up a small proportion of the population (5.0%) (Australian Government Department of Health, 2020). According to Durkheim, those who deviate from societal rules are considered deviant (Durkheim, 1964). Hence, it could be interpreted that people who choose not to immunise themselves or their children fall into the category of deviant. Therefore, the social norm in this case is defined by the

statistics. With most Australian parents immunising their children according to government-prescribed schedules, the small minority who challenge this norm fall outside social expectations. Hence, pro-vaccination is the social norm, which according to Durkheim suggests that those who elect not to immunise make up the deviant minority (Thompson, 2017).

Despite Durkheim's theory being published in the 19th century, this seminal work is arguably still relevant in the 21st century (Durkheim, 1984). According to Adler and Adler (2006) deviance "offers unparalleled insight into society particularly in current times". The deviance theories continue to be applied broadly across many fields including criminology, suicide prevention, politics, the military and to a lesser degree, health and nursing (Bristol et al., 2018; Bury, 2017; Dudley-Rowley, 2000; Taylor, 2013). Deviance has been used recently as a theoretical construct to gain an understanding of the role of both the community and the individual in the context of delinquency, and as a method of investigating and promoting the importance of building social capital to support health (Thorlindsson & Bernburg, 2004; Turner, 2003). Social capital has been described by the Organisation for Economic Co-operation and Development (2021) as shared norms or support networks. The application of deviance in the nursing profession has taken place predominantly in the last 20 years and involves the concept of positive deviance in relation to nursing practice, systems and organisational change (Bristol et al., 2018; Gary, 2013; Lindberg & Clancy, 2010; Longhini et al., 2021). Deviance theory has also been used recently to address both heavy alcohol and marijuana use on university campuses (Dvorak et al., 2015; Dvorak et al., 2018). As a result of the perennial nature of deviance theory, Durkheim's work remains influential across many fields, including criminology, and health, and has an important role to play in understanding deviance across societies (Baxter et al., 2016).

According to Alexander and Smith (2005, p. 1), "when an author's work has staying power beyond its immediate context, this being the quality that distinguishes a truly great contribution". Additionally, the prevailing relevance of this theory could be attributed to the belief that whilst societal values change, a degree of deviance will always persist (Durkheim, 1964). Durkheim believed that without deviance, societies would not advance. His theory postulated that the existence of deviance pushed societies to change by identifying problem areas, and through challenging norms, creates a climate of ambiguity. This in turn reaffirms moral boundaries and leads to cultural stability (Ben-Yehuda, 2015).

The word deviance is often considered to have negative connotations as it appears to describe the purely anti-social behaviour of individuals who act outside the law or morals of society. However, this is not always the case, and, in some cases, deviance may result in necessary and important changes to society. For example, whilst many women have access to legal safe abortion, considerable activism is still needed to achieve this important social change for women in Northern Ireland and parts of the USA (Ntontis & Hopkins, 2018). Whilst fighting for this social change, activists are often branded as deviant or demonstrating deviant behaviour. Goode (2015) describes deviance as a behaviour, belief or characteristic that is not valued and often stigmatised, and a deviant person as someone considered of no value to society. Similarly, Dodge (1985) describes deviance as any violation of societal norms. However, both Durkheim (1964) and Merton (1938) argued that deviance has an important role to play in moderating and advancing social order. They argued that through deviance, the dominant society is encouraged to consider alternative norms and values that subsequently advance society. An example of this includes the attitude changes in relation to the stigma placed on unmarried mothers in the mid-20th century (Gibson-Davis, 2011). This shift in perception took place slowly from the 1970s to more recent times when changing notions of deviance resulted in very different expectations of, and outcomes for, women.

Social deviance does not exist in a vacuum, and according to Curra (2011) the study of human deviance requires an understanding of how social meanings are constructed. Humans construct rules about proper and improper ways to act and think that are influenced by the attitudes, behaviours and conditions that exist at the time. These are subject to change as society progresses and circumstances evolve. For example, the socially acceptable way to cough or sneeze has changed in recent years, and since the H1N1 influenza pandemic it is now considered to be unacceptable to guard the mouth with a hand. Society has constructed new rules to dictate correct ways to cough. It is now accepted practice to cough into our elbows to prevent spreading viral particles onto surfaces and infecting others (Curra, 2011). These social rules quickly become established as a construct of reality, and with any social construct inevitably comes social deviance. According to Curra (2011) deviance offers no serious threat to the dominant constructed reality, rather its existence encourages conformity and conventionality. Ben-Yehuda (2012) expanded this concept by stating that deviance can impact society in two ways; either the challenge succeeds resulting in change, or the challenge fails and the construct is confirmed.

Prior to the advent of COVID-19 in 2020, Australia had a high uptake of immunisation in most areas with overall coverage reported to be 91% for five-year-old children in 2021 (Department of Health, 2021a). In our contemporary COVID-19-affected society, childhood vaccination uptake remains high and COVID-19 vaccines are progressing (Department of Health, 2021b; Tuckerman et al., 2021). Despite low levels of COVID-19 infection in Australia compared to other countries such as the USA, many limitations were imposed on the population to restrict transmission (Mahajan et al., 2021). These included restrictions on travel, infection control measures such as the need for social distancing, and location tracking, among other government-enforced measures (Sturman et al., 2021). These conditions became the new norm and influenced attitudes and behaviours in society, exacerbated by the daily onslaught of media and social media reports of COVID-related news (Cordos & Bolboaca, 2021; Gottlieb et al., 2020). Any person or group diametrically opposed to the attitudes and behaviours and new social norms of the majority, were assigned the role of deviant. In these conditions, even more so than in a pre-pandemic world, vaccine hesitancy is reviled, and vaccine-hesitant individuals were potentially subjected to social isolation, marginalisation and insult (Jenkins & Moreno, 2020). Social media is the main communication method for the vaccine-hesitant population, which can be a source of security and support in a closed group or aggression and criticism in an open group. A recent example included the degrading and insulting attack on a small group of vaccine-hesitant students on a university Facebook page. This case is discussed in detail in Chapter 7. Whilst the concept of deviance has previously been used in the field of health, specifically in relation to social capital, nursing systems and management, deviance theory was not revealed as a theoretical underpinning in any literature included or excluded in the review of the literature, hence, it is believed that this is the first time that deviance is used to underpin research into vaccine hesitancy.

Durkheim's theory proposed four ways in which deviance can be beneficial to society. First, he believed that deviance affirms and defines social norms; second, it clarifies right and wrong and third, as a result it increases conformity amongst those who react to it. Finally, Durkheim argued that social deviance could lead to positive change (Alexander & Smith, 2005; Hada, 2001). Both Émile Durkheim (1964) and Robert Merton (1938) argued that a functioning society has a value consensus, or a shared set of rules by which society abides, and deviance plays an important role in affirming and defining those norms (Fenton, 2019; Herington & van de Fliert, 2017; Thompson, 2017). Deviant behaviour can illicit shock, anger or even outrage in the conforming population, and it is these emotional responses that act to define the social norm.

As previously stated, the anti-vaccination movement in general, and vaccine-hesitant individuals specifically, attract considerable criticism from the pro-vaccination population as well as from some healthcare professionals (Silverman & Wiley, 2017). Additionally, the pro-vaccination movement stigmatises and marginalises the anti-vaccination movement, which acts to affirm and define the social norm by reaffirming the negative image of an arguably uninformed anti-science movement (Ward et al., 2019). Whilst for at least some vaccine-hesitant individuals, this anti-science label is far from the truth, it is apparent that the outraged majority apply this label to the entire movement. This in turn, acts to affirm and define what is socially acceptable in our 21st century pandemic aware societies.

In Australia, legislation titled No Jab No Pay, and No Jab No Play was introduced in 2016, as a means of promoting immunisation amongst those who were undecided or hesitant (Beard et al., 2017). This legislation gave the government the right to withhold state payments and to exclude children from kindergartens and childcare centres who were not fully immunised. Through this legislation the government has prescribed the expected norm, and those who choose not to immunise according to the prescribed schedule are wrong or deviant and place the majority at risk by reducing herd immunity (Helps et al., 2018). Whilst the government policies are designed to promote immunisation and increase herd immunity, it could be suggested that apart from placing financial and emotional pressure on parents who do not immunise according to the prescribed schedule, this legislation also acts to define what is legally and morally right and wrong, and as a result acts to strengthen bonds within the dominant group. This is despite the important fact that this legislation only includes social and financial restrictions. According to Durkheim, “law reproduces the principal forms of social solidarity” (Durkheim, 1982; Fenton, 2019, pp. 175-201).

3.2 Stronger bonds and increased conformity

Durkheim argued that social deviance acts to increase conformity and strengthen bonds amongst those who react to deviance. Durkheim also believed that deviance serves a vital function in maintaining social order (Herington & van de Fliert, 2017). He believed that by observing the consequences of deviant behaviour, right and wrong are affirmed (Bryant, 2011). However, it is apparent that deviance and conformity affect males and females in different ways, and oppression and social control has a major impact on women (Davis & Keith, 1984). Social control issues such as abortion, domestic violence, prostitution and teenage pregnancies are issues of deviance that

predominantly and profoundly affect women, with those who react to this form of deviance being predominantly male (Davis & Keith, 1984). However, Heidensohn (2010, p. 112) reminds us that "deviance is not a quality of the act the person commits, but rather a consequence of the application by others of rules and sanctions to an 'offender' ".

The presence of strong bonds and increased conformity is also evident when observing the value judgements and degree of animosity directed at vaccine-hesitant parents by pro-vaccine parents in society (Attwell et al., 2017; Silverman & Hensel, 2017). With Australian legislation clearly defining social norms, strong bonds and a combined animosity has been reported in the academic literature as being evident in those reacting to vaccine refusal (Helps et al., 2019; Rumetta et al., 2020). Beyond increasing conformity and strengthening societal bonds, deviance also forces society to consider alternatives to customary practices. Durkheim argued that "all social change begins with some form of deviance", and as a result can lead to positive benefits (Herington & van de Fliert, 2017).

3.3 Positive deviance – a new movement

Social rules and constructs vary from one era to another, but there are always those who challenge the norms or deviate in one way or another. According to Durkheim, deviance can lead to positive change. Whilst Ben-Yehuda (2012) believes that the sociology of deviance had changed little since the 1960s–1970s, it could be argued that social change has taken place, as has the understanding of deviance in general (Spreitzer & Sonenshein, 2004). A more recent change is the appearance of the "positive deviance" debate. The concept of positive deviance, presented in the seminal work of Wilkins (1964) first appeared in the 1960s (Herington & van de Fliert, 2017). Wilkins (1964) argued that deviance from the norm may be positive and even honourable. Positive deviance as a practical strategy has been used to find better solutions, promote change, achieve desirable outcomes and has been associated with creative behaviour (Escobar et al., 2017; Herington & van de Fliert, 2017; Spreitzer & Sonenshein, 2004; Wells et al., 2006). The concept of positive deviance has more recently become accepted as a valuable theoretical concept and arguably, an extension of Durkheim's theory. Unlike Goode (2002) who believes that deviance is always negative, Ben Yehuda argues that deviance is "a part of a process of cultural change and stability" (Ben-Yehuda, 2012, pp. 124-140; Goode, 2002). Progressing this concept, Lindblom and Jacobsson (2014) introduced the notion of entrepreneurial deviancy and argue that it varies from traditional deviancy in that the aim is to challenge mainstream beliefs by actively questioning the

dominant norm. Examples of this type of deviance are the Black Lives Matter movement and animal rights activists (Hooker, 2016; Jacobsson, 2016). These groups challenge the dominant norm but in a way that could be viewed as positive and honourable (Herington & van de Fliert, 2017).

Whether the anti-vaccination movement can be included in this group is debatable; however, the anti-vaccination movement is influential and regularly challenges mainstream beliefs. Lindblom and Jacobsson (2014) argue that activists in general strive for social change by challenging existing norms and do this by using unconventional methods to challenge dominant worldviews. Unlike the animal rights activists, where the message is largely seen as selfless and worthy, the anti-vaccination movement appears self-focused and unlikely to benefit the population in general. Adamo et al. (2019); Ward et al. (2019) argue that this could be because the application of the label "anti-vaxxers" both stigmatises and delegitimises the movement, placing it in the domain of anti-science. Applying the concept of entrepreneurial deviance to the anti-vaccination movement may be drawing a long bow; however, there are several ways this movement may in time, result in benefits to society. This could result in improved education of healthcare professionals, in the production of safer and more effective vaccines, or in the establishment of an Australian vaccine-related injury fund. However, this is pure supposition, and positive change is yet to be documented (Isaacs, 2004; Regan et al., 2018; Smith et al., 2021).

3.4 Moral panic

Durkheim's theory of social order and deviance has been lauded, criticised and expanded on over the ensuing years since it was first published. The concept of moral panic was first introduced in 1972 by Cohen (2011). It was described by Erich Goode and Nachman Ben-Yehuda as "an episode of exaggerated concern about a threatening, or supposedly threatening condition, which many members or sectors of a society blame on 'folk devils' or 'deviants'" (Bryant, 2011). In a moral panic, sectors of society express hostility towards deviant groups who are considered harmful, and individuals are negatively stereotyped and vilified. According to Bryant (2011), moral panic is informed by five main players: society in general, media, the internet, legislators and often the police in issues of social unrest. In a moral panic, emotions are heightened and aggression towards the "deviants" increases. To qualify as a moral panic there must be agreement amongst the dominant group that the behaviour of a sub-group is a threat to society. In the case of immunisation, an individual who refuses to be immunised is a threat only to themselves; however,

the presence of large numbers of vaccine refusers becomes a threat to herd immunity in a society (Logan et al., 2018). In most pandemics, herd immunity is a key consideration in epidemic control however, this has not been the case with COVID-19 (Fontanet & Cauchemez, 2020; Mayo Clinic, 2023). Accompanying the importance of herd immunity with anxiety about infection creates an opportunity for moral panic. The current COVID-19 pandemic has brought new constraints on individual freedoms and increased social expectations. Combining this with the fear of catching COVID-19 and anxiety about side effects from vaccines has produced heightened anxiety. This combined with poorer than usual public mental health, has combined to create the perfect storm for moral panic (Kadkhoda, 2021; McElroy et al., 2020). Evidence of moral panic in the current social construct is also discussed in Chapter 8.

3.5 Social change as vital for growth

Durkheim's theory of social order and deviance of the 19th century includes the concept that deviance results in positive change. Durkheim believed that individuals who anticipated the need for social change, whilst initially stigmatised and perhaps considered criminal, may subsequently become the drivers of essential social change. Durkheim also believed that social change was necessary to achieving social progress and stated "the criminal no longer seems a totally unsociable being" but has an important role in facilitating social progress (Fenton, 2019, pp. 175-201). The concept of deviance having a positive impact has been applied in various fields of study including business and information technology (Herington & van de Fliert, 2017). Positive deviance has also been used as a method of engaging nurses in improving clinical and administrative performance in healthcare and improving professional standards and infection control (Gary, 2013; Lindberg & Clancy, 2010). Durkheim's deviance theory, coupled with the concept of positive deviance, has also been used in recent years to support research on cohesion amongst officers in the military, crews on space and polar expeditions as well as social integration and mental health (Bury, 2017; Dudley-Rowley, 2000; Rose et al., 2014). Whilst this research is not suggesting that the anti-vaccination movement is aiming to achieve positive change by encouraging others to refuse to immunise, nor is it condemning the people and groups who are vaccine hesitant. One of the aims of this research is to give a voice to vaccine-hesitant parents. It is important therefore to represent their experiences accurately, whether positive or negative, and to approach the phenomenon of vaccine hesitancy with an open mind. Therefore, the choice of Émile Durkheim's deviance theory as the theoretical underpinning provides the best fit and widest choice of

concepts to accurately represent both the results of this research and the beliefs and experiences of vaccine-hesitant parents in the social context of a pandemic.

3.6 Chapter summary

Chapter 3 introduced and explored the theoretical underpinning of this thesis and how it plays a part in understanding the concept of vaccine hesitancy. It provided a description of Émile Durkheim's theory of social order and deviance as published in his 1893 paper, The Division of Labour in Society. It demonstrated how vaccine hesitancy can be considered a form of deviance in contemporary society. This chapter described the effect of deviance on society in general, including how it defines right and wrong and acts to strengthen bonds amongst those who react to it. The role of deviance in contemporary society, including the value judgements of the vaccine hesitant, was also discussed. This chapter also introduced the concept of moral panic and linked this to current times. Examples were presented explaining how the vaccine hesitant have been vilified and exposed to extreme hostility. Additionally, this chapter described the role of the internet and social media in spreading fear of the unimmunised, exacerbated by the existence of the global pandemic. The concept of positive deviance was also introduced, and the application of both deviance and positive deviance in contemporary healthcare were discussed (Durkheim, 1964). Finally, this chapter served as an introduction to the methodology presented in Chapter 4.

Chapter 4 Methodology and Research Methods

> Science works. It is not perfect. It can be misused. It is only a tool. But it is by far the best tool we have, self-correcting, ongoing, applicable to everything. Carl Sagan (2013, p. 352)

Chapter 1 of this thesis provided the background to the study as well as the aims and objectives. The integrative review contained in Chapter 2 identified factors in the current literature that influence vaccine uptake, including three main themes identified in the review. These were the role of healthcare professionals and information provision, the influence of vaccine safety concerns and alternative influences. These themes set the scene and established a starting point for this research. Chapter 3 presented the theoretical underpinning of this research, which is Émile Durkheim's deviance theory. The purpose of this chapter is to introduce the research design including the ontological and epistemological foci, the research paradigm and methodology as well as the research methods, ethical considerations and the rigour applied. This chapter also discusses the strengths and weaknesses of the methodology. A methodology paper is currently in the final stages of drafting for possible submission to the *Journal of qualitative research methods*. A version of that paper is attached at Appendix 18.

4.1 Research design

Figure 4.1 provides a visual snapshot of the research design.

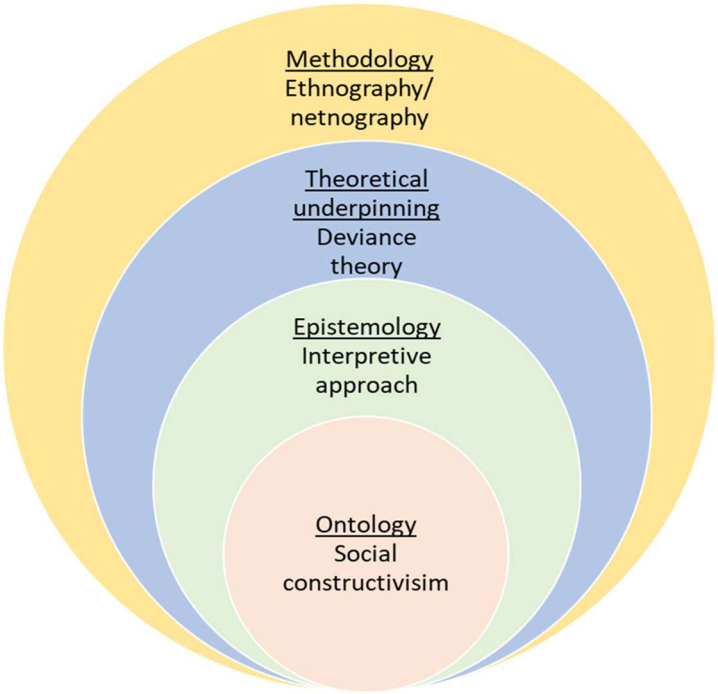


Figure 4.1 Research design

4.2 Ontology and epistemology

Ontology has been described as the study of existence. It is the worldview through which research is undertaken. Both ontology and epistemology are vital elements of the philosophy of knowledge and reality (Creswell, 2018; Lewis, 2015). In this case, a social constructivist ontology was taken with the specific aim of seeking understanding. Social constructivism has been described simply as having reflected upon the construct of society (Hay, 2016). In this research the social construct of vaccine hesitancy as well as the online world in which some vaccine-hesitant parents seek information and connections, is at the heart of this research. The concept of social constructivism has its roots in the works of both Berger & Luckman (1966) and Searle (1995). This ontology holds the belief that there is no ultimate reality, or one-size-fits-all approach, rather, individuals construct their own reality through their experiences, language and interactions. To the social constructivist, reality is not a fixed entity and is subject to change. This ontology acknowledges that society makes sense and applies labels to the world based on what is observed and experienced. For example, some sections of society apply feelings of protection and safety from disease to the process of immunisation, whilst others experience feelings of anxiety and danger, based upon their own reality. This ontology was chosen as it supports the existence of multiple realities and accurately reflects the real-world situation which encompasses vaccine decision-making (Searle, 1995).

This research focused on the research participants' views and understanding of the world they share. Along with meta-physics, epistemology is one of the fundamental philosophical pillars of any research and has been described as the theoretical study of knowledge, providing a focus for research (Pernecky, 2016). Epistemology, simply speaking, is the theory of knowledge and describes how knowledge is gathered. In research terms the researcher's view of the world strongly influences the way data are gathered. By taking an interpretive epistemology, the researcher interacts with the participants rather than remaining independent from them (Polit, 2016). In this research the interaction with participants took place in interviews via telephone and online on Facebook. Interpretive methods aim to describe, explore and generate meaning within a social context or culture (Schneider, 2013). There is a focus on dialogue between participant and researcher to construct a meaningful reality. The researcher is not separate from the study but assumes a vital role within it. Because of this important role, the researcher must maintain an ongoing self-reflexive engagement with the phenomena under investigation (O'Reilly, 2009) (see the preface for a more detailed explanation).

In this case an interpretive approach was chosen, which does not begin with preconceived ideas but allows concepts to emerge from encounters in the field. It is based on the belief that reality is not fixed and meaning and understandings are contextual. An interpretive approach also encompasses social theories and perspectives to gain a deep understanding of the social context being researched. This research has adopted deviance theory as the methodological underpinning (Chapter 3). Deviance theory is a study of how social meanings are constructed as well as their role in society (Curra, 2011). By combining an ethnographic and netnographic methodology, where the concept of culture is fundamental, with Durkheim's deviance theory, which also focuses on the role of culture and societal rules, a deeper understanding of the research problem can be achieved.

4.3 Qualitative research paradigm

A qualitative paradigm was chosen for this study. Humans are complex beings who attribute unique meanings to situations. The qualitative or naturalistic paradigm aims to explore and gain a depth of knowledge and understanding of the meaning people give to human problems (DePoy & Gitlin, 2015). For the naturalistic researcher, reality is not a fixed construct but exists in context. There is a strong focus on humans and their ability to create their own reality. This paradigm explores the unique experiences of both individuals and groups. In this research, the experiences of vaccine-hesitant individuals were explored through both an exploratory survey and semi-structured interviews, and group experiences were explored through online interactions via social media.

Qualitative research has a long and distinguished history and is well suited to gaining an in-depth understanding about relationships between concepts and behaviours by producing data that support understanding (Denzin & Lincoln, 2017; Patton, 1990). A further advantage in participating in qualitative public health research is the co-construction of knowledge between researcher and participant, which is vital to addressing the health needs of the minority (Pratt, 2019). Co-construction of knowledge is a process of bringing together multiple types of knowledge, which was achieved in this research by using multiple data sources and perspectives on the issue of vaccination refusal (Pratt, 2019). It also involves jointly constructing knowledge with multiple players. In this case, knowledge was constructed between researcher and research participants through building relationships of respect to both influence the knowledge produced, and ultimately meet the health needs of groups considered disadvantaged. For example, vaccine-

refusing parents reported a reluctance to access healthcare due predominantly to a desire to avoid confrontation, thereby placing themselves and their children at risk (Costa-Pinto et al., 2018). Through in-depth discussions, knowledge of parental experiences and choices can be gained through the interview process, thereby resulting in the co-construction of knowledge.

The use of a naturalistic paradigm is well suited to research in the field of vaccine decision-making and refusal. It is important to gain an understanding of how external influences affect decision-making behaviour, and this can be best achieved through a search for meaning in a naturalistic setting as opposed to a controlled environment. For example, Helps et al. (2018) used qualitative research methods to explore the impact of the No Jab No Pay legislation on vaccine-hesitant parents, and Peretti-Watel et al. (2019) used qualitative methods to compare two populations with contrasting socio-economic profiles to evaluate vaccine hesitancy. Additionally, by adopting an ethnographic and netnographic methodology, underpinned by Durkheim's deviance theory, a deep understanding of the research problem can be achieved.

4.4 Blended ethnography and netnography

To fully explore vaccine-hesitant pregnant women and parents' experiences of vaccine decision-making and the factors that influence their choices, a naturalistic approach included a blended ethnographic and netnographic methodology, underpinned by Émile Durkheim's deviance theory as discussed in Chapter 3 (Fenton, 1984). The main advantages in the choice of ethnography and netnography as methodology are both the methodological durability of ethnography and the adaptability of netnography to a predominantly online culture (Kozinets, 2007).

Ethnography has been described as a methodological tool that "gets close to a particular group or subgroup to uncover cultural phenomenon" (Hayre & Hackett, 2021, p. 3). Traditionally, the ethnographic approach has been used by both anthropologists and sociologists as a way of studying people within a culture group and predominantly in their natural environment (Madden, 2010). Ethnographers have studied cultural patterns and experiences in a holistic fashion since its inception. Anthropology and sociology have been described as the disciplinary forerunner of qualitative research, and ethnography was one of the earliest forms used to study customs, cultures, and traditions. Early researchers recognised the need to focus on the richness and diversity of people's existence (Pernecky, 2016). The term ethnography derives from the Greek word *ethnos*, which means a culture group or people (Brewer, 2000; Scott-Jones & Watt, 2010).

Ethnography grew out of a desire to understand other culture groups, and its origins date back centuries (Denzin & Lincoln, 1994). Ethnographers typically conduct research by systematically observing and participating in the lives of people who are perceived to be different in some way and is a good fit with the methodological underpinning of deviance. The degree of participation varies according to the needs of the research (Madden, 2010).

Ethnography has a long history and is a well-established methodology with its beginnings dating back centuries (Scott-Jones & Watt, 2010). This methodology had its beginnings in the British school of anthropology and American anthropology (Scott-Jones & Watt, 2010). Studies were undertaken by the Chicago School during the 1920s and 1930s and these works were an important factor in establishing qualitative research as a tool in other domains of inquiry (Pernecky, 2016). By the early 1900s the term ethnography was adopted to describe descriptive accounts of predominantly non-literate people (Scott-Jones & Watt, 2010). In 1914, Bronislaw Malinowski conducted important ethnographic research in New Guinea and is considered a founding father of the methodology. He stressed the importance of linking data to social theory and favoured a functionalist approach, which states that all social phenomena have a function within society. An example of a functionalist approach is the work of Émile Durkheim and his deviance theory, which has been adopted as the theoretical underpinning for this research (Chapter 3) (Scott-Jones & Watt, 2010).

Ethnography involves both iterative and inductive research and describes a methodology that evolves throughout the study (O'Reilly, 2009). Ethnography is underpinned by the understanding that knowledge is transmitted through language and shared meaning (Brewer, 2000). In this research, which focuses on immunisation decision-making, vaccine knowledge is transmitted through language and shared meaning. The population who are pro-vaccination make up the majority of society and rely on written information supported by scientific evidence, which is available in many forms including on government websites (SA Health, 2021b). Similarly, the anti-vaccination group, a small population considered by many to be deviant, rely on language and shared meaning to communicate. However, their information often uses stories as an information source, which are disseminated through the utilisation of a largely online environment. Anti-vaccination information can be emotive and persuasive, and only rarely supported by scientific evidence. This small group of parents and pregnant women who refuse vaccines, their culture and experiences, as well as the factors that impact their decision-making, is poorly understood, often

misjudged, and requires in-depth description and interpretation. Ethnography was chosen as the most suitable methodology for this.

There are three important aspects to an ethnographic study: it can gather rich description; provides both an emic and etic approach and focuses strongly on researcher reflexivity that, in this thesis, is included in the preface. Reflexivity is the method by which researchers identify personal biases, recognise potential influences on the interpretation of data and by being reflexive the researcher gains a deep understanding of their beliefs and preferences (Horsburgh, 2003). The primary tool of ethnographic research is the researcher; therefore, understanding the beliefs and background of the researcher is vital to ensure rigour and scientific validity (Madden, 2010). According to Watson (1987), "reflexivity is a pervasive and ineluctable feature of all accounts" as it underpins the entire thesis and is central to ethnographic research (Fetterman, 1989). However, whilst reflexivity is not always considered to be a special problem or something to be managed, it is a vital part of all ethnographic research and in this thesis the primary researcher and research participants hold diametrically opposed beliefs. For this reason, reflexivity is situated in the preface as it underpins and influences the entire research project (Madden, 2010).

Amongst the advantages of ethnography is the methodology's ability to take both an emic and etic approach (Jones & Watt, 2010; Madden, 2010). These terms were borrowed from the field of linguistics. Etic refers to the study of cross-cultural differences, whilst emic refers traditionally to a study of one culture with no cross-cultural focus and usually from within that culture (Hoare et al., 2013). This research adopted both an emic and etic approach to gain an in-depth understanding of a culture group, vaccine-hesitant pregnant women and parents, as both insider and outsider. The term culture in this instance refers to a group of people who share similar beliefs and practices in an online world. Traditionally ethnographers adopt an emic view and place significant importance on fieldwork, subsequently describing and interpreting the culture of a single group. However, this research also included an etic approach in order to provide a balanced or synthesised view of the human phenomenon that is vaccine hesitancy (Madden, 2010). It did this by highlighting the differences in beliefs and practices between the predominant culture of pro-immunisers and the anti-vaccination subculture. Additionally, as ethnography utilises the researcher as the main research tool, it is useful to understand and position the researcher within the concept of cultural insider or outsider, that is, emic or etic. Reflexivity has been addressed at length in the preface; however, for the purpose of this discussion, the researcher is both emic, as a parent, and etic, as a person with pro-vaccination beliefs.

Ethnographers traditionally immersed themselves within the cultural setting under investigation, and subsequently described and interpreted the culture. However, living within the culture is not always possible, nor is it desirable (Scott-Jones & Watt, 2010). In this case, the researcher cannot assume the beliefs of the anti-vaccination culture group; however, whilst this has been done in the past, it is no longer ethically acceptable to either conceal or misrepresent the purpose of the researcher's presence in a group. In contemporary ethnography it is expected that research participants are given as much information as possible to ensure consent is informed, and this is not possible when the research is covert (O'Reilly, 2009). However, it is possible and desirable to faithfully record, report and learn from the beliefs, influences and experiences that can be attributed to this culture group (Scott-Jones & Watt, 2010). It is also possible to experience the culture where the anti-vaccination groups seek information and support from within their own network. Historically, ethnographic studies were considered a long-term commitment, with some of the early researchers living in communities for years to produce thick sociocultural descriptions of the exotic population. Through systematically observing and taking part in the lives of the people, a deep understanding was achieved (Denzin & Lincoln, 1994). Traditionally, ethnography was closely associated with anthropological pursuits; however, the late 20th century and into the 21st century has seen a change in the type of cultures and societies under investigation (Madden, 2010). Ethnographic studies are now conducted over shorter periods and the methods used and subject matter have become more refined and diverse (Denzin & Lincoln, 1994). Ethnographers now study within cultures and societies, in both local and diverse settings (Madden, 2010). Recent ethnographic research has included studies of the disinvestment in health as well as telemedicine effectiveness in intensive care (Kahn et al., 2019; Rooshenas et al., 2015).

Modern ethnographic methods now include interviews, focus groups and surveys as a means of talking with and listening to participants (Madden, 2010). Interviewing is a cornerstone of ethnographic research and has been described as a pervasive form of information gathering. However, for interviews to be ethnographic they must be conducted respectfully, ethically and sensitively, and for some researchers this is their main form of data collection (Madden, 2010; O'Reilly, 2009). This research utilised both an exploratory survey and semi-structured interviews to gain a deep understanding of the lives and experiences of the participants.

The relationship between humans and places has been described as "complex and multi-layered". Historically, ethnography "turned someone's everyday place into a thing called a field" (Madden, 2010). Fieldwork and participant observation are a vitally important part of ethnography and

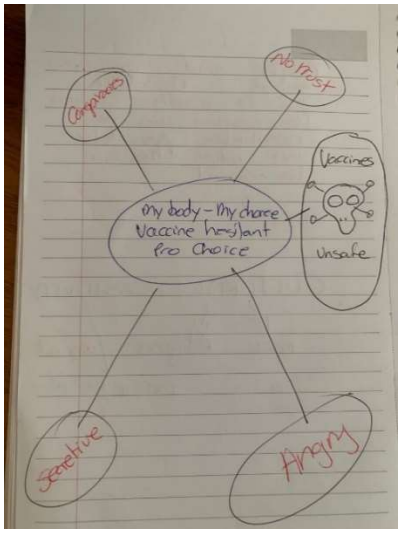
include gaining access, recruitment of participants, accessing gatekeepers, establishing the researcher role and gathering data (Scott-Jones & Watt, 2010). Ethnographic fields have been described as part geographical, part social and part mental construct (Madden, 2010). This means that the research field can be a town (geographical) a social group (a club) or a group with shared ideals (mental construct). In this research the field is largely a mental construct or group of like-minded people (vaccine hesitant) existing within the digital world. According to Kozinets (2007, p. 1) social media is a "complex world that not only reflects and reveals their lived experiences, but is also, itself, a unique social phenomenon". This research is supported by both an exploratory survey and semi-structured interviews as well as Facebook interactions. This is considered appropriate as the online environment, specifically Facebook, Instagram, and other platforms have become the chosen location for vaccine-hesitant individuals. This is because parents and pregnant women who refuse vaccines are often subject to criticism and even aggression and have reported avoiding conflict by avoiding face-to-face discourses. When online, it is possible to choose their own level of interaction.

4.4.1 Working in the field

Fieldwork has been described as a dynamic process in which the researcher constantly observes and evaluates information. A researcher in the field follows four basic principles: investigator involvement, an interactive process of gathering information, prolonged engagement and the use of multiple data-collection strategies (DePoy & Gitlin, 2015). The use of field notes is a vitally important aspect of both ethnography and netnography. Fieldnotes often provide insight into not only social interactions, but also the researcher's emotional response to them (Kozinets, 2018; O'Reilly, 2009; Scott-Jones & Watt, 2010). Netnographers record their personal journey through the research process, including emotions and insights, and these provide an uncensored link from the online to the offline world. The field notes taken throughout this research process were analysed using thematic analysis and the results are presented in Chapter 8 (Braun & Clarke, 2006).

Whilst field notes were traditionally taken down by hand, it has been suggested by Madden (2010, p. 120) that we have entered the age of the "digital native" and the use of computers has become second nature. However, despite the methods used to record field notes, they arguably retain an important role in both ethnographic and netnographic research. According to (Hayre & Hackett, 2021); Kozinets (2007, p. 259), "in healthcare research field notes can be considered data which

can be analysed and interpreted". Kozinets (2007) expands on this by claiming that whilst field notes provide key insights into online social interaction, reflective field notes also play an important role in deciphering the rationale for cultural actions. The taking of field notes is where initial patterns emerge, and connections are forged. It can be the "ah ha" moment when a beginning understanding is reached. In this research, field notes were taken by hand throughout the data-gathering process. During this research, field notes were taken at moments of insight, and at times of confusion and frustration. These moments arose during interviews and at times when reading comments on social media, as well as when contemplating meaning in a broader sense. The handwriting of field notes has also enhanced this research by recording moments of clarity and insight. An example of notes taken during this research are at Figure 4.2, where concepts were explored. Despite the acceptable use of digital field notes in both ethnography and netnography, the researcher also used handwritten field notes as a means of working through a thought process.



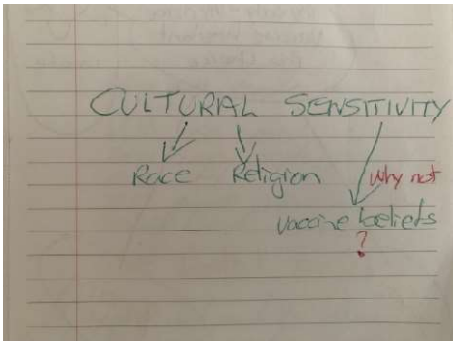


Figure 4.2 Field notes

4.5 Ethnography

In recent years the employment of ethnography as methodology has broadened, and is now used across many academic disciplines including business, sociology, politics and healthcare (Hayre & Hackett, 2021). Both ethnography and netnography have been used recently to investigate wellbeing in sport and views on assisted dying in subjects with dementia (Colón, 2020; Dehkhoda et al., 2020). As the primary aim of ethnography is to investigate sub-groups to uncover social reality, there are obvious advantages in the use of this methodology to both health and healthcare (Hayre & Hackett, 2021). One distinct advantage to health research is that ethnography "gets close" to a cultural group to uncover cultural phenomena, aids description and enhances clarity (Brewer, 2000). For example, one study of newly graduated registered nurses used ethnography to gain a deep understanding of the knowledge sources used to support clinical decision-making (Voldbjerg et al., 2017). Vaccine-refusing parents make up a small proportion of parents, who are both difficult to locate and engage in research. Ethnography and netnography were therefore considered the most appropriate methodology to gain access to this culture group and to gain accurate and in-depth data.

Anthropologists and ethnographers traditionally study culture and community, whilst netnographers study online or cyberculture (Kozinets, 2015). Historically, ethnographic research took place in distant and exotic settings. However, with the development of the internet and billions of users taking an active role in a complex online world, netnography became a valid means of conducting research in cyberspace. Netnography uses the principles of ethnography to conduct ethical observation in the online environment. According to Denzin and Lincoln (2017) the ethnographic attitude is unchanged in a digital world; however, it could be argued that the digital world is changing what it means to be a socially connected human. Culture groups such as vaccine-hesitant parents, exist predominantly in a digital world due largely to the attitudes of the pro-vaccine majority.

4.6 Netnography

Netnography was constructed using the principles of ethnography whilst using online observation of textual discourses (Kozinets, 2007). It has been described as "a form of ethnographic research, adopting the participant-observation approach and taking online interactions as its fieldwork" (Dumitrica, 2013, pp. 156-158). Netnography has been used since its creation by Robert Kozinets

in 1995 and has become a popular methodology for studying the online environment. In comparison with ethnography, netnography is a less obtrusive and more naturalistic approach (Kozinets, 2018). Netnography focuses on social media specifically and includes not only the written word but also the connections and communication styles. It has a strong focus on the meaning behind posts and tweets and includes analysis of graphics and memes, and is a relevant, rapid and unobtrusive method of data collection (Kozinets, 2007). This methodology was originally used predominantly for marketing and market research; however, in more recent years, has been employed extensively in the social sciences. As early as 2013 Gustavsson (2013) used netnography to investigate death and dying through memorial sites on the internet. More recently, netnography was used to evaluate postnatal depression in an online community of lesbian mothers (Alang & Fomotar, 2015). Netnography was also used to assess discussion content in virtual peer communities of Parkinson's disease sufferers (Bayen et al., 2021). Similarly, because of the nature of this condition, and the virtual nature of the support communities, netnography was an obvious choice of methodology. In all these examples, a netnographic approach has enabled the researcher to gain access to difficult to reach and engage communities and provided large amounts of rich data.

Table 4.1 Differences between ethnography and netnography

Differences	Meaning	Ethnography	Netnography
Alteration	Different communication style	This methodology uses observation and description of people and cultures with a focus on customs habits and differences.	This methodology also observes people and culture but involves the digital medium. Data can take the form of the written word, photos, memes, likes and a range of social innuendo.
Access	Access to data	Access to subjects generally takes place during daylight hours and within a specific area of interest.	Access to data is available constantly, across time zones and between complete strangers.
Archiving	Data availability	A researcher only has access to the data they have collected.	The internet is an archive and has been referred to as a persistent world where data can be obtained retrospectively using search engines' data scrapers.
Analysis	Types of analysis	Ethnography utilises limited forms of analysis.	Netnography produces a wealth of data including memes, posts and emoji, which can be subjected to multiple types of analysis including

			mining, scraping, automatic coding etc.
Ethics	Ethics requirements	Subject to strict ethical requirements.	This is a grey area in netnography. Online data is often considered to be public, ethical requirements should ideally be enforced.
Colonisation	Refers to presence of other influences	The presence of large corporate interests is rarely a concern.	Corporate involvement is evident online and can influence posts and other data.

There are many similarities and six fundamental differences between ethnography and netnography. The differences include alteration, access, archiving, analysis, ethics and colonisation as summarised in Table 4.1. Alteration refers to the changes in communication style to suit the medium. In this case the media selected was Facebook, where communication can be shorter and more succinct, and often interspersed with photographs and memes. Whilst different to face-to-face communication, this communication style is arguably no less effective (Kozinets, 2007). On the contrary, Facebook provides a multitude of options for communicating including like, text, direct messaging, photo sharing and a range of social innuendo (Hodge et al., 2015; Kozinets, 2007).

The second difference is the level of access that exists online where friends and strangers can communicate over a 24-hour period between countries, and online interactions become commonplace, simple, and seemingly a life priority for some. This enhanced access to the field of study offers considerable advantages to the netnographic researcher, whereas the ethnographer in the field is restricted by the clock and social mores (Kozinets, 2007; Madden, 2010). Additionally, online interactions go on without the presence of the researcher and can be easily recalled by the archiving functionality of most social media (Dumitrica, 2013; Kozinets, 2007).

Archiving refers to the archiving functionality of most online media. Unlike an in-person interaction, an online interaction leaves a trace, can be downloaded and accessed for years to come unless the social media platform elects to block that page. In terms of analysis, netnography offers more options for analysis than ethnography and other methodologies. This is largely due to the wealth of data available in an online world, including the potential for automatic download from social media. This data can then be analysed on a post-by-post basis using a range of analytical methods including computer assisted or paper-based iterative analysis (Kozinets, 2007, 2020).

Finally, colonisation is a term applied to the online presence of corporate and organisational interests in social media that have impacted and influenced the nature of social interactions (Kozinets, 2007). The presence of activists, influencers and corporate influences on social media impact all aspects of the online world and must be considered in any analysis of interactions (Kozinets, 2007; Shan et al., 2020; Youmans & York, 2012). Furthermore, the presence of conspiracy theories, rumours and misinformation is also prevalent on social media sites, and this must be considered when conducting netnographic analysis, more so than in ethnographic research.

Ethics in netnography can be a grey area, as many researchers are of the opinion that online data are public. However, it was a major consideration for this netnographic research. In netnography, the researcher can choose between observation or participation in the online environment, and the level of ethics approval required will vary according to the choice of method. Beyond this, there are numerous other considerations, including consent, whether to reveal the intentions of the researcher or to remain anonymous, amongst others (Dumitrica, 2013; Kozinets, 2007, 2020; Lehner-Mear, 2020). In this research full disclosure of the purpose of the social networking site was made initially and throughout the research. The researcher chose to participate in discussions; hence an interactive approach was adopted as opposed to a purely voyeuristic approach.

The first step in any study is introspection, and netnography recognises the importance of addressing reflexivity. In this step, the researcher reflects upon their personal experiences and identifies any potential biases. In this research, as the methodology of choice is a blended ethnography and netnography, it was deemed essential to address researcher bias prior to commencing data collection. Because of the importance assigned to this aspect of the study, researcher reflexivity is situated at the beginning of the thesis in the preface.

Social media is an important part of cyberculture (Stanford, 2016). Facebook is a popular social media platform, which has been described as any interactive site that allows people to create content or share media (Acar, 2014). Social media sites are continuously evolving platforms that support communication, socialisation and change (Stanford, 2016). Whilst communication and socialisation are essential elements of cyberculture, change has been described as a by-product of it. Stanford (2016) argues that cyberculture teaches individuals what is socially acceptable; however, it could also be argued that what is acceptable online varies enormously from what is acceptable in the real world. This type of content makes up a large part of online data, and for this

reason, some content described and displayed in this thesis could be considered socially inappropriate in some circles; however, it was not considered the role of the researcher to censor participants' commentary. When posts are quoted, they are presented as they appeared online with minimal spelling corrections for clarity.

Netnography can take many forms and adopt differing analytical and interpretive methods. However, as a form of qualitative inquiry with its roots in ethnography, netnography can also adopt a humanist approach whilst relying on field notes, introspection and contemplation (Kozinets, 2015). Analysis can be manual or use computer-assisted qualitative data analysis software (CAQDAS) or a combination of both. In this phase of the research, thematic analysis, using both manual and computer-assisted methods was conducted on the data obtained from two social media pages on Facebook to gain a deep understanding of relevant contemporary issues and influences (Braun & Clarke, 2006).

Evidence has shown that when information is not readily available from traditional sources, or if the therapeutic relationship has broken down, the internet and social media is the source of choice for immunisation information (Costa-Pinto et al., 2018; Duchsherer et al., 2020; Jenkins & Moreno, 2020; Rumetta et al., 2020). Hence, the natural setting for vaccine-hesitant pregnant woman and parents, is an online environment. Vaccine-hesitant parents have reported being distrustful of healthcare professionals and have both avoided connecting with people of pro-vaccine beliefs and lied to avoid conflict, thereby making recruitment to a scientific research study difficult (Costa-Pinto et al., 2018). Even extremely vocal anti-vaccination advocates prefer to express their views in a relatively safe online environment. This is largely due to the degree of animosity directed at them from the pro-vaccination majority. For this reason, traditional research methods investigating the vaccine-hesitant population are not always successful (Lehner-Mear, 2020). This, combined with the onset of a global pandemic in early 2020 and the adoption of social-distancing guidelines, made the choice of a blended ethnography and netnography as the methodology for this research clear. In this research ethnography was the methodology used to guide the survey and interview phases and netnography employed in the digital phase conducted on Facebook across two Facebook pages.

Qualitative research methods have been criticised by some quantitative researchers for lacking rigour and subjectivity. Unlike quantitative research methods that utilise randomisation and research control to protect against bias, qualitative researchers rely on reflexivity, the process of

self-reflection, to reduce bias and ensure rigour (Polit, 2016). Reflexivity, a vital part of ethnography and netnography, is closely associated with reflective practice, which is also an important part of healthcare professional practice (Hayre & Hackett, 2021). Reflection is often used to gain perspective on health issues, similarly ethnographic reflexivity assists in critical reflection on both the biases of the researcher and their influences on the development of new knowledge (see preface) (Hayre & Hackett, 2021). Ethnography, which utilises the researcher as the primary research tool, has also been subject to criticism. To reduce bias in ethnographic research it is vital to critically analyse both the practice of ethnography, the researchers own role, as well as the values they bring to data collection and interpretation (O'Reilly, 2009). Despite criticism of subjectivity, the naturalistic paradigm was considered the best fit for research into vaccine decision-making as it would produce insight and a deep understanding of the research problem (Polit, 2016).

Netnography has been described as having a 12-step approach to conducting research. These steps provided a guide to the netnographic process. The preparation phase moved through introspection as reflexivity was addressed (see preface), the development of the research question and ethics approval was obtained. The planning phase included the development of the Facebook page, the choice of online interaction and recruitment of participants. Finally, immersion in the data and subsequent selection of small amounts of high-quality data and the dissemination of data in the form of publications and presentations. These phases are presented in Table 4.2.

Table 4.2 Netnographic principles

Phases of netnography	**Explanation**
Introspection	This phase requires researcher introspection and reflexivity (preface).
Investigation	This phase involves the development of a research question and preliminary investigation of online environments to position the research appropriately.
Interview	The interview phase involves recruitment and initial contact with potential participants whether it is via interview, survey or simply a preliminary search of appropriate sites for further investigation.
Inspection	This phase involves the choice of sites for data collection, or in this research, the development of a research-specific site.
Interaction	This phase is when ethics are considered and issues pertinent to the specific research are identified and addressed.
Immersion	This phase involves immersion in the site and developing understanding.

Indexing	This phase involved the selection of an adequate but not overwhelming amount of data.
Interpretation	Once data is collected, interpretation begins in depth and involves striving for a depth of understanding. In this case a humanist approach was adopted.
Iteration	Iterations are phases within phases and involve using the data we have to expand traditional scholarship into more accessible forms.
Instantiation	In this phase netnography is instantiated or manifested using different approaches, in this case a humanist approach was selected with methodological implications.
Integration	This phase involves dissemination of the research, publication and presentation of results.

Source: (Kozinets, 2007)

4.7 Ethical considerations

Qualitative research inherently involves exploring a person's life experiences, in this case, vaccine decision-making and the influences upon it. For this reason, and because this can be a difficult and fraught decision, the rights of the participants must be protected in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (National Health and Medical Research Council, 2018). The study population, which included pregnant women, is a high-risk population according to this national statement (National Health and Medical Research Council, 2018). This is because any stress placed on the mother can have a negative effect on the fetus. For this reason, the principles of research merit and integrity, justice and beneficence, non-maleficence, and respect for human dignity were a vital consideration in the planning of this study. Additionally, the internet and social media have become fundamental to the lives of many people and a cyberculture has evolved over the years since it became public in 2006 (Zittrain, 2014). Despite the popularity of social networking sites, conducting research in these spaces are still subject to ethics and privacy. There are a few issues pertinent specifically to the netnography phase of this research. Consent is an important aspect in any research and participants on social networking sites may be unaware that data is being collected and as such are unable to make a conscious choice to participate in a study or give informed consent (Buck & Ralston, 2021). The Association of Internet Researchers recommends obtaining informed consent when conducting internet research where possible. This study used a purpose-designed Facebook page, which was assigned the category of Medical Research Centre. For full disclosure, the primary researcher made occasional posts both seeking discussion and to

clarify the purpose of the social networking site (see Figure 7.2 for an example). For anonymity, where online users are quoted names are either not used or pseudonyms applied to protect the privacy and online presence of the participants, and to meet the requirement for ethical conduct of research. By adhering to these principles, the rights of the participants are maintained. Ethics approval was sought and granted by Flinders University Human Research Ethics Committee on 1st December 2020, Ethics Approval Number 2464 (Appendix 10).

4.8 Research merit and integrity

For research to be ethically sound the primary aim must be to achieve research merit whilst ensuring the welfare of research participants (NHMRC, 2018). The research must also be justifiable and designed using suitable methods. The aim of this study was to gain a deep understanding of the beliefs, values and decision-making processes of vaccine-hesitant parents, thereby improving healthcare professionals' knowledge and subsequently improving therapeutic relationships with this small population whose needs are not currently being met. It is hoped that through this improved knowledge, healthcare worker communication will be enhanced, resulting in an increase in vaccine uptake. This in turn may contribute to improved herd immunity and outcomes in pregnancy and early childhood, and ultimately save lives and enhance health and wellbeing. However, no harm must be done to participants in the process. The methods used were selected to meet the aim of the study.

Integrity in the way a researcher conducts themselves in interactions with participants is another vital part of the research process. As a qualitative researcher, it is vital to ensure all interactions are conducted in a respectful way and to ensure the research process respects the needs of participants (NHMRC,2018). In this research, participants were respected by offering short breaks or rescheduling as required. Interviews were driven largely by the participant and participant family responsibilities were always respected. For example, interview medium such as the choice of video or audio call was the sole choice of the participants.

4.8.1 Respect and justice for participants

The NHMRC guidelines recommend that participants are treated with respect in recognition of their intrinsic value (National Health and Medical Research Council, 2018). This includes respect for privacy and confidentiality. Anonymity, and confidentiality when anonymity cannot be assured,

was a major focus of this research. The nature of survey research ensures anonymity by not assigning any form of identification. Volunteers for the interview phase of this study were recruited via the final question on the survey. They were initially asked to provide a first name and contact number or email address only. On first contact participants were then asked to choose a pseudonym and all data obtained were allocated that identifying feature only, including in audio recording and printed material. De-identification and appropriate storage of data in accordance with Flinders University policy was adopted throughout this study (Flinders University, 2016). Only the primary researcher and academic supervisors had access to this data at any time. Audio recordings and transcripts were stored according to Flinders University and the Social and Behavioural Research Ethics Committee policy, which required that all physical and digital data be stored in a safe secure and accessible location at Flinders University for a minimum of five years after publication (Flinders University, 2019). In this instance digital data were stored on Flinders University one-drive under password protection. This data can be re-identifiable by using a printed key held only by the primary researcher in a secure location. This data included only minimal personal information such as first name and phone number and assigned pseudonym. After the prescribed five-year period, all data will be confidentially destroyed in a secure and safe manner according to Flinders University and Social and Behavioural Research Ethics Committee policy (Flinders University, 2019).

Justice was assured by providing a full explanation of the time commitment to interviews prior to commencement and no undue burden was placed on the participants. Additionally, findings of this research will be disseminated through publications in a timely manner, with copies sent to participants to ensure fair access to the benefits of this research (National Health and Medical Research Council, 2018).

4.8.2 Risk and benefit: Beneficence and non-maleficence

This study did not expose participants to physical harm and psychological harm was minimised. Psychological harm can manifest as discomfort, anxiety or physical distress. To minimise the potential for this form of harm, participants were assured that they could elect to stop the survey at any time simply by closing the browser. Participants were also encouraged to report any feelings of distress to the research team and phone numbers were provided to three online counselling sites – Lifeline, Beyond Blue and BetterHelp. The survey could be taken at the

participants' leisure, they were able to stop or withdraw at any time and their responses are completely anonymous.

Interview-based research, on the other hand, whilst non-invasive, has the potential to cause emotional distress as participants recall and/or retell their decision-making process. In this case the participants were parents of young children and pregnant women who are a vulnerable group. To minimise distress and ensure respect for human dignity, several steps were put in place. Participants were made aware, through the informed consent process, that they were free to withdraw at any time. Their identity was protected using pseudonyms throughout the interview and data-recording process. Additionally, by being alert to verbal and non-verbal cues to distress and offering regular breaks, participant wellbeing was protected. The primary researcher has a background in midwifery and maternal and child health nursing and is qualified and experienced in counselling and interacting with at-risk populations.

4.8.3 Informed consent

Consent in qualitative research is an ongoing process, subject to continuous negotiation and renegotiation, rather than achieved at a single point in time (Klykken, 2021). In this study, the researcher continually monitored for signs of distress and distraction in the participants and offered breaks or rescheduling when these were observed or interruptions occurred (Klykken, 2021; National Health and Medical Research Council, 2018). Many of the participants were parents of young children, who on several occasions needed parental assistance. In this situation the participant was encouraged to meet the needs of the child and was offered the chance to stop the interview and/or continue at another time. On all occasions the participants preferred to continue after a short break. On completion of the interview, participants were offered the opportunity to add to the discussion and were asked if they were still happy for their data to be used for research. All interviewees agreed to this.

Consent in ethnographic research has been described by Klykken (2021) as both a reflexive and ethical tool. In the interview phase of this research, consent took place both prior to, throughout and on completion of the interview, thereby ensuring continuous ongoing consent. A referral process was put in place to an online counselling service for participants who identified the need to discuss issues that the interview raised. This involved referral to counselling services such as Lifeline, Beyond Blue or BetterHelp. All services are available both online and by telephone;

however, none of the participants reported any issues raised because of the interview or through retelling their story.

Consent in netnography is a more complex issue and can be a grey area. Participants on social media sites are not always aware that their posts are to be used for research. However, in this study, the purpose-designed social media site was classified as a Medical Research Page. Additionally, the researcher made frequent mention to the purpose of the site and clarified any confusion that existed. Whilst written informed consent to the use of their content was not possible on this occasion, every effort was made to ensure participants understood the purpose of the site (NHMRC, 2018).

4.9 Method

The research methods covered in this section are those relating to the setting, selection criteria, recruitment and consent.

4.9.1 Setting

The setting for this study was predominantly online both via Qualtrics [XM] and social media, specifically Facebook for recruitment of participants (Qualtrics, 2019). Pregnant women and parents of preschool-aged children were the target population and a paid advertisement on Facebook sought participation from vaccine-refusing members of this group. An example of the Facebook page is attached at Figure 4.3.

Preliminary investigations of online environments took place to position the research within a social networking site with anti-vaccination sentiments. However, due to the COVID-19 pandemic, it proved difficult to identify a social networking site for participation, observation and analysis. Accessing these social networking sites became more difficult upon the declaration of a global pandemic. The pandemic, combined with the release of COVID-19 vaccines, resulted in the forced closure of many social networking sites deemed to have an anti-vaccination aspect. The rationale behind these closures was concern about the risk of harm due to the proliferation of inaccurate information and subsequent loss of public confidence in the COVID-19 vaccination programs (Facebook, 2021). Many Facebook sites that were shut down subsequently rebirthed under names that did not reflect their purpose. Some of these sites, which were closed on Facebook, subsequently reappeared under different names on Instagram. These sites were extremely

difficult to locate and even more difficult to gain access to. For this reason, and to avoid misrepresenting the researcher's presence on a private page, a research-specific Facebook page (Figure 7.1), was established to act as a recruiting point for the exploratory survey and interviews, as well as a medium for open discussions on vaccine choices in pregnancy and early childhood and analysed using netnography. There could be no control over who elected to complete the survey; however, by selecting appropriate demographics for dissemination, it was anticipated that the participants were predominantly from the target group. Additionally, one of the early questions on the survey sought immunisation status. This provided a guide to the participants' beliefs. Vaccine-hesitant parents are not easily identified, therefore some of the participants in this survey may not have vaccine-hesitant characteristics. However, given the results of recent studies that have identified that up to 50% of parents experience a degree of vaccine hesitancy, it is likely that a large proportion of participants would have experienced vaccine hesitancy at some point in their decision-making process (Danchin et al., 2018).

Figure 4.3 Facebook page

The Facebook page established to promote the study was titled "Vaccine Hesitancy in Pregnancy and Early Childhood". This site acted as the primary source of recruitment to all phases of this research. It also acted as a conduit through which prospective participants and interested parties could view the study's progress, comment on varying aspects of the study and contact the primary

researcher. This website released information irregularly with the main aim of promoting and attracting attention to the research. For example, one of the first posts announced the receipt of ethics approval for the study. Subsequent posts promoted the survey and sought participants through both sharing the page and actively advertising the study by means of a paid Facebook advertisement.

4.9.2 Selection criteria and inclusion/exclusion criteria

The inclusion criteria for all aspects of this research were parents of preschool-aged children and pregnant women, over the age of 18 years who identified as vaccine hesitant. Anyone under 18 years and not a parent or pregnant, were excluded from this research. No other inclusion/exclusion criteria were applied to this study for several reasons. Primarily, the initial recruitment for the study was conducted via social media. For this reason, it was considered unlikely that very young or people with a cognitive impairment would volunteer for the study. However, Question 3 in the survey required the participants to confirm that they were over 18 years in line with ethical requirements. As qualitative research relies upon the participants' ability to express their thoughts and feelings, this method of recruitment ensured that only the most appropriate candidates would volunteer. Additionally, as the study aimed to recruit pregnant women or parents, it was considered unlikely the volunteers would be under 18 years of age. The first question on the survey was to determine consent for participation in the study. If participants answered no to this question, the survey was excluded from data analysis; however, all volunteers gave consent, and their data were included in analysis. Additionally, Questions 3, 4 and 17 were designed to ensure participants were over 18 years and were either pregnant or parents. If participants answered no to any of these questions, the data were also excluded from analysis.

4.9.3 Sampling and recruitment

This study utilised convenience and snowball sampling to obtain the opinions of vaccine-hesitant pregnant women and parents. This sampling method uses the most convenient people available. Convenience sampling has been described as the weakest form of sampling and has been associated with potential bias (Polit, 2016). However, in this case, the advantage of convenience sampling is access to parents and pregnant women who have experienced vaccine hesitancy. This form of sampling is the most used method of sampling in some disciplines, and particularly when the target population may be otherwise difficult to locate. Sampling bias was not considered an

issue in this study as this form of sampling was the most likely to gain access to the target population.

However, whilst the use of social media platforms may access a population that is non-representative of the population, in this case, this recruiting method was considered the most suitable method of recruitment. This is because of the nature of pregnant women and parents of young children (Polit, 2016). This group of parents are very technology savvy and have been shown to use the internet and social media, especially Facebook and Instagram, on a daily basis (Tomfohrde & Reinke, 2016).

Recruitment to this study was largely via paid advertising and unpaid dissemination of the ethics approved advertisement on Facebook. A research-specific Facebook page was established to report on the progress of the study and to support the dissemination of the survey as widely as possible. The "Vaccine Hesitancy in Pregnancy and Early Childhood" page was established by the primary researcher primarily as a data-collection tool and clearly stated the purpose of the page, which was predominantly as a conduit for advertising the survey. The researcher announced the purpose of the page on creation and posted highlights and progress of the study. This Facebook page very quickly became an opportunity for both pro- and anti-vaccination advocates to express their beliefs, and at times became highly animated. The posts and memes applied to this Facebook page were analysed using netnography as the methodology (Chapter 8).

The study was also promoted on Twitter and Instagram and was disseminated by members of an international closed group supporting midwives undertaking a PhD. Further promotion of the study and survey dissemination on websites and Facebook pages was undertaken by Healthy Development Adelaide, Still Aware and other closed groups with a focus on maternal, child and fetal wellbeing. Their support is acknowledged and has been invaluable throughout this research.

4.10 Consent

This study was conducted in three parts. The first part was an online exploratory survey (Braun et al., 2020). Participation in the survey was purely voluntary and consent was obtained by selecting a tick box prior to completing the survey. The data provided were completely anonymous and could not be identified or connected to an individual in any way. Participants who volunteered for this phase of the study via the final question on the survey, were asked to provide a first name and a telephone number or email address to enable contact to arrange an interview time and method.

The survey instrument was identified as a potential bias given that only participants who were computer literate would be recruited. As this survey was purely exploratory, the instrument needed to have a broad focus and included both open- and closed-ended questions. After ethics approval was received, the survey was piloted on 29 parents, four of whom also identified as pregnant. The results of this pilot demonstrated that the survey had both face and content validity (Litwin, 1995). Face validity was demonstrated by the participants' willingness to be measured and was confirmed by the academic supervisory team. Content validity was demonstrated by the relevance, comprehensiveness and balance of data obtained (Polit, 2016).

Participants who volunteered for the interview phase of the study were provided with an information sheet describing the study and their role in it. This included information about the goals of the research, the type of data to be collected, the nature of the commitment, risks and benefits involved, their right to withdraw and any funding or conflict of interest issues (Polit, 2016). The information sheet that was provided either in hard copy or electronically is attached at Appendix 7.

Upon receiving permission from the participant, they were asked to provide written informed consent. Participants were advised that they could withdraw from the study at any time and could also refuse to answer any question without retribution. Participants were also advised that if they no longer wished to participate in the study after data collection, they could do so at any time simply by sending a text message to the primary researcher. A standard message thanking them for considering the study would have been sent back to them and any written material provided by them returned by email or post as soon as practical. However, all participants completed interview, and none withdrew after data collection. Audio-recorded data obtained in the semi-structured interviews were immediately deidentified on completion of recording and all completed transcripts recorded the participant's pseudonym only.

Participants were free to respond to the survey and/or respond to the request to be interviewed. By obtaining informed consent from participants, their dignity was maintained. Both the consent form and information sheet are attached in Appendix 7. Participants who completed the survey phase of this study had access to the information sheet which specified the purpose and benefits of the study, who would have access to the data, who to contact for more information and contact details for online counselling services should they be required.

Gaining informed consent from research participants is the cornerstone of ethical research; however, netnography poses some specific ethical issues. A netnographic researcher has the option of being interactive in an online world or purely voyeuristic. Additionally, the information given in an online environment is not necessarily given for the purposes of research, nor is consent given or implied (Kozinets, 2007). Much debate about internet research ethics has questioned whether online interactions are public or private (Munt, 2001). The confusion lies in the nature of the internet, which is arguably neither private nor public (Kozinets, 2007).

Previous research has highlighted that the use of social networking sites as the focus of research presents ethical dilemmas in terms of privacy, confidentiality and respectful representation (Golder et al., 2017; Kozinets, 2015, 2020). Concerns also exist about the participants' inability to provide informed consent. For this reason, netnographic research is often considered to be covert in nature, with the debate over who owns the content inconclusive. According to Kozinets (2015), data in the public domain could be considered a cultural artefact and therefore a public document. Despite this, in compliance with the National Statement on Ethical Conduct in Human Research, and to ensure the privacy and confidentiality of social networking site participants, any identifying information including photos, profile name or pseudonym have been redacted in this thesis and any subsequent publications. Additionally, from the outset, the purpose of the "Vaccine Hesitancy in Pregnancy and Early Childhood" site was made clear and at no time was the purpose of the primary investigator's presence online concealed. Figure 7.2 demonstrates that the social networking site is a research-specific site, and this was continually restated to participants when confusion was evident (Figure 7.3). This was also the case in the "Overheard at Flinders" site where the same ethics approved advertisement was used.

Ideally, informed consent would be gained prior to and throughout the data-collection process; however, the ease of anonymity and the use of pseudonyms in the online environment poses significant logistical difficulties in implementing the informed consent process (Bassett & O'Riordan, 2002). This study included data drawn from two Facebook pages. Any comments added were with full knowledge of the purpose of the page. The "Overheard at Flinders" Facebook page was used to advertise the research project and drew large numbers of sometimes derogatory comments aimed at vaccine-hesitant parents. These comments were used in data collection, but identity was concealed, and pseudonyms applied by the researcher.

4.11 Research design

The use of a blended ethnographic and netnographic methodology benefits from flexibility in the data-collection methods used (DePoy & Gitlin, 2015; Kozinets, 2007). Therefore, this research included three separate approaches to data collection, the results of which were analysed using thematic analysis, triangulated and are discussed in detail in Chapter 9 (Braun & Clarke, 2006). These separate studies included: an online exploratory survey via Qualtrics^{XM}, semi-structured interviews predominantly conducted by phone due to the social-distancing requirements imposed as a result of the pandemic; an investigation of posts on two Facebook pages following the principle of netnography; including an analysis of the comments and posts on the study specific Facebook page as well as some commentary on the Flinders University "Overheard at Flinders" webpage and finally field notes taken throughout the course of data collection (Table 4.3 at the end of Section 4.5 provides a summary of data-collection methods and analysis).

Data collection began with the survey and participants for the interview phase were recruited via the final question in the survey. The advertisement promoting the survey was first published on Facebook in January 2021 and data collection continued until 25th of May when the survey was closed. A total of 123 surveys were completed, and 12 people volunteered for the interview phase including two pregnant women amongst the 12 parents. The survey response rate was unable to be calculated as the percentage of the population who are vaccine hesitant is unknown; however, a recent study suggests that up to 50% of parents experience vaccine hesitancy at some point (Danchin et al., 2018). Whilst an estimated 3.3% of the Australian children are unvaccinated or under-vaccinated, this number provides a guide only to the depth of the problem (Costa-Pinto et al., 2018).

4.11.1 Exploratory survey

The aim of the study was to explore the values, beliefs and choices made by pregnant women and parents regarding their decision not to vaccinate their child/children and to determine the factors that influence this decision-making. Additionally, the objectives of the survey were to answer the first three research objectives, which were to identify when parents and pregnant women make immunisation decisions, to discover from whom and when pregnant women and parents obtain the bulk of their immunisation education, and to explore the factors that influence the vaccine choices parents and pregnant women make. A further objective was to identify if parents and

pregnant women would accept a COVID-19 vaccine. Hence, the survey had a strong focus on questions that would provide these answers (Dillman, 2000, 2014). Additionally, there was a focus on vaccines and concern about side effects, and the preference for a natural lifestyle and focus on salutogenic parenting.

The exploratory survey (Appendix 6) was developed by the primary researcher in conjunction with all members of the academic supervisory team, and was based on the results obtained in the integrative review conducted as part of this research (Ben Natan et al., 2017; Betsch et al., 2018; Clarke, Sirota, et al., 2019; Costa-Pinto et al., 2018; Danchin et al., 2018; Dube, Gagnon, Ouakki, et al., 2016; Giambi et al., 2018; Lama et al., 2020; Rossen et al., 2019; Rosso et al., 2019; Rozbroj et al., 2020; Tomljenovic et al., 2020; Tustin et al., 2018) (see Chapter 2). The exploratory survey included 31 questions with the first question including the information sheet and consent, and the last question (Question 31) seeking participation in the interview phase of the study. Question 2 sought informed consent in the form of a yes/no answer. Questions 2–5 gathered demographic data including participant age, location, pregnancy state etc. The survey questions were expressed in simple English and in a clear and concise manner. The bulk of the questions were simple yes/no/unsure or multiple-choice answers, whilst 13 were open-ended questions allowing for a written response. Data obtained from answers to these open-ended questions were analysed using the six-step thematic analysis as described by Braun and Clarke (2006).

The survey was promoted in several ways, including advertising via both posters placed in public places, such as community notice boards and in suburbs of low immunisation uptake, and a paid advertisement on Facebook. Informed consent was assured by providing full disclosure of the purpose of the study, data-storage requirements and other ethical requirements. This was provided on the information sheet and at the beginning of the survey. Participation in the survey was voluntary and consent was obtained by selecting a tick box prior to completing the survey. Subsequent data collected were anonymous and could not be identified, reidentified or connected to an individual in any way unless the participant also volunteered to participate in the interview phase of the study. Participants who volunteered for the interview phase of the study via the final question on the survey were asked to provide only a first name and a telephone number or email address to enable initial contact to arrange an interview time and method. Only the primary researcher had access to this information, which was stored on a secure Flinders University database under password protection. Ethics approval was obtained from Flinders University Human Research Ethics committee (Appendix 10), on the 1st of December 2020. An annual report

was submitted on 1st December 2021 (Appendix 11). The survey was piloted on parents of preschool-aged children (*n* = 29), four of whom were also pregnant, to evaluate the quality of the instrument and its usability. One change was made after the pilot – the removal of one question. This question had caused confusion in participants, was similar to another question and removed rather than reworded.

Once ethics approval was obtained, the survey was piloted on 29 parents of preschool-aged children, four who identified as pregnant, to evaluate the quality of the instrument. Data from these responses were not included in the final analysis. Feedback on readability, clarity, simplicity and accessibility of the survey was sought. Discussions were conducted with these participants and any difficulty experienced or feedback received was incorporated into the final survey instrument. One question was reported to confuse some participants, and this was subsequently removed from the survey. The data collected from pilot participants were not included in the final analysis. A great deal of consideration went into the length of the survey. Longer surveys often result in participant disengagement; however, the final survey included 31 questions, and this did not present a challenge with 123 surveys completed between January and May 2021. No surveys were partially completed.

The exploratory questionnaire is a relatively new concept but has several advantages in a predominantly qualitative study. It provides a wide-angled lens on a topic and in qualitative research, it is a rare opportunity of gaining diverse data from differing perspectives (Braun et al., 2020). Online qualitative surveys are also an opportunity to give voice to groups who may otherwise remain silent and have the advantage of presenting a series of questions in a fixed order to a population in a safe environment. As this was an objective of this research, the qualitative survey was deemed the most suitable to obtain data from this hard-to-reach group. The vaccine-hesitant population is a group of people who receive a great deal of animosity from the pro-immunisation majority. This method has proven to be successful in other studies where the topic has been sensitive and one where face-to-face interviewing techniques may induce embarrassment or anxiety in the participants (Braun et al., 2020). There are also benefits in using online qualitative surveys when the subject group is marginalised. Vaccine-hesitant pregnant women and parents are subject to considerable abuse from the dominant majority, and this method has proven to be acceptable to them as demonstrated by their willingness to complete the survey. It provides not only anonymity, security and relative safety, but also is an opportunity for this minority group to express their beliefs and concerns in safety. Whilst qualitative studies

are unable to achieve statistical representativeness, it could be argued that an online survey may provide some justification of generalisability (Braun et al., 2020). The results of this phase of the study are presented in Chapter 5.

4.11.2 Semi-structured interviews

The aim of the interview phase was to further explore the values, beliefs and choices made by pregnant women and parents regarding their decision not to vaccinate their child/children and to determine the factors that influence this decision-making. Additionally, this aspect of the research was designed to gain deeper information with a strong focus on gaining an understanding of the experiences of vaccine-hesitant pregnant women and parents. This study included telephone-based semi-structured interviews with two pregnant women and 10 parents. The use of telephone rather than face-to-face interviews was taken as a direct result of the existing COVID-19 pandemic and the requirement for social-distancing measures for infection control. From a methodological perspective, limitations on telephone-based interviews have been identified (BrajkoviČ, 2011). However, there are several advantages in the use of this method. These include decreased travel and costs, versality of the method and access to geographically dispersed participants. Evidence also suggests that participants are more relaxed and can share sensitive information in this medium (Lechuga, 2012; Novick, 2008; Trier-Bieniek, 2012). As vaccine decision-making is often a sensitive issue, telephone interviews were an acceptable option to replace face-to-face interviewing. Open-ended survey questions were designed to form the basis of these interviews and allowed flexibility for the participants to elaborate on aspects important to them. The interview schedule is listed at Appendix 9. This framework allowed the interviewee to speak freely and thereby ensured lengthy and in-depth responses (Polit, 2016). Several techniques were employed by the primary researcher to achieve optimal data were obtained. These included active listening; paraphrasing the responses to ensure accuracy and clarity; funnelling, which involves beginning with a broad open-ended question and then narrowing the topic to specifics; and probing to elicit details or to seek clarity (Polit, 2016; Schneider, 2013). The interviews varied in length between 35 and 75 minutes in duration but averaged 50 minutes. All interviews were audio recorded. Transcription was conducted by Transcription Services Adelaide (Digital and Audio Transcription Services) who had a signed a confidentiality agreement. Participants were also given the option of submitting written data in the form of journals, diaries or a story; however, this option was not taken up. Participants adopted a pseudonym that was used throughout the

interview and no identifying features were attached to the transcripts. An interview guide (Appendix 9) was developed by the primary researcher in conjunction with the academic supervisory team and informed by the results of the literature review (Chapter 2). The main benefit of semi-structured interviews is their flexibility as well as the ability to follow the participant's conversation. This method allows their thoughts to flow without interruption thereby achieving more in-depth communication. The pre-prepared interview guide (Appendix 9) ensured that all areas were discussed at some point during the interview (Galletta & Cross, 2013; Green, 2018).

The results of this phase of the study are presented in Chapter 6. Thematic analysis was undertaken on data obtained from semi-structured interviews using the six-step process as described by Braun and Clarke (2006). Any quotes used in the findings of this research were presented as spoken, with no modification or corrections to language, removal of "um" or expletives.

4.11.3 Netnography

The objective of the netnographic phase was to gain a deeper understanding of the experiences of vaccine-hesitant pregnant women and parents but with a focus on cyberspace and the online experiences of this group. This is an area that is not fully understood. According to Kozinets (2018), both ethnography and netnography can be either observation or participation based. This research used both approaches. This phase gained a thorough understanding of the contemporary influences on the vaccine choices of pregnant women and parents of preschool children. In this case the online communication consisted of posts written by parents on the "Vaccine Hesitancy in Pregnancy and Early Childhood" site. There is strong evidence to suggest that online communities have a significant influence on immunisation beliefs and decision-making (Duchsherer et al., 2020). Evidence suggests that parents show a preference for networks that offer a sense of community and support, as well as providing the opportunity to connect with other like-minded people. Therefore, parents tend to remain connected to and influenced by sites that offer this kind of support and a sense of community (Duchsherer et al., 2020).

The results of the netnographic phase of the research are presented in Chapter 8. Preliminary investigations of online environments took place to position the research within a social networking site with anti-vaccination sentiments. However, due to the COVID-19 pandemic, it

proved difficult to identify a social networking site for participation, observation and analysis. Accessing these social networking sites became more difficult upon the declaration of a global pandemic. The pandemic, combined with the release of COVID-19 vaccines, resulted in the forced closure of many social networking sites deemed to have an anti-vaccination aspect. The rationale behind these closures was concern about the risk of harm due to the proliferation of inaccurate information and subsequent loss of public confidence in the COVID-19 vaccination programs (Facebook, 2021). Many Facebook sites that were shut down subsequently rebirthed under names that did not reflect their purpose. Some of these sites, which were closed on Facebook, subsequently reappeared under different names on Instagram. These sites were extremely difficult to locate and even more difficult to gain access to. For this reason, and to avoid misrepresenting the researcher's presence on a private page, a research-specific Facebook page (Figure 7.1), was established to act as a recruiting point for the exploratory survey and interviews, as well as a medium for open discussions on vaccine choices in pregnancy and early childhood and analysed using netnography.

A small number of posts were initiated on the "Vaccine Hesitancy in Pregnancy and Early Childhood" page to create discussion, and to moderate responses when commentary became aggressive or argumentative. Posts that were researcher initiated are attached at Appendix 13. These specific questions were posted to seek data in areas that had been less addressed in previous discussion threads and to further investigate issues pertinent to the objectives of this research. Full disclosure of the researcher's presence, affiliations and purpose of the study were made on several occasions when confusion about the role of the research social networking site became evident. Examples of these posts are listed below (Figure 7.2). In addition to the purpose-designed Facebook page, data were also obtained from the Flinders University "Overheard at Flinders" page. This page serves as a social media connection for students enrolled at the university.

A small number of posts were initiated on the "Vaccine Hesitancy in Pregnancy and Early Childhood" page to create discussion, and to moderate responses when commentary became aggressive or argumentative. Posts that were researcher initiated are attached at Appendix 13. These specific questions were posted to seek data in areas that had been less addressed in previous discussion threads and to further investigate issues pertinent to the objectives of this research. Full disclosure of the researcher's presence, affiliations and purpose of the study were

made on several occasions when confusion about the role of the research social networking site became evident (Figure 7.2). In addition, to the purpose -designed Business Facebook page, data were also obtained from the Flinders University "Overheard at Flinders University" page. This page serves as a social media connection for students enrolled at the university. An advertisement was placed on this page in the same format as the advertisement (Figure 7.1) for recruitment and to access students who were vaccine hesitant and may have fitted the recruitment criteria. The commentary from students on this page was also analysed and results discussed.

On two occasions during this research Facebook was used as a method of disseminating information about the study and recruitment. An initial paid advertisement was placed on a Research-Specific Business Facebook page to seek participants to the survey and interviews. This advertisement was also placed on the "Overheard at Flinders" Facebook page. On both occasions, significant amounts of unsolicited commentary were posted on these sites. These data were both critical and supportive of the vaccine-hesitant population and is an invaluable example of the types of discussions that take place in a digital environment where people feel safe to express strong beliefs. For this reason, the data will be analysed and included in this research. The results of this phase of the study as well as analysis of the field notes are presented at Chapter 8.

4.12 Data analysis

This section outlines the data analysis process, including analysis of survey data, interview data and Facebook data.

4.12.1 Survey data analysis

Analysis of the survey data was initially undertaken by the primary researcher in consultation with the academic supervisory team. Data analysis incorporated two approaches dependent upon the data type. Descriptive data were collected and analysed using the inbuilt analytical framework of Qualtrics [XM.] Open-ended question responses were analysed manually using thematic analysis (Braun & Clarke, 2006). After reading and rereading the responses, initial codes were generated. Overarching themes were then sought from the codes, which focused the analysis at the broader level. These themes were subsequently reviewed, and names were allocated (Braun & Clarke, 2006). Coding was performed by hand. Initial thematic analysis was performed by the primary researcher. Any queries were addressed in group meetings where consensus and final analyses

took place. This process "offers an accessible and theoretically flexible approach to analysing qualitative data" (Braun & Clarke, 2006, p. 77).

4.12.2 Interview data analysis

Thematic analysis was also used to organise and provide a rich description of the data obtained from the semi-structured interviews, following the six-step guidelines of Braun and Clark (2006). Transcripts of interviews were uploaded into NVivo for identification of codes and themes. The first step was to become familiar with the data (Braun & Clarke, 2006). This involved repeated reading of the transcripts and note taking which subsequently led to initial coding. The next step was to generate initial codes. The codes were then focused into themes (Table 6.1). The themes were subsequently reviewed and reworked at this point whilst others were recoded. The themes were subsequently defined and named. The final step was the report production (Braun & Clarke, 2006). The final codes and themes are listed in Table 6.2.

4.12.3 Facebook data analysis

Facebook data were analysed using both manual and computer-assisted methods. The use of both manual and CAQDAS in the same study is an accepted method of data analysis. It is also accepted practice to swap between manual and CAQDAS methods throughout data analysis (Flick, 2014). Analysis of data collected from the social networking site was conducted using a combination of paper-based iterative and computer-assisted methods. Thematic analysis was employed using the six-step framework of Braun and Clarke (2006). Thematic analysis treats the dataset as a mass of information and the analysis that takes place breaks the data down into small but significant pieces. The first step in analysing the Facebook data was to read and reread the large volumes of posts and memes. Initial codes were generated in collaboration with the supervisory team, and these were subsequently refined and renamed. Netnography studies the realm of social interactions and data varies from written, graphical and visual representations, hence the need for a combination of analysis methods. Initial coding was conducted by hand and themes sought, assisted by NVivo (Version 12) (QSR International Pty Ltd., 2018). Final themes were achieved in collaboration with the academic supervisory team and are listed in Table 7.1.

Table 4.3 Summary of data-collection methods and analysis

Data Collection method	Description	Data Analysis
Online qualitative survey	Qualitative survey	Descriptive statistics. Manual thematic analysis using the six-point approach of Braun and Clarke (2006).
Ethnography	Semi-structured Interviews	Thematic analysis using the six-point approach of Braun and Clarke supported by NVivo (version 12) (Braun & Clarke, 2006).
Netnography	Facebook observation using Kozinets' 12 steps (Kozinets, 2007)	Thematic analysis using the six-point approach of Braun and Clarke supported by both manual and NVivo (version 12) (Braun & Clarke, 2006).
Netnography and Ethnography	Field notes	Thematic analysis using the six-point approach of Braun and Clarke (Braun & Clarke, 2006).

4.13 Rigour and trustworthiness in naturalistic inquiry

The use of the descriptors rigour and validity to describe quality in qualitative research, are much debated. Whilst these remain sought-after qualities in all research, several alternatives have been proposed (Polit, 2016). The most commonly cited framework was originally proposed by Lincoln and Guba (1985), who recommend four criteria for developing quality and trustworthiness. This includes credibility, dependability, confirmability, transferability and authenticity (Polit, 2016). To ensure rigour in this research these criteria were applied. Additionally, the following steps were taken to ensure rigour: careful and methodical planning of each phase of the research, recruitment of parents and pregnant women from diverse locations across Australia who identified as vaccine hesitant, the use of broad inclusion criteria, and all data analyses were confirmed by at least two people.

Credibility refers to the confidence that can be placed in the truth of the data as well as accuracy in its interpretation. In the data-collection phase, several measures were employed to enhance the overall trustworthiness and credibility of the study. These included the use of multiple data sources and the employment of reflexivity and extensive field notes to limit interviewer bias. Additionally, the use of audio recording and verbatim transcription were also employed to support

credibility. In the data coding and analysis phase the use of a transcription service and inter-coder checks enhanced transcription rigour and credibility. Subsequent triangulation of data from all sources also ensured dependability and enhanced credibility (Polit, 2016).

Dependability refers to reliability of the data and whether the findings could be replicated in similar circumstances. This is more difficult to achieve in qualitative research, however, the use of careful documentation and an audit trail, as well as triangulation between data sources, act to support dependability and enhance confirmability. In this research, which employed both ethnographic and netnographic methodologies, the taking of field notes also supported dependability (Polit, 2016).

Confirmability is closely related to objectivity and whether the findings accurately represent the intentions of the participants. In this research confirmability was enhanced using inter-coder checks, the use of multiple data sources and subsequent triangulation. It is important to accurately represent the information provided by participants and avoid researcher bias. Reflexivity plays an important part in maintaining the focus on the experiences and beliefs of vaccine-hesitant pregnant women and parents of young children and reflecting their voices (Polit, 2016).

Transferability is a measure of whether the findings can be applied to other settings. This was achieved by providing adequate descriptive data to demonstrate its potential for application to other contexts. Additionally, the taking of comprehensive field notes, providing a vivid description of the context and the provision of thick descriptions in the presentation of the findings, support transferability. Hence, transferability was achieved by ensuring the reader can gain a proper understanding of the phenomena being researched (Polit, 2016).

Authenticity refers to the fair and faithful representation of the participants experiences and beliefs. This is of primary concern in this research and features as a major objective of the study. To ensure that authenticity is supported in this research, reflexivity and reflexive journaling was employed throughout the study. This can be viewed in the preface of this thesis as its importance in assuring authenticity is recognised as pivotal to the study. Authenticity was also enhanced by audio recording and verbatim transcription of interviews as well as prolonged engagement with the target population. In this research this was achieved by employing multiple sources of data collection including an exploratory survey, interviews and internet access over the course of 12 months in 2021.

4.14 Potential for bias

Bias is an influence that can threaten a study's trustworthiness. To limit potential for interviewer bias, open-ended questions were used, and participants were encouraged to expand on their experiences and beliefs as a vaccine-hesitant parent or pregnant woman. A professional transcription service was used to ensure accuracy of data transcription. Two coders (SS and AD), also referred to as investigator triangulation, were used to reduce the intrinsic bias that accompanies a single-observer study and confirm meaning in data obtained from interviews. Bias can also be introduced into a study when the primary research tool is also the researcher, as is the case in ethnography and netnography. The researcher's background, characteristics and life experiences all act to impose bias into a study. Reflexivity was used to guard against this type of bias and its importance is acknowledged by placing this in the preface at the beginning of this thesis.

4.15 Chapter summary

The aim of this chapter was to provide a detailed account of the research process, discuss the research paradigm, ethical considerations of the study, recruitment strategies, setting, consent process and data collection and analysis methods. This chapter also discussed the methodology chosen for this research. A blended netnography and ethnography approach was considered the most appropriate as it is specifically designed for research in an online environment, is appropriate for answering the research question and for exploring the influences on vaccine-hesitant pregnant women and parents of young children from a cultural perspective, survey design and the participant inclusion criteria. Additionally, trustworthiness and potential for bias was discussed.

Chapter 5 Weighing up the risks: Exploratory survey findings

> Nothing in life is to be feared, it is only to be understood. Now is the time to understand more, so that we may fear less. Marie Curie (n.d.).

The next three chapters present the findings from three elements of complementary research studies. These three studies took place concurrently between January and December 2021. This chapter presents the results of the exploratory survey, a predominantly qualitative online survey conducted via Qualtrics [XM]. A version of this chapter was published and the first page is attached at Appendix 8 with permission from *Women and Birth Journal* (Smith et al, 2022). Whilst adaptations to this chapter were made for the purpose of publication, there is still direct overlap in content and phrasing. Co-author approvals and individual contributions to the article are also attached (Appendix 16).

5.1 Survey

The exploratory survey was designed in conjunction with the academic supervisory team following the guidelines of Braun et al. (2020) and was conducted online via Qualtrics [XM] (Qualtrics, 2019). A total of 106 surveys were completed that enabled the researcher to gain an understanding of vaccine decision-making in pregnant women and parents. Included in the survey were seven demographic questions seeking information on participant age range, immunisation status, place of residence, immunisation status of themselves and their partner, parenting status, ages of their children and pregnancy status. These data were analysed using descriptive statistical analysis. Additionally, the survey contained nine questions seeking information on sources of immunisation information, five questions seeking information on their immunisation opinions and two questions on the current COVID-19 pandemic, including their perception of risk to their children and whether they would elect to immunise their children should a paediatric vaccine become available. Overall, the survey included 20 short-answer questions, 11 open-ended questions that allowed for a written response, six multiple-choice questions and one that employed a Likert scale (Appendix 6).

Vaccine-hesitant pregnant women and parents were surveyed to assess their perceived level of immunisation knowledge, the source of immunisation education and the immunisation status of their children. Their opinion on immunisation in general, and the advice and education they

received during pregnancy was also sought. In addition, the survey investigated the source of that information as well as when the participant began to consider immunisation options. Pregnant women were also asked if they sought other opinions on immunisation and the source of that information. The survey investigated their preferred source of immunisation information, what vaccines they were most concerned about and their perception of risks versus benefits of childhood vaccines.

The answers to the open-ended questions were analysed on a question-by-question basis using inductive thematic analysis (Braun & Clarke, 2006). For instance, after reading and rereading the responses, initial codes were generated. Overarching themes were then sought from the codes, focusing the analysis at the broader level. These themes were subsequently reviewed, and names were allocated (Braun & Clarke, 2006). Coding was performed by hand. Initial thematic analysis was performed by the principal investigator. Any queries were addressed in group meetings where consensus and final analyses took place. Thematic analysis treats the dataset as a mass of information and the analysis that takes place breaks the data down into small but significant pieces (Braun & Clarke, 2006). This process "offers an accessible and theoretically flexible approach to analysing qualitative data" (Braun & Clarke, 2006, p. 77). Finally, the survey sought opinions from all participants regarding their views on the COVID-19 pandemic, their perception of risk to their family and whether they would accept a COVID-19 vaccine for their children if one were offered.

5.2 Demographic data

The survey was opened on 19th of January 2021 and closed on 1st June 2021. A total of 135 surveys were completed. All surveys were completed; however, several participants (*n* = 7) elected not answer some questions. The aim of this research was to explore the values, beliefs and choices made by pregnant women and parents regarding their decision not to vaccinate their child or children, and to determine the factors that influenced this decision-making. It was therefore deemed necessary to avoid skewing the results by including data from parents with pro-immunisation opinions. Hence, only data from participants who stated they were not in favour of immunisation (*n* = 106), were included in the analysis. All participants stated that they were over 18 years of age (100%) (*n* = 106). Gender was not a prerequisite for participation in the survey nor was it asked. Some participants identified as pregnant (14.80%) (*n* = 17) with participant ages

ranging from 18 to 29 years (9.60%) (*n* = 10), 30 to 39 years (41.50%) (*n* = 45), 40 to 49 years (33.30%) (*n* = 35) and 50 years and over (15.60%) (*n* = 16) (Table 5.1).

Table 5.1 Ages of participants

Age (years)	Percentage (%)	Number
18–29	9.60	10
30–39	41.50	45
40–49	33.30	35
50+	15.60	16
Total	100.00	106

5.3 Socio-economic influence using the Socio-Economic Indexes for Areas

Most participants (*n* = 104) in this survey were from Australia with representation from all states (but not the Northern Territory or the Australian Capital Territory). This included South Australia (*n* = 38), Victoria (*n* = 19), New South Wales (*n* = 18), Queensland (*n* = 19), and Western Australia (*n* = 10). However, two participants were from the USA and were unable to be included in this analysis of Australian postcodes, but data from these participants were included in all other analyses (Table 5.2). Data were obtained from participants across 85 Australian postcodes with the lowest Australian Bureau of Statistics (ABS) Socio-Economic Index for Areas (SEIFA) score of 754 on the 1st decile and the highest score of 1150 on the 10th decile (ABS, 2018).

Table 5.2 Country and state of residence

Country/state of residence	Number
USA	2
Australia	104
South Australia	38
Queensland	19
Victoria	19
New South Wales	18
Western Australia	10

SEIFA is a product developed by the ABS that ranks areas in Australia by postcode according to relative socioeconomic advantage and disadvantage, with the mean SEIFA score of 1000 (Australian Bureau of Statistics, 2018). All the 104 Australian-based participants revealed their postcode, with the mean SEIFA score being 1002 and the median 1008, with a range of 396. This data indicate that most respondents were from areas of middle- to high-socioeconomic advantage. These data were used to compare the self-reported level of childhood vaccine refusal with socioeconomic status. Analysis was conducted using IBM SPSS (version 25) to compare partial or full vaccine refusal with SEIFA score according to postcodes using an analysis of variance (ANOVA). Although the sample size obtained in this research is too small to enable a conclusion on this issue, these results suggested a trend for vaccine refusers to reside in areas of higher socioeconomic status $F(1,82) = 2.50$, $p = 0.118$ (IBM Corp., Released 2017). These results were supported by some participants who stated that they "*immunise only enough to continue to receive government support" (*Participant 35*)*. Hence, these results could indicate that the No Jab No Pay legislation introduced by the Australian Government had more effect on people of lower- to middle-economic status, whilst people of higher socioeconomic status were able to survive without government support. The legislation was described as "*taking advantage of lower socioeconomic families*" and a "*coerced choice*" (Participant 72). For some families ($n = 7$)) the No Jab No Pay legislation resulted in the loss of a substantial second income for a minimum of five years or until a child commenced schooling. These results support the findings of Helps et. al. (2018) which demonstrated the legislation can result in financial hardship for some and a sense of marginalisation for others.

5.4 Immunisation status

Participants who were not in favour of immunisation (*n* = 106) included a large number who were not fully immunised (57.60%) (*n* = 61), some who were fully immunised (30.20%) (*n* = 32) and a small number (12.30%) (*n* = 13) who were unsure of their current immunisation status. Additionally, some stated that their partner was fully immunised (33.00%) (*n* = 34), whilst many stated that their partner was not fully immunised (45.20%) (*n* = 47) and some were unsure (22.12%) (*n* = 23). All identified that their children were not fully immunised or not immunised at all. Two participants did not respond to this question (Figure 5.1).

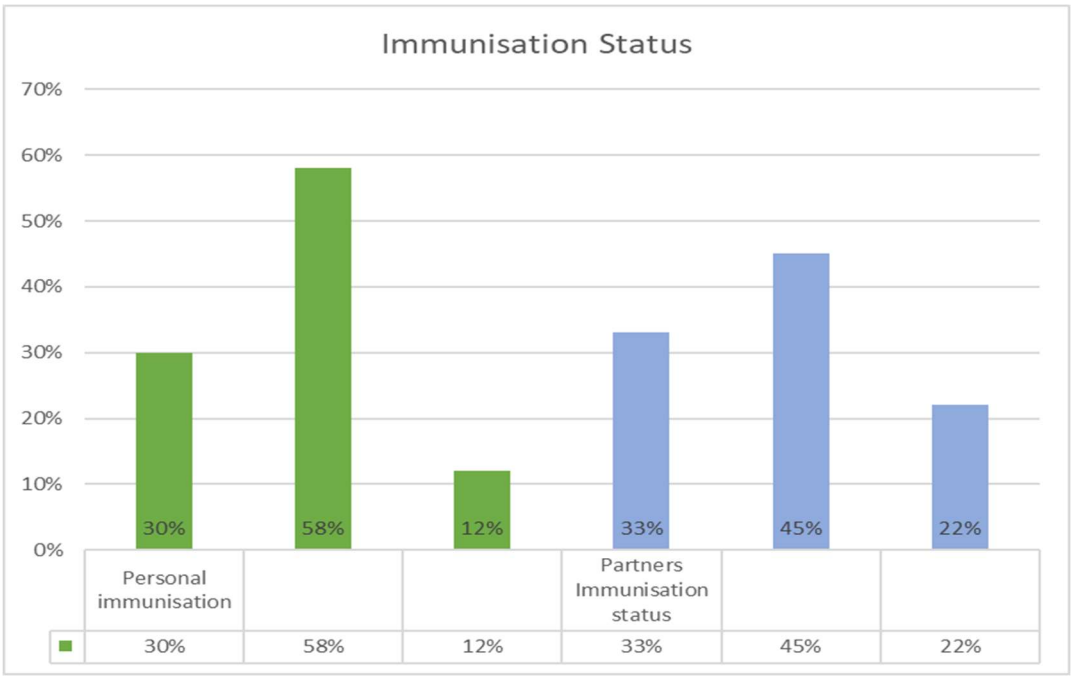


Figure 5.1 Immunisation status

5.5 Personal immunisation belief

This survey had a strong focus on personal immunisation beliefs as well as factors that influenced decision-making. Of the 106 survey participants, most (87.80%) (*n* = 93) clearly stated that they were not in favour of immunisation, whilst a small number (12.30%) (*n* = 13) identified as undecided. This question also sought in-depth feedback from participants by asking why they were not in favour of vaccination.

In response to the question, “Are you in favour of vaccination? If not, can you tell us why?” 12 initial codes were identified: vaccine content, vaccine reactions, insufficient information, corruption in health and pharmaceutical companies, pro-choice, risk versus benefits, financial

constraints, too many vaccines too early, religion, vaccines are unnecessary, no vaccine liability and no adverse event liability. From these initial codes, three main themes emerged: vaccine safety concerns, legal issues, and a strong preference for personal choice or pro-choice. Analysis of these themes is discussed below.

5.5.1 Vaccine safety concerns

Vaccine safety was a major consideration for participants. Concerns raised largely followed the risks-versus-benefits debate, with many participants rating the risks associated with side effects of vaccines to be far greater than the risks associated with acquiring the diseases. One participant stated, *"Some vaccines are riskier than the diseases they protect from"* (Participant 42). Additionally, concerns were raised about vaccine content, with one participant stating, *"I believe many vaccines contain substances that are unhealthy"* (Participant 1). Vaccine reactions including vaccine injury, insufficient testing of vaccines and the timing and number of vaccines given to children were also raised by multiple participants. One participant stated, *"There are way too many and they are given too soon"* (Participant 65). Another stated, *"The schedule is too heavily loaded. The increase since our own childhood is ridiculous, and many vaccinations are not warranted given the actual risk of the disease"* (Participant 77).

Another participant discussing immunisation stated, *"It has not been proven safe, effective nor for the benefit of society"* (Participant 37). Similarly, participants expressed concerns about the apparent declining health of children, *"Health decline in children, seeing firsthand vaccine injury, the ingredients are terrifying"* (Participant 63). Additionally, the issue of personal immunity was raised by one participant who stated, *"Our bodies have their own way of creating immunity and adding dangerous chemicals only creates problems to our systems"* (Participant 26). Further:

> *I am a primary school teacher and have witnessed the deterioration of children's health from the 80s before vaccines were granted blanket immunity removing any incentive to do safety studies and the consequent over vaccination of children. My oldest is vaccine injured. (Participant 8)*

5.5.2 Legal issues

This theme included concerns about insufficient information being provided about vaccine content, hence not achieving the legal requirement for informed consent. Other issues raised

included corruption in both the health and the pharmaceutical industry, the lack of liability and poor adverse-event reporting. Several participants believed that there was *"insufficient safety data"* (Participant 72) and definitely *"not enough information given to make informed consent"* (Participant 7). Another participant asked, *"Why have the vaccine companies been made exempt from liability?"* (Participant 102). Similarly, the *"lack of proper reporting on adverse reactions"* was raised on several occasions. Whilst it is a legal requirement of all healthcare professionals to provide adequate information to achieve informed consent, parents in this study believed this requirement was not being met. Additionally, whilst reporting of adverse events is routinely undertaken with data freely available on the Therapeutic Goods Association (TGA) website, some parents expressed distrust in this information and held a general distrust in the pharmaceutical and medical industries in general.

5.5.3 Pro-choice

This theme was linked strongly to an individual's right to decide what and if any vaccines were right for their family, *"I believe everyone has the right to choose whether themselves or their children are vaccinated"* (Participant 15). Resistance to the term vaccine hesitant became apparent in responses to some questions. Some expressed frustration and irritation at the term and its suggestion that they may be undecided or hesitant about their decisions not to vaccinate their children, *"We are not hesitant; we want to be able to make an informed decision"* (Participant 47). Some participants linked this to the No Jab No Pay and No Jab No Play legislation, *"I am in favour of one having the choice to vaccinate, without mandate or coercion from the government by withholding family payments or excluding my child from certain centres/activities* (Participant 10).

From these responses it can be assumed that some participants believed that the No Jab No Pay and No Jab No Play legislation is a form of mandate. Whilst this is not the intention of the legislation, these responses suggest that it may be time for this legislation to be revisited. There is also evidence to suggest that support for vaccine mandates may be high in Australia (Smith et al., 2020).Whilst the term vaccine hesitant is a poor descriptor for a proportion of the parents involved in this research evidence suggests that at least half of Australian parents have been hesitant about immunising their child at some stage (Danchin et al., 2018). There is also evidence to suggest that support for vaccine mandates is high in Australia (Smith et al., 2020). For these reasons, the term vaccine hesitant was retained throughout this thesis.

5.6 Pregnancy and immunisation

Pregnancy is a time when information and advice is essential to decision-making, which can impact both the pregnant woman and the fetus/infant. A small number of participants (16.00%) (*n* = 17) identified as currently pregnant, but most stated that they were not pregnant (84.00%) (*n* = 89). However, most participants had been recently pregnant, and for this reason their opinions were valued and were included in data analysis.

There are currently three vaccines recommended for pregnant women, pertussis (whooping cough), influenza and COVID-19 (Pfizer) vaccines (Australian Government Department of Health, 2021d). Pregnancy places women at considerable risk of morbidity and mortality from infection and whilst there are limited studies on the impact of COVID-19 acquired in pregnancy it is thought to exacerbate these risks (Arthurs et al., 2021; Smith et al., 2021) Of the 106 survey participants most (68.90%) (*n* = 73) were advised to receive vaccines during their pregnancy, whilst some received no recommendations to be immunised (25.50%) (*n* = 27) or were unsure (5.70%) (*n* = 6) (Figure 5.2).

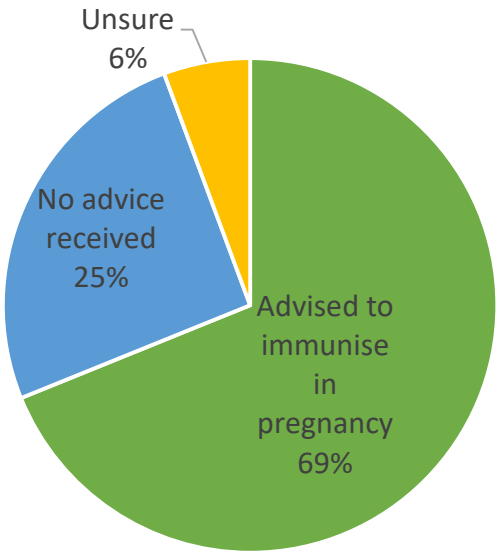


Figure 5.2 Immunisation advice during pregnancy

Having examined the number of participants who received advice regarding immunisation in pregnancy, the survey also sought information on the sources of advice. Of the 106 participants, many stated that their general practitioner provided immunisation information during pregnancy (32.90%) (*n* = 65), whilst a similar number received information and advice from their nurse or midwife (32.30%) (*n* = 64). Only a small number stated that they received information from an

obstetrician (15.70%) (*n* = 31). Friends, family, and other sources also featured as sources of immunisation information (19.20%) (*n* = 38). The sources of immunisation information are listed in Figure 5.3.

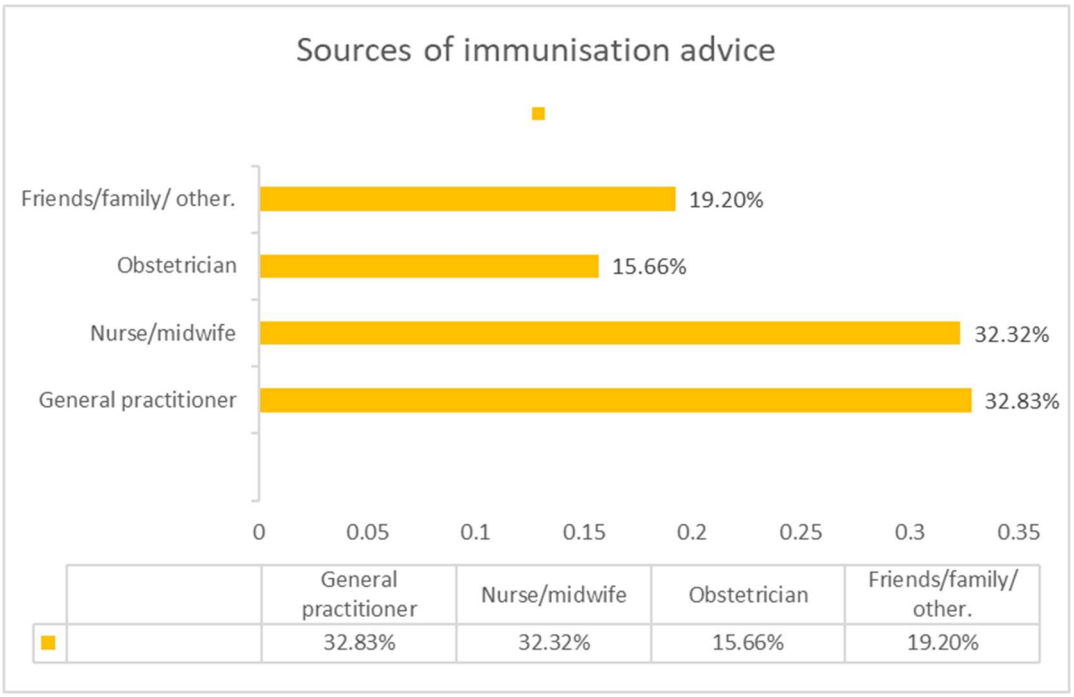


Figure 5.3 Sources of immunisation advice

Participants were also invited to provide information on the additional sources of information they sought, including information provided by tertiary-level providers such as specialists, scientific sources, academic journals, inserts from vaccine packets and government websites. The results suggest that the sources of immunisation information were largely from healthcare professionals, predominantly general practitioners, nurses and midwives, and only a few received information from their obstetrician. However, many participants included additional information sources. This information was allocated codes and subsequently themes. Five initial codes were identified: medical sources, academic sources, allied health, self-research and no information. These codes were then allocated to three themes: tertiary-level information providers, media and allied health, and personal sources. Several participants cited "*academic studies and peer reviewed papers*" (Participant 62) and "*vaccine inserts*" (Participant 57) as important sources of information. Additionally, allied health sources, friends and family members were also identified. The quality of information received ranged from none to considerable self-research. One participant stated, *"I can't remember anyone giving me [immunisation] information"* (Participant 65). Another stated:

I was asked if I wanted to get the vaccines by both my GP and midwife, I explained that I would not be and gave my reasons. As they felt that I am making an informed decision they respected my choice. (Participant 63)

Immunisation information was also received from alternative health sources including information from both homeopathic and naturopathic personnel. One participant cited "*general consensus*" (Participant 50) as a source of information but failed to elaborate. Personal and self-research was also cited as a source of immunisation information, with participants listing multiple links to media sources (*n* = 15), including *"the internet and social media*" and *"thousands of horror stories on the internet*" (Participant 60). These social media sources were largely American and included "Children's health defense" a site operated by Robert F. Kennedy Jr. and other sites with a predominantly anti-vaccination stance (*n* = 132).

When asked what vaccines the participants would accept in pregnancy, most participants (90.65%) (*n* = 97) stated that they would accept no vaccines during pregnancy, whilst a small number stated that they would accept pertussis (whooping cough) (4.70%) (*n* = 5), one (*n* = 1) stated they would accept the influenza vaccine and some (3.80%) (*n* = 4) stated that they were unsure. There was considerable concern expressed about the safety of vaccines in pregnancy. Issues raised ranged from concerns about vaccines being unsafe (*n* = 65), untested and with insufficient data to support their use (*n* = 17). Religious grounds were cited by one participant based on vaccine content; however, most were concerned about the lack of testing, including the lack of studies on the long-term effects of pregnancy immunisation on children. The low efficacy rate of the influenza vaccine was also cited as a consideration, as well as a perceived increased risk of miscarriage. One participant stated, *"They are not tested for safety in pregnancy, nor have they been tested for carcinogenic potential, there are risks to unborn child"* (Participant 42).

There is evidence to suggest that pregnancy is the time when both pregnancy and childhood immunisation decisions are made (Danchin et al., 2018). Participants were asked, "*Did you receive advice on childhood immunisation during your pregnancy?"* Most (64.80%) (*n* = 68) participants stated they did receive information on childhood immunisation during their pregnancy, whilst some (30.50%) (*n* = 32) did not receive any information or were unsure (4.70%) (*n* = 5). One participant did not respond to this question. Participants were also asked whether they began thinking about childhood immunisation during their pregnancy. Of the 106 participants, most parents (70.80%) (*n* = 75) agreed that they began thinking about childhood immunisation during

their pregnancy, whilst some (29.30%) (*n* = 31) stated that they did not consider childhood immunisation whilst pregnant. Figure 5.4 presents the data on advice received during pregnancy.

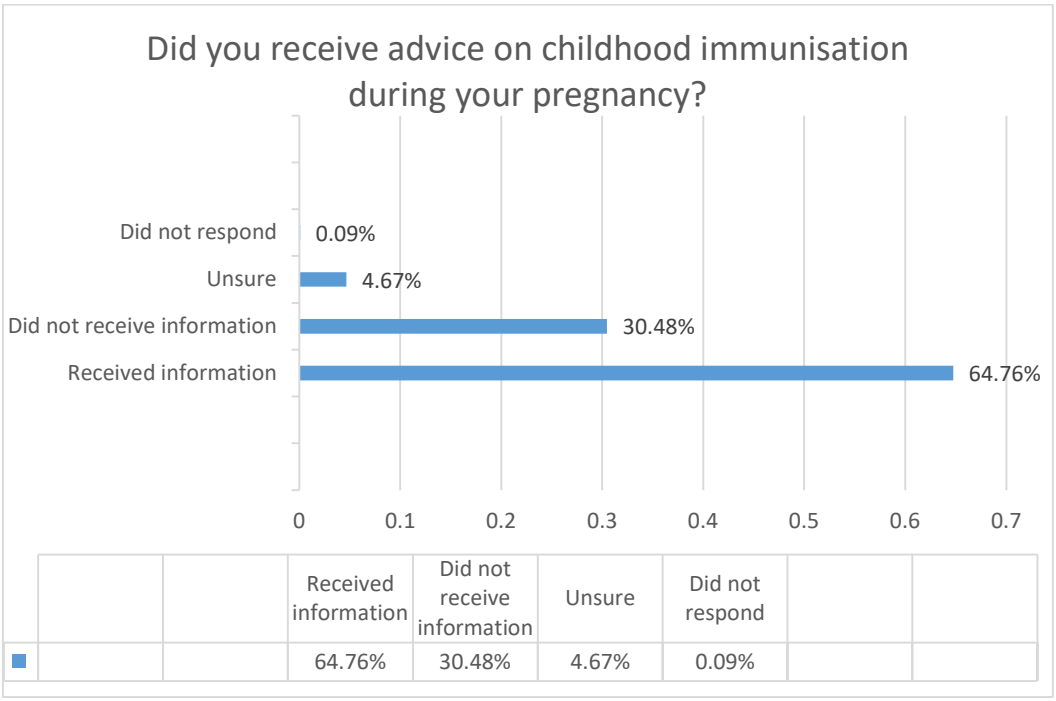


Figure 5.4 Advice on childhood immunisation during pregnancy

Participants were asked whether they sought differing opinions on the risks and benefits of immunisation. Most participants (65.10%) (*n* = 69) stated that they had sought different opinions on the risks and benefits of immunisation during their pregnancy, whilst some did not (31.20%) (*n* = 33) and some were unsure (3.80%) (*n* = 4). This question asked, "*What was the source of this information?*" Many responses were received to this question. Eight initial codes were generated, and five themes emerged from this data: alternative sources, official sources, the internet and social media, friends and family, and allied health. One respondent reported reading Hansard from the trial of Dr Andrew Wakefield, a former British physician, who was struck off the medical register because of fraudulent research that was published in *The Lancet* in 1998 (Participant 45). This research has subsequently been disproven and his findings of a link between the MMR vaccine and autism were debunked; however, not before creating considerable anxiety amongst parents (Miller & Reynolds, 2009). This continues despite the evidence.

A variety of sources were included in response to this question about the source of information. These ranged from traditional sources to more alternative sources. Books *(n* = 8*),* homeopaths *(n* = 6*),* general practitioners (*n* = 20) and nurses/midwives (*n* = 21) were cited, as were other

sources, such as the WHO website and other public health authorities. Social media sites such as the "*Australian vaccine information network, vaccine podcasts, books and doctors who tell the truth*" (Participant 4), were also cited as sources of information on the risks and benefits of immunisation. The diverse nature of resources used by participants in this research suggests a desire for truth. With sources ranging from the WHO to anti-vaccination sources such as the Australian Vaccination Network, the results are likely to be conflicting and cause fear and confusion.

5.7 COVID-19 concerns

The effect of the COVID-19 pandemic and access to three newly approved COVID-19 vaccines are factors that impact both pregnant women and parents. The vaccine is included in pregnancy vaccines and became available for children over five years in 2022 (SA Health, 2021a). This survey also investigated participant opinions on both the pandemic and vaccines. Most participants believed the current COVID-19 pandemic was of minimal risk to their children (89.50%) (*n* = 94) whilst a small number (3.80%) (*n* = 4) agreed it was a risk or were unsure (6.70%) (*n* = 7). One participant did not respond to this question. Participants were asked whether they would elect to give their child a COVID- 19 vaccine if one were available. All participants who responded to this question stated they would not choose to immunise their children (100.00%). Two participants did not provide a response to this question. Participants expressed greater concern about the vaccines than the potential risk of COVID-19 disease. One participant cited a "*0.0006% risk of children catching the disease"* (Participant 103) whilst others were very concerned about the new messenger ribonucleic acid (mRNA) technology in use (*n* = 15).

> *Distrust in the system. No animal trial phases for COVID vaccine. No long-term studies. No children in test data. Already 329 deaths reported in VAERS [Vaccine Adverse Event Reporting System] from it let alone disabilities listed. So no thank you to being a guinea pig when there's such a high recovery rate and we focus so highly on keeping our bodies healthy to be able to fight recoverable viruses. (Participant 38)*

At the time of this research COVID-19 was in its second year, and information about the disease and efficacy of the vaccines was still emerging. Parents in this study demonstrated considerable fear of the vaccines but little to no fear of the disease. As a result of the global pandemic,

Facebook and other social media platforms closed sites that displayed anti-vaccination beliefs. This acted to remove a great deal of inaccurate immunisation information. However, misinformation was still accessible, often through sites rebirthing under names and across different platforms that did not reflect their purpose. Anecdotal evidence from the participants suggests that Instagram became the platform of choice for anti-vaccination sites; however, no evidence was found to support this.

5.8 Parents and children

Having examined the impact of vaccine hesitancy in pregnancy, the survey addressed issues affecting parents and their decision not to immunise their children. Participants were asked to identify whether they were a parent or caregiver of a child/children. Most parents participating in this survey (63.20%) (*n* = 48) had children aged 3–5 years. A lesser number (11.80%) (*n* = 9) were parents of children aged 2–3 years, (15.80%) (*n* = 12) were aged 1–2 years and (9.70%) (*n* = 7) under 1 year. Several participants in the study did not respond to this question (*n* = 30) Figure 5.5).

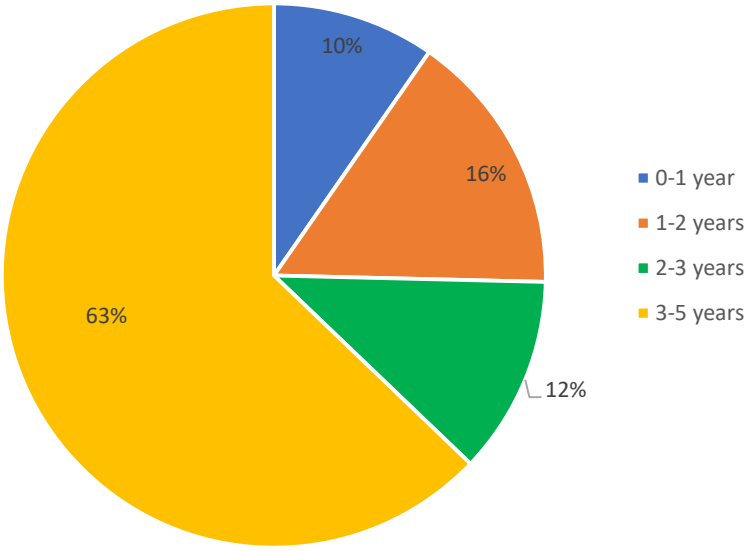


Figure 5.5 Ages of children

5.8.1 Children's immunisation status

Many parents (70.70%) (*n* = 65) stated that their children were unimmunised, whilst some were immunised (29.40%) (*n* = 27) and some participants did not respond to this question (*n* = 14). A small number of participants stated that some of their children were partially immunised (49.50%) (*n* = 48) whilst most were not partially immunised (50.00%) (*n* = 49). Participants were also asked

whether they were considering immunising their children but with the intention of delaying it. Most participants (74.20%) (*n* = 72) answered no to this question, whilst some answered yes (23.70%) (*n* = 23) and a very small number were unsure (2.10%) (*n* = 2). Some participants did not provide a response to this question (*n* = 11).

This question also contained an open-ended component that asked which vaccines they would delay. Responses varied from *"delaying all vaccines"* (Participant 72), to refusing or delaying selected vaccines including MMR, chicken pox and Hep B. These responses did not highlight a specific vaccine of concern, rather a general anxiety surrounding all vaccines. The responses to this question did, however, highlight the influence of the No Jab No Pay and No Jab No Play legislation. One participant stated that they were immunising their child/children *"for childcare purposes only, but really don't want to, but as a single mum on low income I don't have much choice if I wish to return to work sooner than 5 years [school age]"* (Participant 89). This participant felt that immunising her child was the only way that she could access childcare, as not immunising would have precluded her child from attending. This would have also precluded her from gaining employment to support her family. Another stated that they were delaying all vaccines until *"they can make the choice themselves as consenting adults"* (Participant 90). The variety of responses to these questions suggest that parents in this research held a variety of reasons for accepting or rejecting vaccines. Some of these were driven by strong beliefs, others by anxiety whilst some were driven by financial needs. Figure 5.6 presents the level of knowledge participants had about the risks and benefits of immunisation.

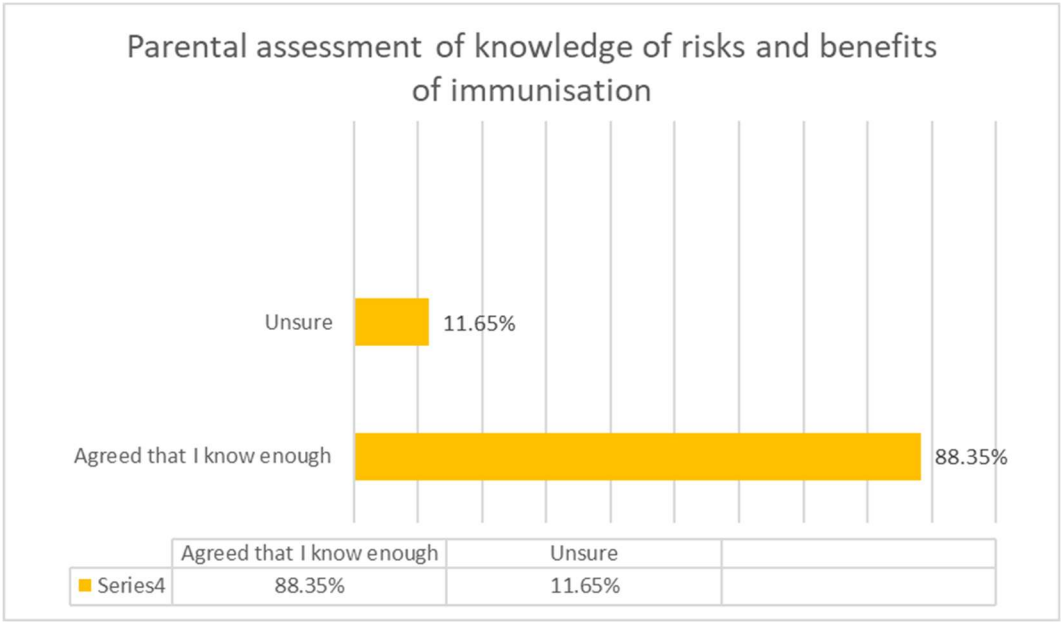


Figure 5.6 Parental knowledge of risks and benefits of immunisation

5.9 Risks of vaccines versus benefits debate

Participants in this research were asked to assess their knowledge of the risks and benefits of immunisation. A high number (88.30%) (*n* = 92) believed they had a good understanding of the risks and benefits. Additionally, many participants strongly agreed that vaccines were more dangerous than the diseases they protected against (91.30%) (*n* = 94), whilst a small number disagreed (3.90%) (*n* = 4) or were unsure (4.90%) (*n* = 5). Three participants did not provide a response to this question. An open-ended component was included that asked what vaccines parents were most concerned about. Responses to this question ranged from *"all of them. Nothing will beat natural lifelong immunity. Vaccines carry the potential to destroy your immunity. Why do you think allergies and autoimmune diseases are on the rise?* (Participant 38). Participants also expressed concerns about specific vaccines and a preference for natural immunity. Additionally, parents expressed concerns about most scheduled vaccines as well as vitamin K (Konakion), a vitamin supplement given at birth to prevent vitamin K deficiency bleeding of the newborn, a condition that can cause bleeding into the brain and is at times fatal (Pairman, 2019a, 2019b). Concern was also raised about the new mRNA COVID-19 vaccines, whilst others had more general concerns. Most participants strongly agreed or agreed that they knew enough about the risks and benefits of immunisation (88.40%) (*n* = 91), whilst a small number disagreed, strongly disagreed or were unsure (11.70%) (*n* = 12). Three participants did not provide a response to this question (*n* = 3).

> *There is a reason for concern regarding all vaccines. All vaccines should be considered dangerous medical interventions. When dealing with otherwise entirely healthy members of the population, there must be transparency about the risk/benefit. It should not be one size fits all, nor should vaccination be dismissed as 'safe and effective' without due attention given to the reality of side effects. (Participant 70)*

Figure 5.7 illustrates the results for the question about risks and benefits of vaccines.

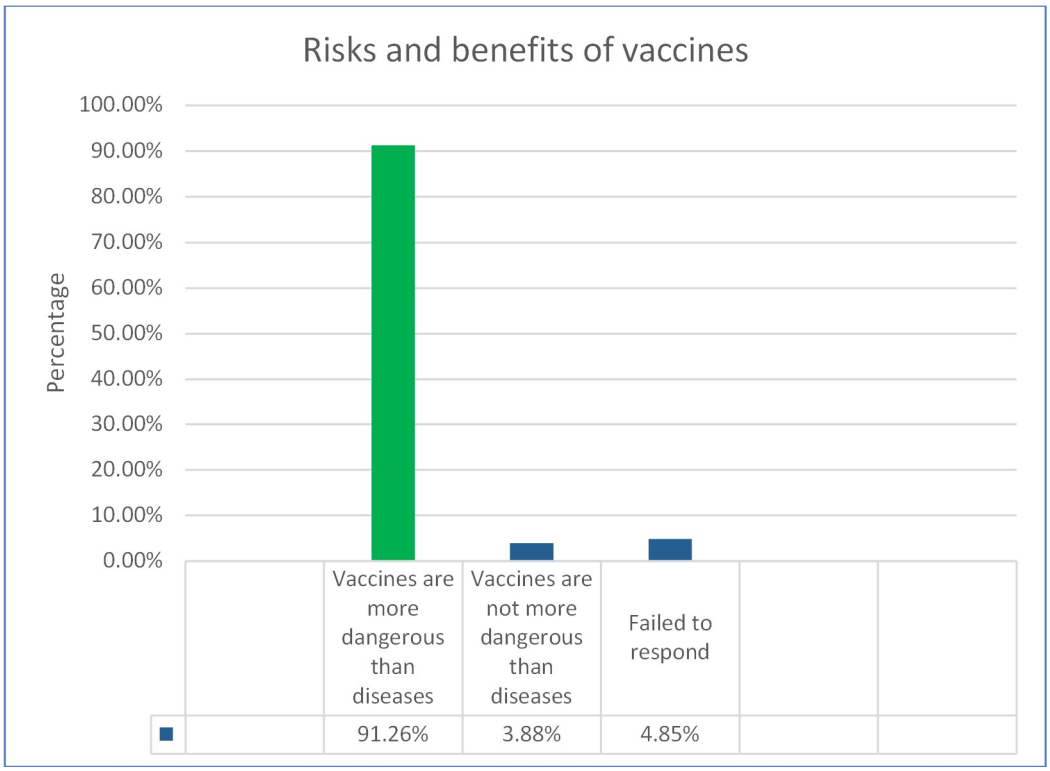


Figure 5.7 Risks and benefits of vaccines

Another key factor in vaccine decision-making is the immunisation information received by pregnant women and parents. Participants reported using a wide variety of information sources including healthcare practitioners, the internet and social media, friends, and family. They also sought additional immunisation information from a variety of other sources. A large number stated that they relied on scientific evidence (*n* = 95). Medical professionals, including general practitioners (*n* = 86), midwives and nurses (*n* = 96) were also a popular source of immunisation information, whilst the internet (*n* = 64) and social media (*n* = 39) featured prominently in information sources. Unexpectedly, friends and family were also influential with some (*n* = 52) seeking information in this area. However, nurses and midwives remain one of the most cited and trusted source of immunisation information (Figure 5.8).

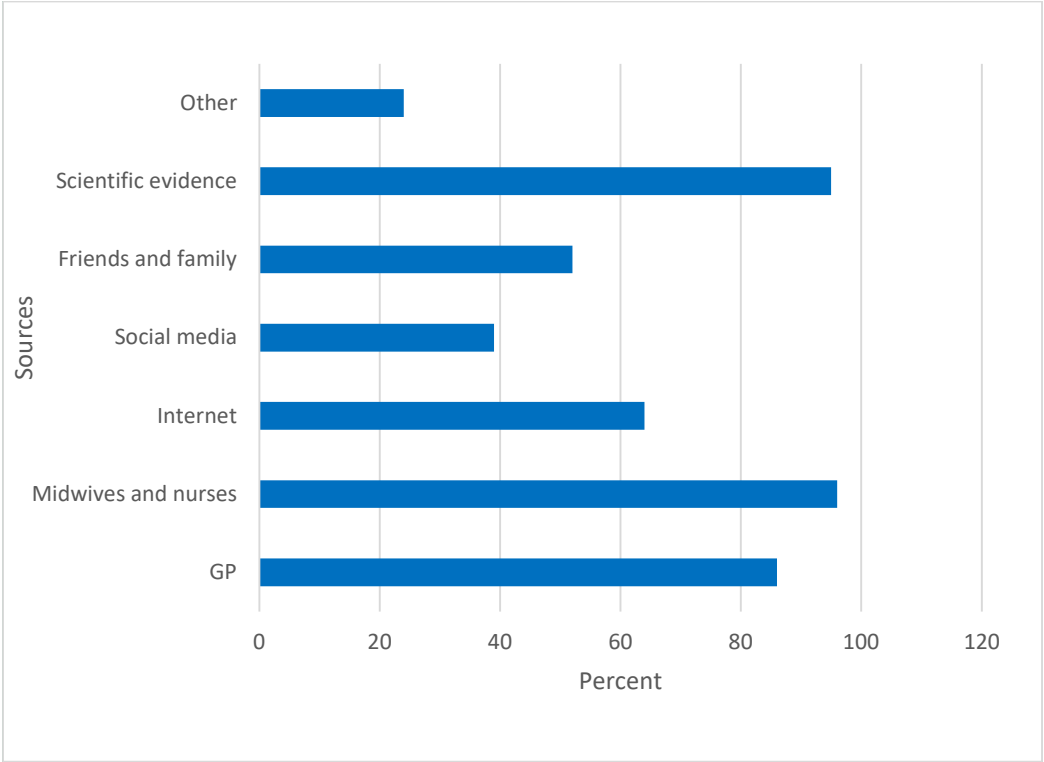


Figure 5.8 Sources of immunisation information

Most participants stated that their source of immunisation information was chosen based on soundness and trustworthiness. This was despite those sources ranging from social media platforms to internet-based websites and allied health practitioners. Perceived financial gain was a reason provided to reject information from various sources. Several participants (*n* = 12) stated a preference for information from family, doctors and nurses who *had "firsthand experience in the area of adverse reactions"* (Participant 45). However, other participants expressed faith in websites such as Children's Health Defense (*n* = 22), books and videos by practitioners, such as Dr Suzanne Humphries (*n* = 18) – sources with known anti-vaccination stance. Concern was raised by several participants about the untrustworthy nature of the pharmaceutical industry, which was referred to as Big Pharma, as well as the need to gather information from a variety of sources (Abadie, 2010). *"I didn't want to rely on just one source, but personal experience with family history of adverse reactions is hard to ignore".* (Participant 27) This participant used the following sources: general practitioner, naturopath, books like *Raising a Vaccine Free Child*, and personal experience with family reactions to vaccines.

In addition to information sources, evidence suggests that negative immunisation experiences can adversely affect future decision-making (Betsch et al., 2018) Participants were asked whether they or someone they knew well had a negative experience during or after an immunisation which may

have affected their decision to not vaccinate. A large number answered yes to this question (90.20%) (*n* = 92) whilst only a few (9.80%) (*n* = 10) answered no to this question. Four participants did not respond to this question. This question also included an open-ended component which sought more information. Participants included a wide variety of responses to this question ranging from experiences of seizures (*n* = 8) (Kawasaki disease, autism, and SIDS (sudden infant death syndrome) (*n* = 15), Guillain Barre Disease and death (*n* = 5).

From the responses to this question, it was evident that many factors influence parents' decisions to refuse some or all vaccines. These ranged from the source of immunisation information, including potential bias due to financial incentive, to knowledge or experience of previous adverse events. However, it was also evident that despite the participants' confidence in their understanding of the risks and benefits of disease, these beliefs were not always based on reliable information.

5.10 Alternative practices

One factor evident in other studies is the use of alternative practices to support health and wellbeing (Helps et al., 2019). Participants were asked about alternative practices used to support their child's immunity. Many responses highlighting a variety of practices were received, which were allocated codes and subsequently themes. Nine initial codes were identified: allied health practitioners, alternative practice, mental health, diet, lifestyle choice, emotional health, natural immunity, reduced exposure to chemicals and public health. These codes were then allocated into four main themes: alternative therapies, lifestyle factors, dietary practices and supplements, and public health factors. Homeoprophylaxis (*n* = 7) or the use of highly diluted preparations to prevent infectious diseases was mentioned, as were diet and long-term breastfeeding (*n* = 35) (Klotter, 2016). One pregnant participant who was not yet a parent stated, "*My child has not been born yet, is due in August, but I intend to breastfeed them and provide them with a healthy lifestyle of nutritious foods, time outdoors, exposure to others and alternative medical practices*" (Participant 18). Homeoprophylaxis has been shown to have no effect on preventing disease (Loeb et al., 2018). One participant responded to this question by stating what she used to promote health:

> *I do not know if this is considered alternative however we eat mostly organic and gluten free diet, we use essential oils and have used homeopaths. We also regularly*

use Chinese herbal supplements for immune boosting including astragalus, reishu [a supplement] and echinacea. (Participant 28)

The use of alternative practices was evident among a proportion of participants in this study. This could be attributed to the fact that only vaccine-hesitant parents and pregnant women were included in this research. However, whilst these practices were adopted by a proportion of parents, equally as many did not use alternative practices. There was also no evidence that alternative therapies or the use of alternative practitioners had any influence on vaccine decision-making.

5.11 Chapter summary

This chapter presented the results of the exploratory survey. A comparison of participant socioeconomic index indicated a trend for participants with a strong anti-vaccination stance to reside in areas of middle to high income. This could be attributed to the No Jab No Pay legislation introduced by the Australian Government to promote vaccine uptake, which had a more positive effect on people of lower- to middle-economic status in that they were more likely to immunise their children, whilst people of middle to higher socioeconomic status were more likely to refuse immunisation because they could manage without government support. As the exploratory survey included only participants who held anti-vaccination beliefs, the results indicate that most participants would accept no vaccines during pregnancy. This survey confirms this, with most participants stating they began thinking about immunisation during their pregnancy. Of those who did receive advice, nurses and midwives were the most cited and trusted source of immunisation information in pregnancy. This is despite nurses and midwives currently receiving minimal undergraduate immunisation education. General practitioners also featured as an important source of immunisation information; however, only those women who elect a shared care or midwifery model of care, will have access to either of these important sources. Other significant areas of concern were vaccine safety issues, legal issues, aspects of personal choice, vaccine content and concern that the risks of immunisation outweighed any benefits. Distrust was also placed on the pharmaceutical industry and whilst vaccine package inserts were a source of information for some, there was considerable overall distrust of Big Pharma. Finally, participants objected to the term vaccine hesitant, being of the opinion they were not hesitant but were in fact pro-choice.

Chapter 6 Labelled, Marginalised and Bullied: Interview Findings

> It takes no compromising to give people their rights. It takes no money to respect the individual. Harvey Milk (Milk et. al., 2013 p.85)

Chapter 5 presented the results of the exploratory online survey, which demonstrated that vaccine decision-making begins in pregnancy. In addition, the previous chapter revealed the important role of nurses and midwives in immunisation promotion and provision, despite being underprepared for their role. This chapter presents the results of the interview phase of this study, which explored the beliefs, influences and experiences of vaccine-hesitant pregnant women and parents. Interviews were conducted with 12 participants with interview duration ranging from 35 to 75 minutes. All participants were female, despite gender not being a requirement for this research, 11 were parents of at least one child, one participant was pregnant with her first child and two others were pregnant but also had other children. Demographic data are included in Table 6.1. The aim of this phase of the study was to take an inductive approach, independent of the results obtained in the survey phase of this research, to gain an in-depth understanding of influences on vaccine decision-making, and to give a voice to vaccine-hesitant parents and pregnant women. The three independent studies conducted in this research, act as a form of triangulation with the results subsequently compared and merged in the discussion. A modified version of this chapter is currently under peer review for publication. Whilst adaptions to this chapter were made for the purpose of publication, there is still direct overlap in content and phrasing. Appendix 12 provides details of the authors. Co-author agreements and contribution to research are attached as Appendix 16.

Table 6.1 Demographic Data

Name (pseudonym)	No. of children	Immunisation status	Pregnancy status
Al	2	Partially	Not pregnant
Annie	5	Partially	Not pregnant
Arlene	1	Unimmunised	Not pregnant
Emma	0	N/A	Pregnant
Jane	1	Unimmunised	Not pregnant
Alexa	3	Partially	Pregnant
Maree	6	Partially	Not pregnant
Persephone	2	Unimmunised	Not pregnant
Rachel	5	Unimmunised	Not pregnant
Rebecca	2	Partially	Not pregnant
Sarah	2	Unimmunised	Not Pregnant
Shan	1	Unimmunised	Pregnant

6.1 The process

All interviews were conducted via telephone due to the social-distancing requirements attributable to the global COVID-19 pandemic social-distancing requirements. Preliminary thematic analysis, supported by CAQDAS, NVivo (Version 12), was used to analyse the data (Braun & Clarke, 2006). Transcriptions were read and reread by the principal researcher prior to coding. The initial sorting of codes took place on NVivo, and similar codes were subsumed into a single code. This process produced initial sub-themes (*n* = 23) and major themes (*n* = 6). This process was repeated for all (*n* = 23) codes. The process of isolating themes and sub-themes, as well as the process of developing these themes, is discussed below. Figure 6.1 demonstrates the development of the major themes and Table 6.2 the final themes and sub-themes.

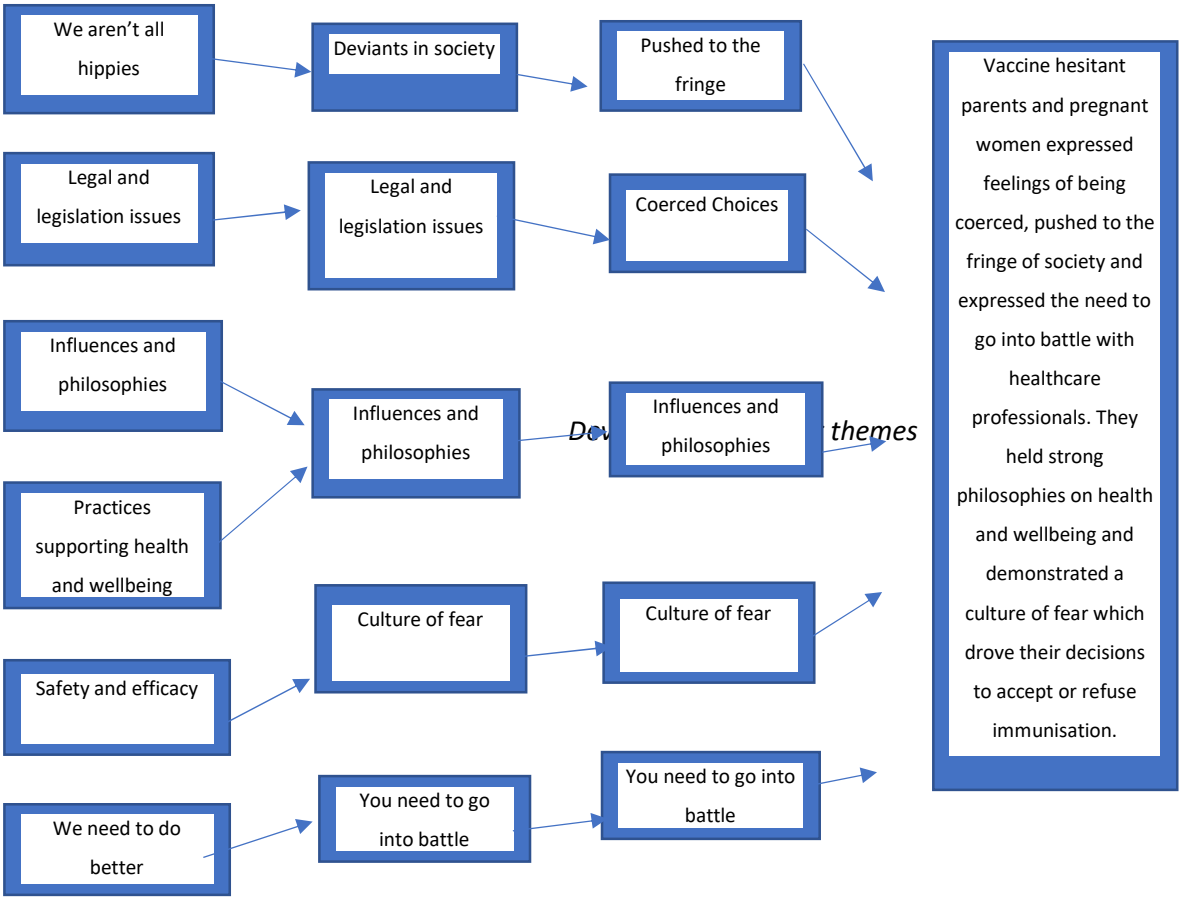


Figure 6.1 Developing the major themes

Investigator triangulation took place between the primary investigator and all members of the academic supervisory team to minimise bias. Meetings were held to ensure agreement between the primary investigator and all members of the supervisory team. Final agreement was reached without conflict. On reflection, further reading, gaining a deeper understanding of the meaning the participants attached to their commentary and using an iterative approach, the initial themes were combined and subsumed into five major themes and 10 subthemes. The final five major themes and sub-themes are displayed in tabular form below (Table 6.2). These themes are discussed in numerical order; however, they are not considered to be in order of importance as all areas of this research are considered vital in terms of the influences on vaccine decision-making.

Table 6.2 Final themes and sub-themes

Theme 1 - Pushed to the fringe	Theme 2 - Influences and philosophies	Theme 3 - Coerced choices	Theme 4 - Culture of fear	Theme 5 - You need to go into battle
Isolated and ostracised	Decision-making and beliefs	Informed consent	Big Pharma	Healthcare professional's role
Labelled	Alternative influences	Legislative issues	Vaccine safety concerns	Critical points and other sources

6.2 Pushed to the fringe

This theme, labelled *Pushed to the fringe*, represents a direct quote from Arlene, who believed that her decision to refuse vaccines had pushed her to the fringe of society. This represents the feelings and emotions of many vaccine-hesitant parents. Parents and pregnant women who participated in this phase of the research expressed feelings of being socially isolated, labelled, verbally attacked and pushed to the fringe of society. They reported incidences of name calling, aggression and have been labelled as a "threat to society". Expanding on the emotional response, vaccine-hesitant parents also reported feeling marginalised politically. Vaccine-hesitant parents and pregnant women have argued that the Australian Government's No Jab No Pay and No Jab No Play legislation has exacerbated their feelings of social isolation within their own community (National Centre for Immunisation Research and Surveillance, 2021). Whilst this will be further expanded upon in another theme entitled *Coerced choices* it is also important in the development of this theme as this legislation adds to the participants feelings of being fringe dwellers and socially isolated within their own society. The theme *Pushed to the fringe* has two sub-themes: *Isolated and ostracised*, and *Labelled*, both of which describe the participants feelings of being deviant.

6.2.1 Isolated and ostracised

This sub-theme reflects the feelings of participants and how they felt in relation to the predominantly pro-immunisation culture. Becoming a parent involves considerable disruption to lifestyle and for many, results in an increasing sense of social isolation due to the social disruption of ceasing employment and the demands of caring for a young child. Pregnancy and parenting a

young child are stressful and is a time when the social support of family and peers is important for emotional wellbeing. However, participants who have chosen to refuse or delay immunisation reported that the resulting social isolation had a devastating effect on their mental health and wellbeing. Participants avoided discussing immunisation and lied about their vaccine choices to retain the supports they had in place. One participant stated, *"because I'm sure you can appreciate how important, um during the first months after having the baby is, and you need that network around you, to keep you sane"* (Shan). Other participants (*n* = 8) admitted to avoiding conversations about their immunisation choices as, for example, *"it comes with so much vilification and so much misunderstanding"* (Sarah), whilst other participants (*n* = 5) lied about their immunisation decision or avoided the discussion altogether. Rachel stated, *"I went through a phase in the early days, just being a mother where I sort of didn't say anything"*. Other comments included:

> *Everybody is vaccinating their kids. And you're, kind of, like, they're, like – I kept quiet about for a really long time. Like, I actually pretended that I had vaccinated my daughter and when they were like, oh, you're going to take such and such for their four-month shots, and I was like, oh, yeah, yeah, us too, you know. To, kind of, um, not isolate ourselves from others. (Shan)*

> *But, you know, to be able to have frank discussions, and informed and intelligent discussions, without name calling, is so – it is so refreshing, and say, for my – for example, my mothers' group, I haven't – I have never mentioned vaccines, and if others say, 'Oh, we had our shots' and this, this, this, I kind of nod my head and that, but I have never actually mentioned that we don't vaccinate, because I don't want to ruin friendships and cause division over something that, um, you know, I feel quite strongly about. (Maree)*

Shan and Maree adopted different approaches to being vaccine hesitant in a pro-immunisation world. Whilst Shan elected to pretend that her child was immunised, Maree chose to avoid any conversation on immunisation. Some participants (*n* = 6) also discussed the difficulties and feelings of social isolation associated with being vaccine hesitant. One participant (Rachel) stated that *"being ostracised is really difficult"* and it *"makes life really hard"*. Similarly, vaccine-hesitant parents felt that the social isolation was not restricted to their peer support networks. Several participants (*n* = 4) suggested that the decision to not immunise their children had impacted their

relationships with their parents and family. Rebecca cited incidences of losing friendships and being *"*unfriended*"* on Facebook. Further:

> *No, you get the very much, you get the vibe from – from saying that, well, you know, it's like the whole cancel culture thing, well if you're going to make this decision, you're not, you know, you're – you're not a person that's worth speaking to, [laugh], or something like that. (Rachel)*

For many young parents, the support obtained through both social networks such as Facebook and Instagram and their peers are vital for acceptance and self-worth. In many cases rejection from support networks, combined with poor relationships with family, could result in diminished mental health, which may subsequently have a knock-on effect to parenting and child wellbeing. Several participants (*n* = 3) discussed the feeling of being labelled as well as experiencing a degree of bullying. They expressed feelings of being threatened by society in general and reported vicious attacks online. Arlene stated, *"People seem to – seem to have – feel completely, um, like – like it's okay to give people a hard time and – and name call and swear at people. I'm finding that quite offensive"*.

Similarly, another participant discussed the degree of animosity and ostracism expressed in an online platform. Whilst discussing the impact of the Light for Riley Campaign, one participant elaborated on the degree of ostracism she experienced. The Light for Riley campaign was designed to raise awareness of the importance of immunisation to maintain herd immunity and protect those too young to be immunised (Immunisation Foundation of Australia, 2019).

> *Look, when a child dies from vaccine preventable illness, like Riley, you know, he could get lots of support and spread awareness and, like, she said, there's nothing wrong with that, but she said, um, you know, her child apparently had died. She said, 'When, you know, my child dies, I get ridiculed and horrible things said about me that I don't know what I'm talking about, or had nothing to do with the vaccination, I get ostracism,' and, um, I had to concede she had a point there. (Jane)*

> *It is really unhelpful that people have preconceived ideas of people who choose not to vaccinate their children, being like, um hippies, or anti-vaxxers or, you know off their heads like they don't know what they are doing, they are uneducated, they are conspiracy theorists, whatever. (Shan)*

Jane and Shan's insights show that choosing to delay or refuse vaccines comes with significant negative impact. Parents and pregnant women are subjecting themselves and their families to animosity and ostracism. However, it has become clear during this research that the decision to refuse vaccines is rarely taken lightly. Parents in this research frequently revisited their decision-making to ensure the correct decision was taken with their child's best interest in mind. Despite this, the participants in the interview phase of this research all expressed some surprise at the extent of society's response to their choices, and either conceal their decisions or accept the subsequent social isolation.

6.2.2 Labelled

This sub-theme represents the feelings of the participants. Although the anti-vax label was one that was rejected by most (*n* = 9) participants, they expressed dislike for the term vaccine hesitant. This is discussed further under the theme *Pro-choice*. Participants (*n* = 7) discussed the impact of being labelled as anti-vax and discussed how this label had impacted them and their families. For example:

> *People get labelled as anti-vaxxers, and demonised as anti-vaxxer, when really, there is no such thing as anti-vaxxer. There are people who are scared, there are people that have questions, but are kind of shouted down and demonised, I guess. (Annie)*

Both Shan and Annie expressed both frustration and irritation at the labels that are often attributed to vaccine-hesitant people. One of the impacts of being labelled an anti-vaxxer is the effect this has on gaining information from a healthcare professional. Maree stated that the effect of being labelled made communication with healthcare professionals difficult. *"It actually was harder to get information second time round without being labelled an 'anti-vaxxer'. And I'm like, I am not. I am trying to find valid, scientific information here"* (Maree). Similarly, other participants discussed the impact of being labelled as anti-vaxxer in the media and an online environment. For instance:

> *I think the whole idea in people's heads are these anti-vaxxers that have read one meme on Facebook, wear the tinfoil hat, you know? Like, it's a very uneducated and a very, um, poor perception of people. (Maree)*

> *So, um, and – and I'm frustrated that we're continuously being painted by the media as a crazy anti-vaxxer that googles … It is so frustrating that there are legitimate concerns, there is stuff we should be talking about. There is an implication that anti-vaxxer is also anti-science. (Rebecca)*

Rebecca also discussed her views on the need to consult with minority groups, such as the vaccine-hesitant community, to better meet their needs. She expanded on this concept by stating that the vaccine-hesitant community should be consulted in a manner like the Aboriginal community, on matters affecting them, and expressed dissatisfaction in the choice of spokespeople the media selected for the vaccine-hesitant community.

> *I don't think they do a good job of actually capturing the right people behind the scenes because they go and talk to prominent people who are either prominent in the media or they go to farmers markets and talk to, … vegans and whatever. Like, it's just … (Rebecca)*

Arlene expressed feelings of being bullied and judged at her doctor's appointment because of being labelled as anti-vax, to the extent that she stopped attending her general practitioner, placing both herself and her infant at risk. She said, *"to be honest, I didn't go to any more appointments because my baby was healthy and every time you go to the doctor you get bullied"*. She also discussed being pushed to the fringe of society because of her decision to not immunise her children.

This research shows that vaccine-hesitant parents and pregnant women are considered deviant by the dominant pro-vaccine population. The role of healthcare professionals is discussed further under the theme *You have to go into battle;* however, from Arlene's comments it is clear that parents who are labelled as anti-vax are, in some cases, subjected to substandard care whilst others are refused care by their healthcare professionals.

6.3 Influences and philosophies

This theme represents the researcher's interpretation of factors that influenced, and philosophies that accompanied, the decision to delay or reject vaccines. These included concerns about the number of vaccines and the predominance of multi-valent vaccines included on the current Australian schedule. A multi-valent vaccine is a vaccine which can provide protection against multiple diseases or strains of diseases, as in the case of MMR (National Health and Medical

Research Council, 2013). In addition, 10 of the 12 participants relied upon the use of alternative therapies as well as labour-intensive parenting practices, often referred to as salutogenic parenting, to support their child's immune system. Whilst salutogenic parenting often accompanied vaccine hesitancy there is no evidence to suggest that the adoption of this parenting style influenced the decision to reject vaccines, rather this practice seemed to accompany the lifestyle choice. This theme included two sub-themes: *Decision-making and beliefs* and *Alternative influences*.

6.3.1 Decision-making and beliefs

This sub-theme represents the factors that drove participants' decisions to accept or reject vaccines, as well as the beliefs that influenced that choice. According to the participants in this phase of the research, the decision to reject vaccines is a simple one for some and subject to ongoing review for others. Several participants (*n* = 4) constantly reassessed their decision to refuse vaccines. For example, Rebecca stated, *"So, it's not like we decided, you know, 18 years ago, when the first kid was born, yep, that's it, we've made our decision and we're going to stand by it, no matter what, um, changes in the future*". Alexa stated that she was constantly checking and rechecking her choice. Several other participants referred to the risk–benefit analysis that was constantly influencing their choice.

> *Until there's new science to come out to show me that they are actually safe, and I'm talking like quality science, like independent studies, looking at vaccine safety with proper control groups, standardised control trials, I will continue to review the literature and I'll make my decision based on that. But in the near future, I don't think my stance on vaccines will change. (Shan)*

Shan was one parent who continually reassessed her decision-making. Alternatively, Al stated, *"but I am very comfortable with my decision at the moment, um, makes me want to speak out about the, um, fallacies around the topic of vaccination"*. A factor raised by other participants included the prevalence of vaccines on the schedule that contained multiple antigens (multi-valent). Several participants (*n* = 5) stated that the prevalence of these types of vaccines rather than single antigens influenced their decision-making. They believed that if single antigen vaccines were an option in Australia, they may have chosen an alternative immunisation path for their children. For example:

And vaccines - like having to revisit the DTP rather than just the single tetanus vaccine, and weigh that up. That – that – you know, that's changed, obviously, as, um, you know, things changed for us. And so, the availability of vaccines. (Annie)

Annie was particularly concerned about the lack of single antigen vaccines, whilst Sarah believed that it was unnecessary to vaccinate against a lot of diseases, as she felt they were not a threat to her children. She believed that many diseases were either not in existence in Australia or mild and not an issue for her children. Similarly, Al believed *"that diseases were instructive to the body in ways that we are not actually sure about yet"*. She believed that there were benefits in contracting diseases apart from natural immunity, which were not yet understood.

Vaccine decision-making was also influenced by a previous negative vaccine experience. Arlene stated*, "Why would I give the vaccine that has caused me so – so many health issues?"* Another belief system that affected vaccine decision-making was the apparent opposite approaches of the "wellness" and the "sickness" industry. Arlene strongly believed in the benefits of preventative health, *"and the fact that people can't even see that preventative health is just so important, um you know, obviously you are what you eat, and yet doctors will say, no, like that has no relevance and I just sit there, and my brain explodes. I go 'really, how can that not be?'* Further:

You've got the two opposite ends – ends of the spectrum, and the people that love the sickness industry and the drugs and – they oppose natural medicine, which is just the bizarre thing because drugs ultimately come from natural therapies. (Arlene)

Despite the complex nature of parental beliefs and decision-making, participants involved in this research demonstrated varying degrees of distrust in the pharmaceutical industry and dissatisfaction with vaccines in general. Some expressed minimal concern about the risks associated with vaccine preventable diseases whilst others saw disease as beneficial and instructive to the body. However, a common theme was a preference for preventative medicine, and this is discussed further under the sub-theme *Alternative influences*.

6.3.2 Alternative influences

This sub-theme describes the diverse nature of both alternative practices such as salutogenic parenting and alternative therapies used by the participants. These were combined in a sub-theme

as both therapies and practices were seen as complementary to, as opposed to influential on, the decision to refuse vaccines. The use of alternative therapies featured prominently in the health choices of most of the participants. Those who did not use alternative therapies did so based largely on the prohibitive financial cost of doing so. A large variety of alternative practices and allied therapies were in use in this population, including naturopathy, chiropractic, meditation, yoga, homeopathy, Chinese medicine, essential oils, kinesiology, remedial massage and bio resonance. Diet and lifestyle factors were also present in the philosophies of most participants. These ranged from healthy eating and/or organic food to vitamin supplements, sunshine, exercise and long-term breastfeeding. Whilst most participants had rejected all vaccines, Annie chose an alternative schedule and followed a plan from her naturopath on how best to support their child during immunisation:

> *We had circuit tracks around how to best prepare us for – our naturopath – how to best prepare for a vaccine, and then, um, support, after a vaccine, with different supplements and stuff, just to make sure that, um, you know, there's less chance of, you know, the damage or negative interactions. (Annie)*

Arlene, on the other hand, believed in the importance of a healthy immune system and that disease existed to promote kindness, caring and compassion:

> *So, disease is there, I think, as part of being human, as part of our lifecycle. If you eliminated disease then you would lose your compassion, your caring, your bonding, your family, all of that, because that's what those things bring to the table, which is something everyone has forgotten about. (Arlene)*

Throughout this aspect of the study, it became evident that the use of alternative therapies had not influenced the decision to refuse vaccines, rather it was complementary to their lifestyle choices:

> *Like I use complementary therapies myself and I find them really helpful, but I don't use them with a mind for immunising in any way. I think, really, if you look at the whole — the health as a whole person, and you keep everything going smoothly, then it's — it's going to be supportive in the event that someone does come across, um, a transmittable disease, an infectious disease, or a non-infectious disease. Like, I think it's just about — it's just about those pillars of health really, for me. (Alexa)*

Another influence on vaccine decision-making included the effect of the No Jab No Pay and No Jab No Play legislation, which is discussed further in the theme of *Coerced choices*. However, one participant stated that the legislation passed by the Australian Government as a motivation to parents to immunise their children for financial benefits, in fact had the opposite effect on her decision-making:

> *I feel that I have been forced into a corner by the mandatory vaccine lobby, and that I have been forced into a corner that I don't fit into, but yes, I am anti-vax, because I feel influenced by the mandatory vaccination lobby and movement – and we effectively do have mandatory vaccination. (Persephone)*

The choice of a healthy lifestyle, which included complementary therapies, was an obvious one for many participants. However, for some the cost of alternative therapies was prohibitive. Most participants took a holistic approach to health and despite rejecting vaccines, used labour-intensive parenting practices to support wellbeing. One participant, who chose to immunise against selected diseases, used naturopathy to support her child before, during and after immunisation. In summary, the use of alternative therapies was adopted when financial constraints allowed. For those who were unable to afford alternative therapies, other alternative practices were adopted. Despite many vaccine-hesitant individuals adopting healthy lifestyle practices, there was no indication that these influenced the decision to accept or reject vaccines.

6.4 Coerced choices

This major theme of *Coerced choices* was a quote from one of the participants in this study and describes her perception of the choices available to her. It includes issues of informed consent, as well as access to medical treatment and the coercive nature of the No Jab No Pay legislation, which had the greatest impact on families in the lower- to middle-socioeconomic bracket (Chapter 5). Concerns were also raised regarding the adoption of a recommended immunisation schedule in Australia. This theme includes two sub-themes, *Informed consent* and *Legislative issues*. Participants in this research firmly believed that, as vaccine rejectors, they were subject to bullying and coercion at a governmental level and rejected any form of "mandated" health practices.

6.4.1 Informed consent

Several participants raised concerns about the perceived absence of informed consent, a legal requirement for immunisation and other medical procedures. This issue was raised by many participants as a major influence on vaccine decision-making. Annie expressed concerns about accepting medical procedures (immunisation) with no possible support in the event of an adverse event. Rebecca believed that parents were not being advised of the risks associated with immunisation and stated that, "even in America you get a handout which at least warns that death is a possible outcome". Similarly, Maree felt that that she was unable to give legal informed consent without access to sufficient information:

> *I spent a fair bit of time re-evaluating it when I had my next three children, um, just to see what had changed. Just to see, um – and I was really surprised in that, if anything, the situation had gone backwards. It was harder to get information, and you were more stigmatised if you asked questions, so … (Maree)*

Sarah stated, *"I am definitely not in favour of any kind of mandated, um by schedule. Um I don't agree that I – I believe that um and coerced choice is not free choice".*

Maree believed that she could not consent to immunisation as she had received insufficient information to achieve informed consent. Other participants felt that they were financially coerced into immunising their children. Persephone stated that she had received forced medical treatment against her will as a child, which resulted in a doctor and needle phobia as an adult. In addition:

> *I just find that for something that is medical procedure or a medication I guess, like a preventative style medication, prophylactic, um. I should be given information choices rather than be pushed into something. So, I guess my, my stance on immunisation or vaccination is why I aren't I allowed to ask any questions about it? (Emma)*

Participants in this research believed that the information they were receiving from healthcare professionals, if any, was inadequate to reach the threshold for informed consent. Emma had experienced this and felt that asking questions of her healthcare professional was discouraged. Others were not in favour of a "mandated" immunisation schedule and wanted to choose what vaccines their children received. The lack of adequate information to achieve informed consent is

an area of concern and one that healthcare professionals have an obligation to comply with. This perceived lack of information has repercussions that could be addressed through improved healthcare professional education.

6.4.2 Legislative issues

This sub-theme includes issues relating to both legal issues and factors such as the No Jab No Pay legislation. Several participants raised the issue of personal rights and access to medical treatment among other services. Arlene stated that accessing a medical professional during the global COVID-19 pandemic was becoming increasingly more difficult for the unimmunised. She also raised the issue of access to government benefits as well as other services that she believed she may soon require an immunisation certificate for access. Sarah, on the other hand, felt that she was subject to bullying by medical professionals to give her newborn infant a Hep B immunisation against her will:

> *But the paediatrician in the hospital, ah, delayed coming to us, and then came back three times before – to try and convince us to have it before she finally came back with the paperwork, so we could waiver that and that Hep B. I find it, kind of, outrageous that you have to sign a waiver to not get a shot. (Sarah)*

Sarah also cited an incident she was aware of when one of her friends was threatened by her home-birth midwife that she would call an ambulance and child protection if she refused to give her child a vitamin K injection at birth. Whilst vitamin K is not a vaccine, it is a medical procedure that requires informed consent before it can be administered. This vitamin is used routinely to prevent haemorrhage in the newborn and, according to the findings of this study, was often considered by vaccine-hesitant parents to be as concerning as a vaccine.

This research shows that the No Jab No Pay and No Jab No Play legislation has had the greatest effect on families from lower- to middle-income areas of Australia (Chapter 5). It affects not only the family's income, but also the early education and socialisation of preschool-aged children. Several participants expressed dissatisfaction with the No Jab No Play policy. They believed that the legislation had an impact on the early learning of their children as well as having a considerable financial impact on their family. This is caused by restriction of access to government financial support and the resulting loss of a second income as one parent is required to stay home to care for the child. The legislation was discussed by Sarah who stated, *"they say it's a choice, but*

it's a coerced choice, in my opinion". Similarly, Rebecca reported that she was forced to look for childcare that may not meet her child's needs or resign from her high-paying job. Persephone, on the other hand believed that she was subject to financial and legislative coercion to immunise her children. Emma believed that the No Jab No Pay legislation was unconstitutional:

> *Um, with things like childcare, um, I think that the No Jab, No Pay laws that they have brought in are unconstitutional, I really go against, um, the Australian Immunisation Handbook and not putting pressure and coercion on people, so I'd like to know how that is even legal to try and coerce somebody into vaccinating their child, um, so that they can have childcare. (Emma)*

Participants also reported feeling bullied victimised and intimidated by the legislation, which was also referred to as financial bribery. Arlene stated that as a result, she had rejected the entire system by home schooling her children.

The lack of an Australian vaccine injury compensation scheme was also raised. Several participants believed that existing legislation, combined with inadequate support in the event of an adverse reaction, had led them to refuse all vaccines. The No Jab No Pay legislation has been in existence since the bill was first passed in January 2015 and was expanded in July 2016 to include the No Jab No Play legislation. Since then, children who do not meet the requirements of the legislation have been excluded from childcare and kindergarten. Participants in this research believe that the impact of this exclusion is coercive with far-reaching impact.

6.5 Culture of fear

This theme represents the anxiety, fear and distrust associated with vaccination. This fear was multifactorial and began with a general distrust of the pharmaceutical industry and the perceived influence on healthcare professionals. There was also evidence of anxiety surrounding distrust in vaccine safety testing as well as the safety of vaccines in general, including vaccines containing aluminium. Concerns were also raised about the potential for short- and long-term side effects, including adverse reactions and long-term conditions such as autism and auto-immune conditions. This theme includes two sub themes: *Big Pharma* and *Vaccine safety concerns*, one of the biggest influences on vaccine rejection.

6.5.1 Big pharma

Big Pharma is a term used by several participants to describe the pharmaceutical industry and is used by many vaccine-hesitant people. This term was used frequently by participants in this research who expressed a distrust in Big Pharma. This research shows that vaccine decision-making has been influenced by both a culture of fear and a distrust in the pharmaceutical industry. Arlene discussed her perception of the cycle resulting from immunisation: "*Then the pharmaceutical industry gets customers for life, because there's no stop button on our vaccine, which is designed to stimulate your immune system and then there's no stop button*". She also believed that *"it is a drug industry, so the more drugs you sell the more you make"*.

Concerns were also raised about the quality of vaccine safety studies, including the lack of placebo studies conducted by the pharmaceutical industry prior to releasing new vaccines to the public. Several participants criticised the use of a control group containing another vaccine as opposed to a saline placebo. Shan discussed the testing process and stated, *"Even the science behind all of them was quite poor. The safety studies, I mean – basic principles of science, you have a test group and a control group. And if you look at the control group that was used in a lot of these studies, it's hardly a control group."* Additionally, concern was raised about the use of aluminium adjuvants in vaccines:

> *I'm actually putting out there, we actually don't know, and if the proper studies were done, the proper research, um, I acknowledge that I could be proven wrong. Like, maybe they are safe, but all of what I'm seeing, and investigating is they're not doing the proper studies and I'm fearful of cover-ups. And, you know, and there's evidence of that, like stuff just being brushed under the, you know, under the carpet and whatever. (Rebecca)*

Despite distrust in the pharmaceutical industry and the science behind procedures used in vaccine testing, there was also the suggestion that healthcare professionals were influenced by Big Pharma, which subsequently affected the quality of care provided. These findings are consistent with those of Attwell and Smith (2017) who demonstrated that opinions of the perceived profit motivated pharmaceutical industry resulted in a general distrust in the expert systems such as Healthcare Professionals. The expression "customers for life" was used frequently. This research reveals considerable fear and distrust in the pharmaceutical industry. This distrust had an

apparent knock-on effect to the healthcare industry and formed the basis of distrust in healthcare professionals and concerns about the safety and efficacy of vaccines.

6.5.2 Vaccine safety concerns

Safety issues were raised by most of the participants. Whilst some of these were based on misinformation and conspiracy theories, they were discussed under the theme *Vaccine safety concerns* to demonstrate the factors that influence vaccine decision-making. These concerns largely followed the risk associated with the disease versus benefits of the vaccine debate with many participants raising concerns about specific vaccines. Annie raised concerns about the number of vaccines in the current schedule. She believed that the number of vaccines administered to young children was around 40. This is incorrect information; children following the Australian schedule are immunised against 17 vaccine preventable diseases (Government of South Australia, 2021a). Annie was also concerned about long-term health complications and potential chronic health conditions like asthma, allergies and autoimmune deficiencies resulting from childhood immunisation. She also believed that there was no requirement to report adverse events. Rebecca believed that there should be more education for doctors in the reporting of these adverse events. Reporting adverse events is a requirement of all immunisation providers (National Health and Medical Research Council, 2013). Arlene also raised concerns about the lack of genetic or allergy testing prior to receiving an immunisation, stating, *"you know, pulling the trigger and hoping for the best"*. She went on to state that immunisation was akin to child abuse. Other participants discussed their concerns about multiple antigens in one vaccine as well as concerns about the medical community's response to any possible reaction. For example:

> *And I think giving children multiple vaccinations in one shot like DTP, MMR, I think that that is dangerous because you don't know which vaccination that the child is reacting to if they are having a reaction. If vaccinations were singular, um, then I would be more likely to consider vaccination because I could give my child one vaccination at a time. I could space them out. (Emma)*

Whilst Emma was concerned about multi-valent vaccines, Jane expressed concerns about the potential for an adverse reaction and the potential for it being ignored:

> *I was worried that, okay if she has a reaction, from the stories I've heard from these parents the response from the medical community, if she had a bad reaction or*

something severe, it would be ignored, the vaccine aspect wouldn't be – what's it called, um, considered and they would waste time learning other things and she wouldn't get, like, the treatment she needed on time. (Jane)

Whilst Emma and Jane expressed concerns about vaccine content and immediate adverse reactions, Alexa held grave fears about the potential for long-term side effects and auto-immune diseases:

My concern with vaccines in general is not the immediate adverse outcomes, it's all the insidious stuff, um, and we know that auto immune diseases and things like that have increased in lockstep, really, with our vaccination schedule and I think this is one of those things, you know, you can have the vaccine and you feel fine the next day and you feel fine even a month from now and maybe down the track, that you just don't know. (Alexa)

Several participants raised issues of prior adverse events and the effect these had on subsequent vaccine decision-making. Arlene reported a personal adverse event connected to the Hep B vaccine, whilst Emma, Maree and Rebecca discussed events connected to people close to them, including siblings and children. Additionally, Shan also discussed reactions to vaccines, which she considered to be child abuse:

Later that afternoon, we were sitting on the lounge with him, rocking him in the pram. He was a little bit miserable. He went off to sleep, I was watching my TV and, um, the next minute I looked at him and he was actually going blue, and he'd stopped breathing. (Maree)

So many children are being damaged. You know, their parents taking them and having them vaccinated, the child's up screaming through the middle of the night, their arm gets – or they get a rash or they – what – what – however it looks but that – and you're just sitting there going, 'Wow, why?' and then the next time it happens again and again, there – there comes a point where that – you've got to look at that and go, that's child abuse. (Shan)

A culture of fear existed surrounding vaccine decision-making among vaccine-hesitant parents. Fear of the influence of Big Pharma and the "incompetent science" behind vaccine testing as well

as anxiety surrounding vaccine content and side effects of vaccines was evident. There was also evidence of conspiracy theories and the existence of incorrect information driving vaccine choices.

6.6 You need to go into battle

According to the participants, healthcare professionals had a vital role to play in providing information, correcting misinformation and educating vaccine-hesitant parents. This theme, *You have to go into battle,* was a direct quote from Arlene. Criticisms have been made about healthcare professionals' knowledge levels and attitudes displayed to vaccine-hesitant parents and pregnant women. Some participants in this research reported positive and respectful relationships with their healthcare professional, whilst others commonly experienced the breakdown of the therapeutic relationship. This theme includes two sub-themes: *Healthcare professional role* and *Critical points and other sources*.

6.6.1 Healthcare professional role

Healthcare professionals' role is descriptive of the issues raised by the participants. One of the most prevalent criticisms of healthcare professionals by participants was their inability to answer questions and address the concerns of vaccine-hesitant parents, as well as their reluctance to provide information. Annie stated, *"I think when you roll up to the general practitioner, if you don't ask questions, you don't get any information"*. Several participants also believed that general practitioners were not very well educated or informed, whilst Arlene referred to them as *"drug pushers".* Further:

> *All these consent forms were shoved in front of me, and I think, like, I was just asked to sign without reading anything or explained anything to me and I said to the nurse, I said, 'What am I signing here?' and she said, 'Oh, you're signing that you accept all the risks,' and I said, 'Well what risks?' (Rebecca)*

The degree of care and respect shown by healthcare professionals varied. Whilst Annie reported both a respectful midwife and general practitioner, others reported very negative experiences.

> *Um, we have one really good supportive GP, who's supportive of our decisions, and our decisions to delay and to, you know, vaccinate on an alternate schedule, and provide that information. But I – I have encountered some GPs who are, um,*

unwilling to provide further information, or to, you know, sort of, backup their – their statements – no, safe, there's no risks. (Annie)

Al stated that her doctor had refused to care for her during her high-risk pregnancy because of her refusal to accept a Syntocinon injection immediately after birth. Syntocinon is a synthetic oxytocin hormone that is given immediately after birth to ensure expulsion of the placenta and contraction of the uterus. Annie reported encountering general practitioners who refused to treat her unvaccinated child for unrelated medical issues:

In the circumstances where they've been refused treatment, it's directly impacted the wellbeing of the children. Um, I think it does make you a little bit reluctant to go and see, you know, new GPs, or disclose fully. There have been incidences where we've said to people, 'Oh yeah, they're fully vaccinated,' because we're fearful of their response, which can potentially jeopardise their health. I mean, you have to be very aware though, if you're going to start lying about, you know, their health status, then – then you're putting them at risk. So, it can get really, really, awfully tricky. (Annie)

Participants also reported considerable emotional manipulation and bullying as well as coercion to give consent for the Hep B vaccine at birth. Arlene explained it was like having to *"go into battle"*. She stated that pressure was placed on her by midwives and other healthcare professionals. Arlene also stated that the attitudes of some healthcare professionals resulted in avoidance and expressed concerns that this was *"putting children's lives at risks because mums that don't vaccinate don't want to go to the doctor because every time they do they are bullied and intimidated and belittled"*. Several other participants lied about their child's vaccination status to avoid any confrontation:

It was – you were kind of, um, bullied, I guess. I definitely felt intimidated at the time. I vividly remember the first time that happened and, yeah, it was really confronting. It was like, 'What?' Yeah, they were really – really nasty and confronting and it was just a, 'No'. So, then I had to research, yes. (Arlene)

Several participants also believed general practitioners lacked knowledge in alternative therapies, natural health and nutrition. The medical system was referred to as a sickness industry. Emma

lamented the lack of good quality information, but also asked *"why aren't I allowed to ask questions?"* She was also critical of the knowledge of general practitioners:

> *So, I think doctors don't get a lot of information about vaccinations in regard to research and even how vaccines work and how different vaccines may react to each other. Um, they get a lot of information about the vaccine schedules and when babies and children should be vaccinated. But not necessarily actual information about production and reaction. (Emma)*

Nurses were also criticised by some participants, for example Alexa, for their lack of immunological training and for taking a hostile attitude to parents who refused vaccines. Jane stated, *"It would be nice if people were educated on, I guess people with medical issues, um, that to, you know, not be so hostile, be open, more dialogue, um offer these alternatives".* Further:

> *Why do people feel like they have to lie to me to coerce — you know, it was a coercive thing — why do people feel like they have to lie to me about my baby's chances of catching, you know, like a needle borne/fluid borne sexually transmitted disease? (Alexa)*

Rebecca reported a general practitioner's resistance to report an adverse reaction and general unwillingness to discuss the possibility that her son's Kawasaki disease may have been the result of a vaccine. Sarah reported a general reluctance to discuss any aspect of her vaccine hesitancy. Most concerning was Shan's experience of a healthcare professional giving a vaccine against her express wishes. She discussed how she felt like a horrible parent that she had allowed it to happen:

> *I'm pregnant, this time around and I've opted for a home birth, um, to try and just avoid that whole system altogether, because obviously my wishes, and my views, and my, I guess, rights, as a birthing woman weren't respected in that instance. (Shan)*

The degree of animosity, bullying and disrespect experienced at the hands of some healthcare professionals indicate that there is a significant knowledge deficit in this space (Smith et.al., 2021). Previous research has demonstrated that nurses and midwives receive little to no undergraduate immunisation education. However, it was also evident that some general practitioners lacked knowledge and the ability to communicate effectively with vaccine-hesitant parents. Withdrawing

services, as in the case of Al, was bullying, disrespectful and dangerous, placing both mother and infant at risk, particularly as this took place in a small regional centre where options for alternative specialised care of her high-risk pregnancy was limited.

6.6.2 Critical points and other sources

One of the objectives of this research is to discover when parents make vaccine decisions. This sub-theme was named *Critical points and other sources* as it demonstrates the optimum time for providing immunisation information and education. This theme also addresses the other sources pregnant women use when they are unable to have their questions answered by their healthcare professional. This research has already revealed that pregnancy is the time when most people begin to think about immunising their children (Chapter 5). This aspect of the study confirms that many participants begin investigating immunisation during their pregnancy. One participant attempted to discuss concerns with her paediatrician but was unable to get answers to her questions:

> *So, they give you a kit, yeah, in the hospital and all the charming, lovely, your child's going to die of whooping cough, um, and they scare the crap out of you. And then I went to the paediatrician at six weeks, for my appointment, and I had said to him, 'Convince me to vaccinate,' and he couldn't, because he can't answer the questions because the questions are unanswerable, and nobody would guarantee a vaccination. (Arlene)*

Arlene was not alone in her inability to have her questions answered. Several other participants reported how difficult they found it to access information on which to base their choices. Those who did not make vaccine decisions in pregnancy stated that they were confronted by the first vaccine (Hep B). One participant stated that *"it just really didn't make sense to me anyway, that you would vaccinate a tiny baby against something that they are unlikely to catch"* (Alexa). Rachel focused on how to keep her child healthy without vaccinating them. Rebecca stated that in her quest for information she *"found discrepancies in the government publishing and discovered that the media is totally misrepresenting so much information, like you know, the whole Wakefield saga for instance",* referring to Dr Andrew Wakefield, a discredited academic and anti-vaccination advocate who conducted fraudulent research into a link between autism and the MMR vaccine.

His research was subsequently discredited, and he was struck off the medical register (Kmietowicz, 2010).

Pregnancy was shown to be the time when families began to investigate immunisation, and if information is not readily available, the participants stated they would look elsewhere. Participants in this aspect of the research reported using a wide variety of information sources. Many of these sources were previously identified in the survey and are discussed at Chapter five. Information identified ranged from traditional sources to non-traditional sources. These sources included evidence-based information obtained from academic journals to books written by anti-vaxxers such as Dr Suzanne Humphries, a physician with strong anti-vaccination views. Additionally, Annie obtained information from her general practitioner, family members and from her peers, whilst another participant relied on information from the TGA as well as vaccine packet inserts. Other participants focused their research in areas of toxicology, autoimmune diseases and the use of preservatives and heavy metals like aluminium and polysorbate 80, as well as some discredited and retracted journal articles.

Throughout this study it was demonstrated that if parent's information needs are not met by healthcare professionals, they will seek it elsewhere. Additionally, the timing of that information was shown to be critical. Pregnancy and early parenting have been shown to be times of high information needs. The role of healthcare professionals in immunisation information provision is well established and knowing the ideal time to offer this information may make these conversations more effective.

6.7 Conclusion

This chapter presented the results of the interview phase of this research. It explored the beliefs of, and influences on, vaccine-hesitant pregnant women and parents. It also provided a platform for participants to share their experiences, which included feeling socially isolated, pushed to the fringe of society, and labelled as deviant and "anti-vax". This research has shown that being vaccine hesitant in a predominantly pro-vaccine world is not without its difficulties. The factors that influence parents and pregnant women to become vaccine hesitant were diverse and ranged from the number and contents of the vaccines in the Australian schedule to a general distrust in the pharmaceutical industry. Parents demonstrated a preference for alternative therapies and labour-intensive parenting styles such as salutogenic parenting. Participants also believed that legislative issues such as informed consent and the No Jab, No Pay legislation influenced their

decision-making. Additionally, the existence of a culture of fear and anxiety surrounding immunisation was evident in this aspect of the research. Participants also expressed distrust in the scientific testing of vaccines. However, one of the most concerning revelations in this study was the failure of healthcare professionals to meet the needs of this small group of the population. Participants reported being denied healthcare, being bullied, and having to “go into battle” to achieve appropriate care for themselves and their children. The impact this had on families and children is of concern. However, this research also revealed that the optimal time for providing immunisation information is early in pregnancy. This was the critical point where pregnant women were seeking information and making decisions that impact their unborn child for life. If this information seeking is ignored, it is likely that vaccine-hesitant parents and pregnant women would broaden their search to less reputable sources.

Chapter 7 Cyberbullying Influences: Netnography Findings

We are all now connected by the Internet, like neurons in a giant brain. Stephen Hawking (n.d.)

Chapter 6 presented the findings from the interview phase of this research. This chapter presents the findings of the social media phase. This phase of the research used netnography as methodology to analyse two social networking Facebook pages: "Overheard at Flinders" page and a purpose-developed Business Facebook page "Vaccine Hesitancy in Pregnancy and Early Childhood" (Chapter 4) as the field (Figure 7.1). The internet has been described as "the largest experiment involving anarchy in history.

> *Hundreds of millions of people are, each minute, creating and consuming an untold amount of digital content in an online world that is not truly bound by territorial laws … Never before in history, have so many people from so many places, had so much power at their fingertips. (Schmidt, 2013)*

Netnography is a relatively recent methodological innovation, developed by Kozinets (2007). It involves the study of "networked society in all its manifestations through a variety of tools and paying particular attention to the cultural insights and conditions that are determined by the varieties of human experience" (Kozinets, 2015, p. 254). Kozinets (2015) describes netnography as a combination of analysis (breaking down into components) and hermeneutics (keeping whole) resulting in a synthesis on which to build a research representation. This study employed the netnographic principles identified by Kozinets (2015) and discussed in detail in Chapter 4 (Table 4.2). A modified version of this chapter is currently under peer review for publication. Whilst adaptions to this chapter were made for the purpose of publication, there is still direct overlap in content and phrasing. Appendix 14 is the first page as presented to the journal for publication. Co-author agreement and research contribution are attached (Appendix 16).

7.1 The process

The process of establishing a research specific Facebook page is presented at length in Chapter 4. av Advertisements were placed on the research specific page and on the Overheard at Flinders Page in the same format as Figure 7.1 for recruitment and to access students who were vaccine hesitant and may have fitted the recruitment criteria (refer to Table 4.3). The commentary from students on this page was also analysed and results discussed.

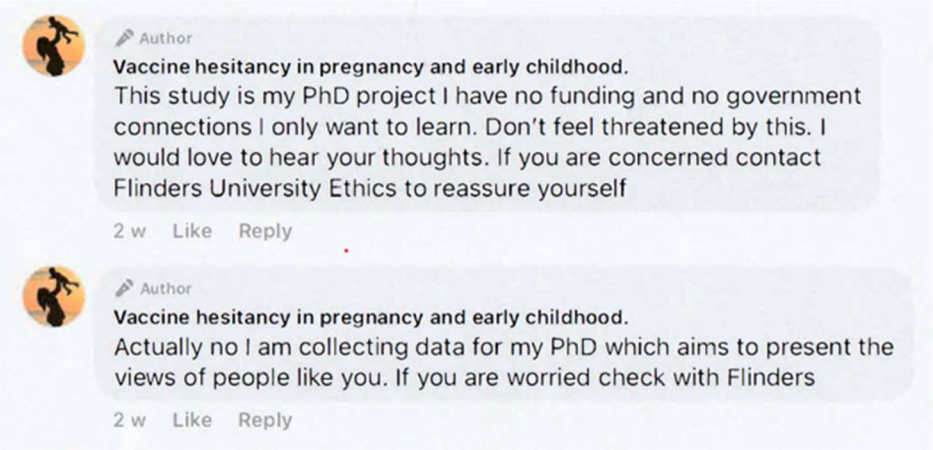


Figure 7.1 Open disclosure on Vaccine Hesitancy in Pregnancy and Early Childhood page

The research-specific Facebook page achieved 13,569 "learn more" clicks, which linked participants with the online Qualtrics [XM] survey. During one month of data collection (August 2021) the social networking site received 2556 posts and 1332 people engaged with the page. Whilst all paid advertising ceased at this time, the page continued to receive views, likes and comments until it was closed in December 2021. Throughout data collection the researcher ensured full and open disclosure of the purpose of the social networking site.

This method of recruitment and data collection as described in Chapter 4 proved to be an ideal choice, particularly during a global pandemic and the shutting down of sites relating to anti-vaccination. Throughout the data collection phase, posts and memes were plentiful and data analysis took place upon closure of the social networking site. Data analysis is also described in Chapter 4. Three major themes emerged from the Facebook data: vaccine safety concerns, emotional debate and COVID-19 issues. The themes and sub-themes are listed in Table 7.1.

Table 7.1 Themes and sub-themes

Major themes	Vaccine safety concerns	Emotional debate	COVID-19 issues
Minor themes	Vaccines are unsafe	Fear, anxiety, aggression, and deviance	Big Pharma
	Vaccines are unnecessary	Pro-vax commentary	COVID-19 commentary
	Pregnancy concerns		Mandated vaccination

7.2 Vaccine safety concerns

Vaccine safety concerns have been a major feature of all phases of this research and were also a regular and emotive feature in Facebook interactions. Many participants raised concerns about vaccine safety, vaccine content, vaccine reactions and the excessive and unnecessary nature of vaccines. This theme included three sub-themes: vaccines are unsafe, vaccines are unnecessary and pregnancy-specific concerns.

7.2.1 Vaccines are unsafe

Discussion threads included commentary about the "toxic and poisonous nature" of many vaccines. Emotive terms such as "toxic vaccines" and the intentional inclusion of neurotoxins in vaccines, as well as the importance of "doing no harm", were raised on several occasions, as was the use of dramatic and often inaccurate memes. One participant referred to immunisation and vaccines as *"crimes against humanity",* whilst another stated*, "nobody should put this toxic garbage into their child, why does the body need poison?"* and *"the original vaccines had both mercury and aluminium … Why vitamin K at birth? Why Hep B jabs for babies in oz? hmmm".* One post directed readers to an American website entitled "Deep roots at home" for further information (Deep roots at home, 2021). This site has been subject to significant censorship since the outbreak of COVID-19 but essentially remains a site promoting alternative lifestyle choices, and anti-vaccination sentiments.

One particularly emotional post referred to the stress placed upon a parent when deciding whether to immunise a second child after a previous child had suffered a severe vaccine reaction:

> *I was SUPER pro vaccine, and it certainly shook my confidence when the youngest was due for the same shots. [After a previous reaction] I was told to delay by my doctor and people still told me that they would 'rather my child was dead' than have*

a reaction. People are jerks. Just don't comment on these issues. You can't imagine how stressful this is for some families.

The meme attached at Figure 7.3 suggests that vaccine content is dangerous, and the long-term side effects of vaccines an unknown and unpleasant mystery. Additionally, the character depicted in this meme is Forrest Gump, who was depicted in the 1994 movie as a man of good intentions but low intelligence.

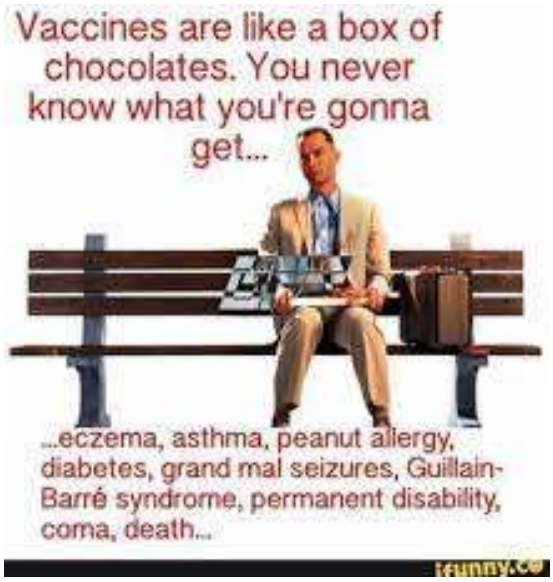


Figure 7.2 Box of chocolates meme on Vaccine Hesitancy in Pregnancy and Early Childhood page

Another participant expressed concerns about the long-term side effects of immunisation by stating, *"vax ingredients are basically poisons, as one child may be immediately affected, the other may take years to have a problem surface (possibly cancers?) Very important to be aware what ingredients are in the vaccines and their side effects, are both short and long term"*. Vaccine safety concerns have been shown to be a major factor influencing parents and pregnant women across all aspects of this research and must be a focus of any education intervention designed for vaccine-hesitant parents and pregnant women.

7.2.2 Vaccines are unnecessary

Whilst many participants were concerned about the safety of vaccines, others were of the belief that vaccines were unnecessary. The conversation thread reproduced below used a conspiracy theory to discredit both Bill Gates and the importance of immunisation. This participant believed the link depicted in the thread linked both COVID-19 and the Spanish flu to Bill Gates and his family.

The only people who lack immunity are immune deficient and their numbers are so low as to be insignificant on a global scale. This will be known as the biggest scam perpetrated on the human race since the 'Spanish Flu', which originated in America on a military base from a vaccine derived from horses by Bill Gates grandfather. It was in fact viral pneumonia. (Lucy)

Wow why am I not surprised it was related to Gates. Must be an ancient satanic blood line. (Emma)

They are related to the Rothschild conglomerate, as is Klaus Schwab head and founder of the W.E.F. (Lucy)

This conversation thread also links the Rothschild conglomerate, an investment banking organisation, the head of the World Economic Forum and Bill Gates, the co-founder of Microsoft and who is the largest private donor to the Gavi – The Vaccine Alliance, an international organisation with the aim of improving access to new and underused vaccines for children living in the world's poorest countries (GAVI, 2022). This link, that may or may not exist, was posted to create doubt in the credibility of immunisation. Other conversation threads used misinformation to express their point about the unnecessary nature of vaccines:

We do not need most of the vaccine. They are rare diseases now and have been for years because of hygiene and antibiotics. Measles was on the decline before the vaccine was rolled out back in the day. Vaccines cause other health issues which can be deadly and debilitating. People are brainwashed into thinking the only way to be healthy is to vaccinate. Terribly wrong. Many vaccines used the virus any way such as measles, whooping cough etc. this is a 'true fact', immune systems are being ruined.

This post received an immediate derogatory response stating:

I was once told there was a family of bears in the woods, ate porridge for breakfast and slept in beds. However, just like your story it is just not true.

Similarly, another post with considerable misinformation stated:

Why would I inject my kid 70 plus times with products made by corporations that are constantly being sued for lying and killing people ... AND aren't liable. I had 24

shots. Mitochondrial disease, a hundred shoulder shrugs from a hundred Drs, constantly.

This post was accompanied by the meme at Figure 7.4, which depicts a baby surrounded by needles, vaccine packets and information leaflets, designed to demonstrate the number of vaccines a child receives in the first five years of life. This participant claimed, incorrectly, that children would receive 70 vaccines during their first few years. Combined with incorrect information and inaccurate emotive memes, participants also used conspiracy theories to argue against the necessity for childhood vaccines. Whilst many participants considered that immunising children against 17 vaccine preventable diseases was excessive, they also argued that many of the diseases were rare and side effects from vaccination was both common and potentially fatal.

Figure 7.3 Seventy vaccines meme on Vaccine Hesitancy in Pregnancy and Early Childhood page

7.2.3 Pregnancy concerns

Pregnancy was an important focus of this research and was included in the title of the research-specific social networking site. Not unexpectedly, the page received negative commentary about the side effects of immunisation in pregnancy. Some participants focused on the lack of safety testing of the COVID-19 vaccine in pregnancy, whilst others were concerned about the risk of miscarriage. For example, one participant stated, *"Don't get jabbed when pregnant. No data please keep them safe",* whilst another said, *"The answer is no it's my body my choice. Just for the record I'm not an anti vaxxer in the last three month's I have had the flu shot & whooping cough vaccine as I have a baby on the way".* One participant stated:

W*hy is this hateful bigoted garbage on my news feed? What kind of psychopath urges pregnant women to take experimental unapproved biologicals that have*

caused HUNDREDS OF MISCARRIAGES??? You would have to be crazy to want an experimental shot that has NOT been through safety tests in animals.

Vaccine safety concerns were evident in many of the posts on the research-specific social networking site. These concerns were consistent with concerns expressed in the online survey and the interview phase of this research. In the netnographic phase, participants also demonstrated concerns about the toxic nature of vaccines and the potential for both short- and long-term side effects. Some participants believed that vaccines were unnecessary and that their existence was due to the involvement of prominent families like the Rothschild's and Gates'. However, participants expressed most concern in relation to pregnancy vaccines. Whilst their arguments relied mainly on conspiracy theories and criticism of scientific practices by the pharmaceutical industry, for some parents and pregnant women these posts could be sufficient to instil doubt and distrust, and subsequently influence vaccine choices. Participants on the social networking site expressed belief in the "My body – My choice concept". They demonstrated considerable distrust in pharmaceutical companies in the posts, were often secretive and angry, demonstrating this using capitalisation and name calling. In addition to the misplaced concerns raised by many vaccine hesitant participants, the use of graphic memes added considerable emotion such as the ones at Figures 7.3 and 7.4.

7.3 The emotional debate

Both social networking sites from which data were extracted contained an unexpected amount of emotive, aggressive and argumentative discussion threads. Whilst some of these were focused discussions on human rights and the absence of an Australian injury compensation scheme, most were simple pro-vax versus anti-vax rhetoric. However, a common thread amongst all discussions on the Facebook page was fear and anxiety which was evident amongst many antivaccination participants. Aggression and cyberbullying were also evident on the sites among both the vaccine hesitant and proimmunisation participants. Two sub-themes were included in the emotional debate. These including fear, anxiety, aggression and deviance; and the pro-vaccination community.

7.3.1 Fear, anxiety, aggression and deviance

Emotive, argumentative and aggressive posts were frequent on both social networking sites. These were often in the form of memes. For example, one meme suggested that vaccine-hesitant

people were clowns. This meme included a picture of a person wearing clown feet and accompanied by an ironic comment “Walk a mile in their shoes”. Contributors posted links to sites including “Children’s Health Defense” which featured a pilot study comparing the incidence of health in vaccinated versus unvaccinated children. This site was founded by Robert F. Kennedy Jr., a well-known activist and anti-vaccination advocate who relied upon the Kennedy name for credibility. The site, “Children’s Health Defense”, is a popular source of anti-vaccination information in both America and Australia. Similarly, an article entitled “Relative incidence of office visits and cumulative rates of billed diagnosis along the axis of vaccination” was cited as reliable proof that unvaccinated children were healthier than vaccinated children. This article was subsequently retracted, the author was deregistered, and his work featured on Retraction Watch, a blog dedicated to reporting retracted scientific papers (Childrens Health Defense, 2019).

The absence of a vaccine injury compensation scheme in Australia attracted considerable commentary, including a quote directing readers to an interview by Robert F. Kennedy:

> *It is a fact that a certain percentage of vaccine recipients will have adverse reactions, in many cases severe/devastating. Twenty-five countries have a compensation scheme. Why does Australia not have such a program? Also, do you believe what you have been taught about vaccines, or have you educated yourself thoroughly? I’m a pro safe-effective-vaxer. (Robert F. Kennedy Interview, 2020)*

One participant called on their experience in the healthcare industry to describe the effects of vaccine-acquired diseases on unborn babies. This post used graphic description to express the side effects of vaccine refusal in pregnant women:

> *Forty years ago, I looked after Rubella babies and children … no eyes … deaf … half their brains missing … fused spines … scaly skin … cerebral palsy … in constant spasm pain … when they weren’t screaming, they were whimpering … the cruellest thing I have ever seen. Living in a dark silent hell … yes let’s bring the good old diseases back.*

In addition to the purpose-designed social networking site, a recruitment advertisement in the same format as the title page (Figure 7.1), was placed on the “Overheard at Flinders” social network site to recruit local participants to this research. After the initial post, the following conversation thread took place:

Lol imagine being a shit parent (Alex pseudonym).

Not shit maybe different (Author).

Nah they are (Sean pseudonym).

Nope sorry but ignoring years of scientific research and testing due to feeling a bad 'vibe' about vaccines is idiotic at best and neglect otherwise (Harry pseudonym).

It's putting your kid at risk of death (Alex).

Translate: Have you decided to be a shit parent? (Harry)

At this point the discussion thread was shut down by the page administrator; however, in the short time that this post was active, it attracted a great many aggressive responses by the pro-vaccine majority. This approach made it difficult or even impossible for any vaccine-hesitant students to comment without criticism or being ostracised. Whilst it was not unexpected that a tertiary education environment would include people with strong pro-vaccination opinions, the degree of animosity and aggression towards the vaccine hesitant was greater than expected. Whilst the discussion thread above is only a small example of the posts on this social networking site, it is representative of the milieu of posts.

Many participants demonstrated fear and anxiety when expressing their beliefs, whilst others used humour, aggression and, in some cases, this verged on cyberbullying. One prolific contributor to the research social networking site spent most of his online time on the attack, mocking the beliefs of the vaccine hesitant:

Came for the antivax comments, stayed for the paranoid delusions. PS My insight is that there is very few 'single issue' anti-vaxers. Being antivax is usually just one of a collection of odd things they believe e... Check out the profiles of some of the commenters here and you'll find chemtrail conspiracies, 5G fears, aliens (!), various COVID conspiracies, flat earth nonsense etc, etc. Their being antivax is just a symptom of a far bigger problem.

Perhaps more pertinently, what's your opinion on water fluoridation/ Do you prefer organic or GMO vegetables? Looking forward to getting a 5G phone? Avoid the instinct to attack and please consider the question. I ask about chemtrails and 5G

*because I notice in your profile that you like some of these things, plus from one of your earlier comments. Do you only like and say these things ironically? Are you the same with vaccines? Is this some kind of performance art? You criticise me for supposedly being not backed by any 'Scientific Fact', yet you seem to have brought in some, well, frankly ridiculous conspiracies. But ignore the ridiculousness for a moment. *Assuming* that all these crazy ideas are true – who do you think is behind it all? Baby eating elites? Lizard people? Barney the dinosaur?*

Don't shirk from a little scrutiny of your beliefs. I'm just engaging in some armchair psychotherapy. I find it fascinating that someone who claims to have [been] a health professional for 30+ years can apparently believe such nonsense. OK given your conspiratorial beliefs around vaccines, chemtrails and 5G (have I missed any?) do you think there is a link between them? Are they separate conspiracies or all part of one evil plan? Who do you think is behind this? The illuminati? Bill Gates? Agenda 20 – something? The Rothschilds are popular.

This conversation thread was an example of the mocking humour used to attack the beliefs and anxieties of vaccine-hesitant participants. This participant used generalisation and assumptions to humiliate vaccine-hesitant participants and to garner the support of other pro-vaccine participants on this social network site. The effect of this kind of commentary was to alienate and ostracise the vaccine hesitant by strengthening bonds in the majority group. One participant asked if any "pro-vaxxers" had looked at anti-vaccination information, a reasonable request that received the following reply:

No, because (and here's the difference between normal people and anti-vaxxers) I don't think I'm a world-renowned expert on vaccines. I also don't research how the pilot flies a plane, the coding that operates my electronics or how to build a space shuttle. There is NO WAY someone without years of education, training and experience can come up with a meaningful view on a subject as complicated as this. The best you can do is check what a few different ACTUAL recognized experts think and trust the combined base of knowledge they're working off. They won't ALWAYS be right, but they're a HELL of a lot better than some random lunatics on a website or video.

There was no sensitivity displayed for the feelings of others on either social network site. On the contrary, from reading the posts, it became evident that social mores were ignored in the online environment. This anarchy was evident across both social networking sites. There was evidence of free speech and opinion sharing with no apparent rules of etiquette or consideration of social sensitivities other than administrator post moderation that occurred on both sites when emotions were running too high or posts were deemed too abusive. As a modern society we have learned the importance of race, religion and cultural sensitivity, but it could be argued that vaccine choice sensitivity is absent in cyberspace. This diversity of strong opinions could potentially influence the decision-making of the undecided.

7.3.2 Pro-vax commentary

Comments from the pro-vaccine camp were also highly emotive, with many using memes and graphics to explain the effect of immunisation over the last 200 years, including the elimination of smallpox and other diseases (Figure 7.5). Whilst others used their experiences in the healthcare industry to describe side effects of vaccine preventable diseases acquired in pregnancy:

> *I don't need experts to tell me either side of the story, as I lived through the epidemics of the pre-vaccine days and nursed children damaged by them in the 50s and 60s. By the time I retired in 2014, I had not seen a child damaged by them for many years.*

Figure 7.4 Vaccines work meme on the Vaccine Hesitancy in Pregnancy and Early Childhood site

In this research, participants who expressed anti-vaccination sentiments were most likely to also demonstrate fear, anxiety and in some instances frustration and aggression, whereas participants who were pro-vaccination demonstrated mocking humour, and aggression which could be considered cyberbullying. Additionally, some pro-vaccination participants demonstrated moral panic by displaying extreme frustration and anger at the possibility of acquiring COVID-19 from an unvaccinated person. These findings are consistent with those of Kadkhoda (2021) who also found that some online platforms are resulting in public panic and the dissemination of misinformation. For example, one participant stated, “You are a threat to society” and “putting my family at risk”. There were few examples of cultural sensitivity from participants and evidence to suggest that social mores are largely ignored in cyberspace.

7.4 COVID-19 related issues

Despite the purpose-designed Facebook page having a clear focus on pregnancy and early childhood research, many participants focused their commentary on COVID-19 specific issues. This was not unexpected given the existence of the COVID-19 pandemic and its effect on the lives of everyone living through it. Additionally, the COVID-19 vaccine was included in the vaccine recommendations for pregnant women in June 2021 at the height of data collection for this study

(Australian Government Department of Health, 2021d). Three sub-themes made up this theme: Big Pharma, COVID-19 commentary and mandated vaccination.

7.4.1 Big Pharma

The pharmaceutical industry (often referred to as Big Pharma) was criticised by many participants in this and other phases of the study. One participant stated, *"Depends which science you are talking about. There is Big Pharma science and then there is the truth".* Another participant commented on the huge profit margins posted by companies such as Pfizer and used a popular meme to express their feelings about the pharmaceutical industry which stated that "If you can buy a politician, you can buy a scientist" as well as the meme at Figure 7.6. In addition to the extreme distrust expressed in the pharmaceutical industry, a similar distrust was expressed in both science and scientists with a potential flow-on effect to healthcare professionals. Posts and memes were used to express concerns about bribery and corruption in the pharmaceutical industry as well as how scientists could be influenced by greed and the pharmaceutical industry in general (Figure 7.6).

> *There is no more corrupt industry than 'Big Pharma'. They are money hungry assholes with no concern for the wellbeing of families. All they are interested in is making money. Their products are poison, they take bribes and are generally not to be trusted.*

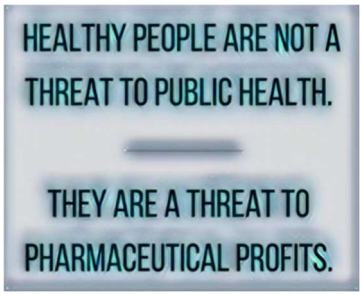


Figure 7.5 Pharmaceutical profits meme

This doubt about the integrity of the pharmaceutical industry was most prevalent in discussions about the new COVID-19 vaccines and included considerable concern about the speed of their development.

Participants expressed a combination of fear and anger about the COVID-19 vaccines with many doubting the integrity of the testing process and others believing that due to the speed in their

development, there must be underlying factors involved. Conspiracy theories were evident and included *"a plot to depopulate the world".*

7.4.2 COVID-19 commentary

Conspiracy theories were evident across all the social media commentary. Several participants expressed beliefs that COVID-19 didn't exist. These posts attracted significant negative attention such as the thread below:

> *Put the bong down, you're delusional. If you are a COVID denying, inoculation dodging carrier then your actions and tin foil hat life do affect mine! You selfish git! The constitution protects me via public health order from selfish fools like you! I have the right to know when I'm likely to be exposed to a communicable disease and who the carriers are!*

Other responses to these comments followed the "do your own research" approach; however, some participants took their response a step further by claiming that the COVID-19 vaccines were an experimental computer-generated model and a plot to depopulate the world.

> *Go and do your research this ONE IS NOT A VACCINE, ITS A POISON, their EVIL AGENDA is to DEPOPULATE our world with this poison. … you know they made the experimental injection from a computer model in CHINA!!!!! Because, they have never been able to isolate the actual virus to make a vaccine from it, it was all guess work, and they don't know what they are doing.*

This participant used capitalisation to express their anger and frustration about the unsafe nature of the COVID-19 vaccine. They continued by stating, *"I am not anti-vax, I'm anti-experiment and suspicious that therapeutics were banned just before the 'pandemic'. I have zero issues with tried and tested vaccines, have had all of them. I do have a problem with being a part of an experimental vaccine trial".*

One participant referred to the pro-vaccine majority as the *"uneducated believers"*, the *"source of the problem"* and vaccines as *"ineffective and dangerous"*, including that COVID-19 vaccines were a plot to depopulate the world:

> *Those that fall into the lie and inject them with vaccines and pathogens only to get sick with something else are the problem. These uneducated believers that have no*

information and have not done any research about vaccines are the problem. There is not a single vaccine that has worked or had a positive result. All of them have given negative and ill health result. These so-called vaccines all were introduced at a time where the disease was already getting a herd immunity only bring the disease back in larger number and we don't even talk about the numbers that vaccines killed or side effects that destroyed and keeps destroying lives far more than non-vaccinated. Vaccines are a con to spin money.

For COVID there is no vaccine only pathogen. This will make you sick, reduce your life and kill you. It is gene therapy that will prime your every cell to fight against a non-existing virus. It will make you a spike protein factory that is a poison. This is nothing more than population control. Almost 8 billion people on a planet that can support 500 million. When they get 7.5 billion people jabbed, they will release the second part of the pathogen a virus where these jabbed people will die. Their immune system will kill them.

Yeah ... we refuse to poison our kids for a scam ... The Covid shot is a bioweapon, this is why they are in such a hurry to jab people before the known deadly effects manifest. It KILLED the test animals … that the unvaccinated might get a virus? Just like me. But they won't have their RNA reprogrammed. Bastards.

Conspiracy theories such as these have the potential to instil doubt and fear in the undecided. Participants expressed anger and distrust as well as a commonly held belief in the conspiracy theory that the COVID-19 vaccines, which use mRNA technology[1], have the capacity to reprogram DNA. In response to these claims, one participant used humour in the form of a meme to express their opinion of the risk associated with acquiring COVID-19 (Figure 7.7). This meme depicts popular South Park cartoon characters Stan and Randy and suggests, inaccurately, that COVID-19 was a minor illness with a very low death rate, an opinion which was well supported early in the pandemic.

[1] The mRNA technology uses messenger RNA to produce an immune response and does not have the capacity to change DNA Fox, A. (2021). *Can mRNA vaccines affect my genetic code?* Retrieved 22 December from https://www.uwa.edu.au/news/Article/2021/June/Can-mRNA-vaccines-affect-my-genetic-code

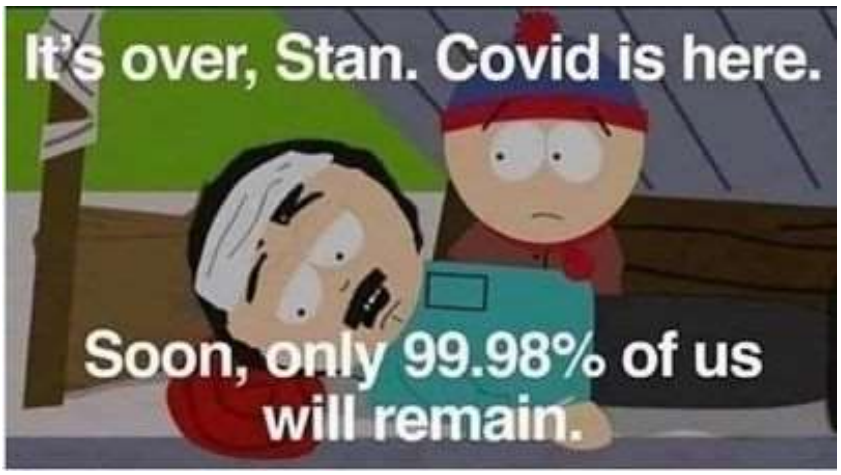


Figure 7.6 "It's over Stan" meme on the Vaccine Hesitancy in Pregnancy and Early Childhood page

7.4.3 Mandated vaccines

The principal researcher posted several posts throughout data collection including the following "How do you feel about COVID-19 vaccines being a condition of employment in some workplaces?" (ABC News, 2021). The responses from participants suggested that the employer-initiated mandates were a threat to human rights with financial side effects due to refusing vaccination. Similarly, the following post drew a link between choosing immunisation or poverty: *"It is a violation of human rights. Submit to medical treatment or live-in poverty. The vaccine is still experimental".*

The Nuremberg code[2] was mentioned on several occasions and by several participants with a meme used to further demonstrate the point (Figure 7.8). These posts were highly emotive and generated a large volume of comments.

[2] The Nuremberg code is a set of research ethics with a focus on the practice of human experimentation. Although not officially accepted as law by any country, it is a guide for practice Moreno, J. D., Schmidt, U., & Joffe, S. (2018). The Nuremberg Code and Informed Consent for Research—Reply. *JAMA*, *319*(1), 86-86. https://doi.org/10.1001/jama.2017.17724 . The argument that COVID-19 immunisation is human experimentation is flawed as vaccines are not mandated in Australia. Whilst some companies are legally able to require COVID-19 immunisation of their frontline staff, including aged care workers, others have elected to require the COVID-19 vaccine to protect their staff and customers Australian government department of health. (2021c). *Is it true? Are Covid -19 vaccines mandatory in Australia?* Retrieved 1st September, from https://www.health.gov.au/initiatives-and-programs/covid-19-vaccines/is-it-true/is-it-true-are-covid-19-vaccines-mandatory-in-australia, ibid., Moreno, J. D., Schmidt, U., & Joffe, S. (2018). The Nuremberg Code and Informed Consent for Research—Reply. *JAMA*, *319*(1), 86-86. https://doi.org/10.1001/jama.2017.17724 .

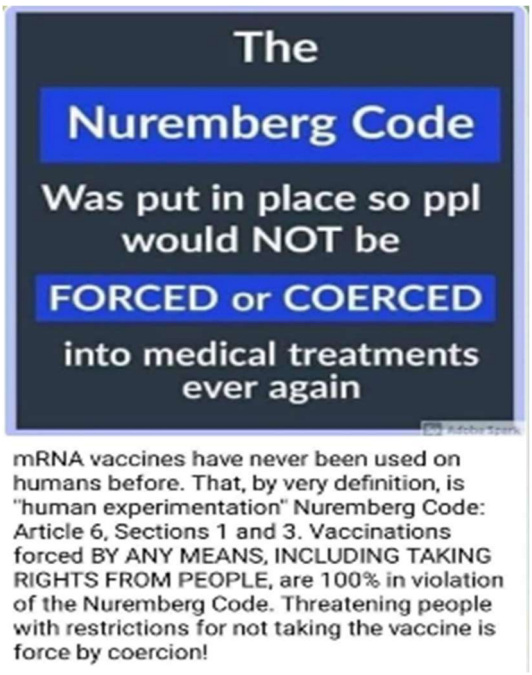


Figure 7.7 The Nuremberg code meme on Vaccine Hesitancy in Pregnancy and Early Childhood page

One participant concisely expressed the majority position on COVID-19 vaccine hesitancy by stating the following:

> *Most people who are COVID vaccine hesitant are okay with other vaccines because they have gone through their required 10 years of clinical trial testing, we have massive amounts of data on them, and they don't use spike proteins.*

Whilst some participants were also in favour of COVID-19 immunisation being a workplace requirement, other participants argued against the legalities of these mandates:

> *According to the Fair work ombudsman statement it's unlikely these mandates will be approved unless the business is in a constant hot spot, and must be assessed on a case-by-case basis? And businesses must also have legal counsel.*

> *Government hasn't moved to offer liability cover for employers … they are cunningly hoping the fools will mandate the jab and save the government from doing it. According to workplace legislation, it's against the law to coerce an employee under threat of dismissal. New employees are another matter.*

There was a significant amount of animosity evident in commentary responding to questions about both COVID-19 vaccines and companies mandating vaccination as a condition of employment. Many called for boycotting of these companies whilst others claimed that mandated

vaccination was both illegal and a breach of constitutional law. One participant stated, "*Fuck the Freemasons poison".* This comment alludes to a conspiracy theory that claims that the COVID-19 pandemic was invented by the Freemasons[3] as a method of global depopulation.

As this research was undertaken during a global pandemic, it was to be expected that COVID-19 commentaries could dominate. These arguments ranged from pro-vaccination to anti-vaccination commentaries. Several discussion threads argued that the COVID-19 virus did not exist and that the vaccines were a plot to depopulate the world. Additionally, there was evidence of mixed opinions on "mandated" immunisation, but there was also evidence of considerable anger at the concept of forced immunisation with the alternative posed of living in poverty due to loss of employment.

7.5 Conclusion

This chapter presented the findings from the netnography phase of this research. This phase of the study provided a platform for pro-vaccination and anti-vaccination beliefs of people to share their thoughts, express their concerns and respond to discussion threads raised by the researcher. Three major themes were evident in the discussions conducted across the two social networking sites: vaccine safety concerns, concerns about the current COVID-19 pandemic and the associated vaccines. In addition, these themes emotionally fuelled debates that underlined all aspects of the online commentary. The online culture was revealed as aggressive, mocking and potentially alienating for vaccine-hesitant people. In the next chapter, the discussion focuses on combining, interpreting and critically examining the main findings of this research. These findings are discussed at length with consideration given to Durkheim's deviance theory and the limitations of this research are also discussed.

[3] The Freemasons is a fraternal group underpinned by belief in the Supreme Being Henderson, K. (1988). *The Masonic Grand Masters of Australia*. Melbourne : Ian Drakeford Publishing. .

Chapter 8 Discussion

> Science is the knowledge of Consequences, and dependence on one fact upon another.
>
> Thomas Hobbes (1651, p. 21)

This thesis has presented the results of three elements of research using different methods and data sources to answer the same research question. This chapter presents the discussion and critically examines the key findings from this research, develops meaning and understanding, and compares this body of research with current evidence. The findings are discussed with consideration given to Durkheim's deviance theory and the culture of vaccine-hesitant parents. The conclusions and recommendations arising from this body of research are presented in Chapter 9.

8.1 Key findings

The key points of this body of research are structured under the following headings describing the main findings:

i) Weighing up the risks and safety: Vaccine-hesitant parents and pregnant women expressed considerable anxiety about their choices and felt that they were constantly weighing up the risks and benefits of immunisation.

ii) Pushed to the fringe of society: Parents who chose to refuse immunisation for their children expressed feelings of being isolated, ostracised and marginalised by the dominant pro-vaccination society.

iii) False narrative and the cyberculture influence: The purpose-designed social media platform used in this research demonstrated that parents and pregnant women who sought immunisation information on social media,may be exposed to cyberbullying, false narratives and conspiracy theories.

iv) The critical timing of immunisation education provision: This research reveals that a critical time exists when parents are actively seeking immunisation information, and this is the time to ensure that accurate information is provided.

8.2 Weighing up the risks and safety

This thesis enabled the voices of vaccine-hesitant parents across all three phases of this research. However, through labelling some parents as vaccine hesitant, the researcher is aware that this

thesis may be perpetuating a culture of deviance by labelling all vaccine refusers as hesitant. This is often not the case, and many participants in this research stated that they are not hesitant, rather they are certain that the decision they have made is the correct one. Parents and pregnant women involved in this research cited multiple influences on vaccine decision-making. These included concerns about vaccine safety, distrust in the pharmaceutical industry and the mistaken belief that vaccine preventable diseases were not dangerous to their children. This belief has the potential to expose children to inadequate immunisation with the potential for serious morbidity and mortality associated with vaccine preventable diseases. One of the most expressed concerns was anxiety about vaccine safety. Vaccine safety, including concerns about vaccine content, adverse reactions and fear of long-term side effects were significant factors associated with vaccine hesitancy and refusal. These findings are consistent with those of other contemporary researchers (Ward et al., 2017). Additionally, contemporary evidence suggests that pregnant women can hold doubts about vaccine effectiveness as well as fears of potential side effects. These doubts and fears may be accompanied by a general distrust in the healthcare system (Ben Natan et al., 2017; Helps et al., 2019; Saada et al., 2015; Swaney & Burns, 2019). Vaccines used in Australia, whilst not 100% safe, have stringent testing prior to approval by the TGA (Australian Government Department of Health and Aging, 2013). Side effects and reactions to vaccines do occur and are routinely investigated by the TGA (Australian Government Department of Health, 2021e). However, despite some side effects and adverse events, vaccines in Australia are, for the most part, of benefit for all. Hence, the risks associated with vaccines, on balance, are much less than the risks associated with vaccine preventable diseases (Australian Government Department of Health, 2021e).

Distrust in the pharmaceutical industry as well as with some healthcare professionals, was reported in this and other contemporary research (Dube, Vivion, et al., 2016; Giambi et al., 2018; Rozbroj et al., 2022). Participants in this research expressed the belief that the pharmaceutical industry was both untrustworthy and used unscientific methods. In Australia, vaccines undergo stringent testing and must be registered with the TGA prior to approval (Australian Government Department of Health, 2021e). Many of the participants in this research (91%) expressed the belief that vaccines were more dangerous than the diseases they protected against. These findings are consistent with other contemporary studies which identified a low-risk perception associated with vaccine preventable diseases (Helps et al., 2019; Swaney & Burns, 2019). However, participants in all phases of this research believed that they were less likely to contract vaccine preventable

diseases than to be affected by a vaccine reaction. Although many vaccine preventable diseases are rarely reported in Australia, they remain common around the world, and areas of low herd immunity have resulted in the resurgence of diseases such as measles (Australian Government Department of Health and Aging, 2013; Dawson & Apte, 2015). The findings presented in this thesis confirm and extend the results of current international and Australian research that has previously found that the risk versus benefit debate was influential in decision-making about vaccines (Giambi et al., 2018; Gidengil et al., 2019). This research has also demonstrated that some vaccine-hesitant parents and pregnant women are making important decisions based on inaccurate information, which should ideally be corrected by a caring healthcare professional.

Another area of concern raised by parents was the lack of information provided by some healthcare professionals, which affected their ability to give informed consent. The role of healthcare professionals is to educate parents about the risks of disease and the benefits of vaccines, potential side effects, even if rare, and to ensure that parents and pregnant women are making important decisions based on accurate information. The findings of this research suggest that vaccine-hesitant parents and pregnant women can be uninformed and lack the knowledge on which to base vaccine choices. However, this research also identified a significant knowledge and attitude gap amongst healthcare professionals, according to the participants, which should be addressed, at least initially, by tertiary educators across the areas of nursing, midwifery and medicine in undergraduate programs (Ben-Natan, 2017). Healthcare professionals have a responsibility to educate parents and pregnant women; however, a lack of tertiary education in immunisation and a reported discomfort in dealing with vaccine-hesitant pregnant women may contribute to parents basing decisions on incomplete information (Smith et al., 2021). This finding suggests that a gap exists in practice, policy and tertiary education, providing an opportunity for further research. Healthcare professionals, particularly general practitioners, midwives, and nurses need to be adequately educated in the undergraduate space to be able to communicate, educate and inform pregnant women respectfully. This research supports the findings of Kaufman, Bagot, et al. (2022) which also found that some healthcare professionals felt under prepared for their role in immunisation promotion.

This body of research shows that parental concerns exist about the number of vaccines on the Australian schedule, including the number of multivalent vaccines. Participants involved in this research were highly informed and as a result, this identification of parental concerns regarding the use of multivalent vaccines is important new information that should be considered when

educating parents and pregnant women on the benefits of immunisation. Currently, Australian children are immunised against 17 preventable diseases in the first four years of life (National Health and Medical Research Council, 2013). A further area of concern was whether the first vaccine on the Australian schedule, the Hep B vaccine, was necessary or safe. The findings from this research confirm those of Rozbroj et al. (2020) who identified that parents questioned the timing of this vaccine, including why their newborn was at risk from this disease. However, these findings conflict with the findings of Betsch et al. (2018) who found that the pain inflicted on the infant associated with early immunisation influenced subsequent vaccine decision-making. The timing of these vaccines have been chosen based upon the optimal timing to provide the best protection (Australian Government Department of Health, 2022). Government websites currently provide little information on the rationale behind their decision-making and include only a very brief sentence describing the safety of vaccines, a factor discussed in the study by Attwell et al, (2021) (SA Health, 2019). This body of research reveals that vaccine-hesitant parents and pregnant women are not reassured by a brief statement, and more in-depth information should be provided on safety and adverse reactions to allow parents to accurately weigh up the risks and benefits of immunisation (see Chapter 9). Additionally, the lack of information provided by healthcare professionals may have legal implications, including the inability to achieve informed consent for immunisation.

This research shows that some parents and pregnant women believe they received insufficient information about safety concerns to provide informed consent for immunisation. It is a legal and ethical requirement of healthcare professionals to provide accurate and relevant information to ensure legal informed consent (Australian Commission for Safety and Quality in Healthcare, 2020). If this is not being met, healthcare professionals are failing in their duty of care, which could be attributed to a lack of education in the undergraduate space (Attwell et al., 2019). Healthcare professionals should be adequately prepared for their role of educators and immunisation providers and tertiary education providers must assume responsibility for including immunisation and safety concerns that may arise in the curricula. There is a need for focused professional development in immunisation and motivational counselling for existing practitioners to ensure they can address parental concerns on vaccine safety and the number and timing of vaccines on the current schedule (Kaufman et al., 2019). Concerns about short- and long-term side effects also influenced vaccine decision-making. This research demonstrated a need for enhanced healthcare professional preparation for the role of educator, promoter and provider of immunisation as well

as continuing professional development. These results support the work of the SKAI project (Sharing knowledge about immunisation) which found that parental concerns should be fully addressed in a consultation (Berry et al., 2018; Kaufman et al., 2022).

Concerns were raised by participants about the potential for vaccine side effects, both short- and long-term, including auto-immune conditions, autism and the fear that any reaction to a vaccine would not be either acknowledged by healthcare professionals, nor treated appropriately and compensated. These findings confirm the results obtained in previous Australian research that found parents falsely believe that vaccines can cause long-term harm including autism (Costa-Pinto et al., 2018; Rozbroj et al., 2020). Any link between measles vaccine and autism spectrum disorder have been repeatedly dispelled (Australian Government Department of Health and Aging, 2013; Chen et al., 2004; Pluviano et al., 2017). However, participants in this research believed that autism was a risk associated with childhood vaccines. Additionally, vaccine-hesitant parents in this research also expressed concerns about the abilities of healthcare professionals to recognise an adverse reaction and respond appropriately, a belief that may have been driven by a general distrust in the healthcare system. Findings from this study extend knowledge obtained in previous research that demonstrated that vaccine-hesitant parents considered healthcare professionals to be uninformed (Clarke, Paterson, et al., 2019; Diaz Crescitelli et al., 2020). These beliefs suggested that vaccine-hesitant parents have a low opinion of healthcare professionals' knowledge around vaccine safety, and as a result, place themselves into the category of deviant from a societal perspective. With high overall levels of vaccine uptake across Australia, the data defines those who conform and those who are potentially deviant (Durkheim, 1964).

Considerable anxiety also surrounded vaccines scheduled in pregnancy, which include the relatively new COVID-19 vaccine (The Royal Australian and New Zealand College of Obstetricians and Gynaecologists, 2021a). This concern was based on the mistaken belief that vaccines were a threat to their unborn child. Most significant was the number of participants (90.65%) who stated that they would not accept any pregnancy vaccines. However, evidence suggests that vaccines in pregnancy are safe and provide protection to mother and child (Akarsu et al., 2021; Gencer et al., 2021). Healthcare professionals have an important role in focusing immunisation education at the critical time when parents are actively information seeking, to ensure decision-making is based on correct information. A reminder should be included in all state and territory pregnancy handbooks and associated guidelines to discuss immunisation concerns and provide education before parents seek information from less reputable sources such as social media (Government of South

Australia, 2021b). The early anti-natal period is a busy time for midwives and general practitioners, and until now immunisation has taken a back seat to other procedures. This research demonstrates the need for a change in focus accompanied by a better understanding of the consequences of non-immunisation to both mother and baby.

New vaccines like the COVID-19 vaccines have traditionally been slow to gain acceptance, and vaccines using new technology such as mRNA technology have raised particular concerns in parents and pregnant women who are already anxious about the safety of immunisation in general. The implication of this is that vaccine uptake is likely to be affected, resulting in a potential increase in morbidity and mortality of pregnant women and their unborn and newborn children. This research shows that most participants (90%) did not perceive COVID-19 to be a risk to themselves or their unborn infant. Although the decision to refuse the vaccine seems counterintuitive, it may have come from a desire to protect their unborn infant from possible vaccine injury such as a misplaced fear of miscarriage. However, evidence suggests that COVID-19 poses a significant risk to pregnant women (Arthurs, 2021).

A recent Australian study suggests that vaccine-hesitant parents are informed through a different epistemic lens, seeing themselves as highly informed health consumers and responsible parents (Rozbroj et al., 2022). The participants in this research were articulate and informed; however, they were also influenced by misinformation and conspiracy theories that questioned the safety of vaccines. This resulted in beliefs that placed them into a culture of deviance (Durkheim, 1984). By refusing immunisation, parents and pregnant women inadvertently become part of a minority group, and as such are subject to criticism and judgement from the pro-vaccine majority.

This research shows that vaccine decision-making can be accompanied by high levels of anxiety and distrust and is often frequently revisited throughout their child's early years. This research demonstrates that decision-making can be driven by concerns surrounding the influence of the pharmaceutical industry as described by the participants, as well as the perceived "incompetent science" behind vaccine testing. Other studies have also demonstrated that distrust in the pharmaceutical industry can influence vaccine choices (Dube, Gagnon, Zhou, et al., 2016; Giambi et al., 2018). Additionally, some of the participants' anxiety and distrust was driven by conspiracy theories and misinformation. This misinformation was particularly evident on the social media site, where conspiracy theories on many topics including COVID-19 vaccines were abundant. This was despite efforts by the social media platform, Facebook, to limit access to COVID-19 content during

the global pandemic by closing sites that may have presented misleading or sensationalised content (Facebook, 2021).

Participants in this research expressed anxiety about negative immunisation experiences that may have affected themselves, their families or others close to them. These results confirm those of Betsch et al. (2018) who believes that a negative immunisation experience influences future vaccine choices. As such, it is vital that healthcare professionals adequately address parental concerns and provide empathy and accurate information about the safety, risks and benefits of immunisation. Vaccine-hesitant parents and pregnant women are already marginalised by their beliefs and a badly handled adverse event is likely to increase any parental anxiety. To discuss adverse events sensitively, healthcare professionals must be appropriately educated in their role to allay anxiety and provide reassurance whilst not discounting the possible rare side effects.

8.3 Pushed to the fringe of society

According to Durkheim (1984), any person who acts outside the social norm is considered to be deviant. Whilst most people choose to immunise and display trust in healthcare professionals, it could be argued that those who do not are displaying ant-social tendencies and are acting outside the social norm, hence, displaying deviant behaviours (Thompson, 2017). The findings of this research add to the body of evidence which describes what it is like to be vaccine hesitant or socially deviant in contemporary society where participants described marginalisation, bullying and discrimination. These findings support those of Wiley et al. (2021), a study which was conducted whilst this research was being undertaken. This research also reported incidences of marginalisation due to vaccine hesitancy (Wiley et al., 2021). Deviance, as described by Durkheim (1964), does not exist in a vacuum but relies on society to construct rules or norms of behaviour, subject to change over time (Durkheim, 1964; Fenton, 1984). In contemporary Australian society, these societal expectations include following the road rules and being fully immunised, despite immunisation not being a legal requirement in Australia. Hence, those who are vaccine hesitant are considered deviant by the conforming majority as described by Durkheim. Participants in this research reported feelings associated with being deviant in societal terms, whereby many kept their vaccination stance hidden because of the negative behaviour towards them that was apparent throughout the findings.

Deviant behaviour has traditionally elicited shock, anger and aggression according to Fenton (1984), which was also observed in all phases of this research, but particularly and significantly in

the netnographic study. Pro-vaccination contributors to the social media sites used aggression and mocking humour to isolate and humiliate anti-vaccination participants. Deviance theory is described as an apparent attempt to increase conformity according to Durkheim (1984), and this was evident in the findings of this research. Additionally, vaccine-hesitant parents reported feeling pushed to the fringe of society by both the pro-vaccination majority and by government legislation. This feeling of marginalisation has been described as affirming or defining social rules within the existing social construct (Durkheim, 1984). Participants also reported feeling coerced by the dominant society into making choices that did not fit with their belief systems and felt marginalised both socially and financially. The global pandemic also contributed to the marginalisation of vaccine-hesitant individuals whereby restrictions were put in place for those who were unimmunised, including access to general practitioners. The social networking site as well as the media, demonstrated a form of moral panic aimed at the vaccine hesitant who refused the COVID-19 vaccine. Moral panic is described as extreme hostility expressed towards a deviant group who are considered harmful to society (Bryant, 2011). This was observed in the degree of aggression shown to vaccine-hesitant individuals who were negatively stereotyped, vilified and abused, with their beliefs mocked in the netnographic study conducted in this research and expressed in the survey and interviews. These findings support the findings of Kadkhoda (2021) who also found that public panic could be attributed to the effects of social media.

Vaccine-hesitant parents stated they feel marginalised by mainstream society, some healthcare professionals, and even friends and family. The healthcare professional role is to educate and inform, not to contribute to feelings of marginalisation and deviance (Nursing and Midwifery Board of Australia, 2017). This research reveals a knowledge deficit in this area and demonstrates a need for professional development on effective communication with vaccine-hesitant parents. This research found that vaccine-hesitant parents are stigmatised and, in some cases, experience dismissive and unhelpful healthcare professionals. This finding is consistent with findings of other current and concurrent studies which found that parents experience systematic stigmatisation and experienced healthcare professionals who were dismissive and unhelpful when faced with vaccine hesitancy (Helps et al., 2019; Wiley et al., 2021). Healthcare professionals have previously identified that dealing with vaccine-hesitant parents and pregnant women was challenging for them (Helps et al., 2021; Smith et al., 2021). This suggests a knowledge deficit and an unhelpful attitude among some healthcare professionals when relating to vaccine-hesitant pregnant women and parents.

Vaccine-hesitant parents have also reported feeling marginalised by government policy. This research found that the No Jab No Pay and No Jab No Play legislation had an impact on parents of lower socioeconomic status, whereby financial support was reduced if they did not choose to vaccinate. Whilst the sample size obtained in this research is small and does not enable a conclusion on this issue, there is an indication that the impact of the No Jab No Pay legislation may have been more significant on families from lower socioeconomic areas. Additionally, these results support those of previous studies which also found the legislation can result in financial hardship for some and a sense of marginalisation for others (Helps et al., 2018). The legislation was designed to promote immunisation compliance through both social and financial limitations; however, participants in this research believed that this legislation placed financial, social and legislative pressures on them, as well as contributing to their feelings stemming from deviance, such as defining legally and morally what was the expected vaccination regime. In this case, the legislation has contributed to the deviance of the vaccine-hesitant minority by precluding unvaccinated children from early learning opportunities, as well as financially impacting families. These findings support those of Beard et. al. (2017) which found that the stated intent of the No Jab No Pay legislation was misplaced and there is limited evidence that monetary sanctions are effective. Additionally, a recent study by Attwell et al. (2021) found that government policies which combine both persuasion and coercion can result in the potential for push back from the community. The findings from this research confirm and extend contemporary knowledge of the impact of the No Jab No Pay and No Jab No Play legislation on vaccine-hesitant parents in Australian society. This goes beyond the financial impact and affects the family socially and emotionally, contributing to their feelings of being driven to the fringe of society as deviants. However, whilst this legislation may have had success in raising the immunisation uptake of children, this research demonstrates that it is time to revisit the impact of this legislation on the wellbeing of families who are vaccine hesitant as well as the educational impacts on preschool-aged children.

Vaccine-hesitant parents have reported feelings of isolation, marginalisation, being labelled and pushed to the fringe of society by the pro-vaccination majority, to the point where they may lie about their child's vaccination status. These sociocultural findings are consistent with the findings of Wiley et.al. (2021), who found that vaccine-hesitant parents can be stigmatised and subject to censure. The media and particularly social media, as well as being a source of information and a socially cohesive group for vaccine-hesitant parents, have previously been highly critical of

vaccine-hesitant parents (Court et al., 2021). Findings from this research also confirms that vaccine-hesitant individuals felt stigmatised and marginalised in the online environment, which affirmed and defined the social norms and reaffirmed the negative image of vaccine-hesitant parents.

This research also shows that some healthcare professionals have contributed to feelings of marginalisation through bullying, refusing care and an anecdotal reluctance to respond appropriately to vaccine-hesitant parents. This research found that in some cases insufficient immunisation information is provided by healthcare professionals. This finding is supported by other literature that also found some healthcare professionals lack knowledge and the ability to communicate with vaccine-hesitant parents and needed to take a more active role in information provision (Ben Natan et al., 2017; Giambi et al., 2018; Smith et al., 2021). This suggests that some healthcare professionals are uninformed or hold beliefs around immunisation, influencing their ability to communicate effectively with vaccine-hesitant parents. Healthcare professionals are generally part of the dominant pro-vaccination group, and discrimination against the deviant minority cannot be ruled out. Education of healthcare professionals does not currently address discrimination or marginalisation of vaccine-hesitant parents, which may act to further cement pro-vaccination views as well as reinforce a tendency to exclude vaccine-hesitant parents from care.

8.4 False narratives and the cyberculture effect

It was previously believed that the internet and social media was influential in decision-making about immunisation; however, the extent of this was never fully investigated (Tustin et al., 2018). Several studies observed discourses on social media, however, none could be found that used netnography to gain a deep understanding of the implications and experiences of vaccine-hesitant parents.

One study in the field of vaccine hesitancy sought to classify and label vaccine-hesitant parents and pregnant women according to their beliefs. They were variously labelled as acceptors, fence sitters, deviants or rejectors (Rossen et al., 2019). It could be argued that this form of emotive labelling is neither useful nor constructive and is more likely to have a negative impact on vaccine uptake. Additionally, a study by Wiyeh et al., (2018) attempted to differentiate vaccine hesitancy as outbreaks, either baseline or reactive. This is further evidence of labelling , which is often neither accurate nor constructive. Additionally, the Australian media has framed vaccine-hesitant

parents as deviant, ignorant and an uneducated cult (Court et al., 2021; Wiyeh et al., 2018). This labelling and naming of vaccine-hesitant parents in both the media and academic literature increases the marginalisation of this minority. Through perpetuating the differences, vaccine-hesitant parents continue to be subject to labelling and discrimination, as well as treatment that confirms and defines the social norm, strengthens bonds in the dominant group, thus confirming the vaccine hesitant as deviant as described by Durkheim (1984). As a result, vaccine-hesitant parents find difficulty in gaining social support and acceptance within their peer group, colleagues and family, and have reported feeling stigmatised. This is of particular significance in pregnancy and early parenting when social support networks have been shown to be vital for mental wellbeing and the provision of support for pregnant women and new parents (McLeish & Redshaw, 2017).

The impacts of marginalisation and isolation have been reported in this research, and findings suggest that labelling is neither helpful nor constructive in improving the uptake of vaccines. This marginalisation may even act to cement views, exacerbate the problem of vaccine hesitancy, and perpetuate the tendency to place vaccine-hesitant parents into categories they cannot always fit. Vaccine-hesitant parents have reported feeling isolated, labelled and marginalised by the dominant societal group; hence, this research demonstrates the relevance of Durkheim (1984) deviance theory to vaccine hesitancy by providing an opportunity for their voices and experiences to be heard. The repercussions of being labelled as deviant has been shown to contribute to parental feelings of isolation and marginalisation which can contribute to poor mental health and wellbeing, with a flow-on effect to less than optimal maternal and child outcomes. This research has demonstrated that vaccine hesitant parents and pregnant women are people who have refused vaccines based on fears, anxieties and often considerable misinformation. Vaccine hesitancy is a complex concept which varies from person to person. However, if labelling is necessary to support the development of policy, the World Health Organisation recommendations should be followed (MacDonald, 2015).

The online experiences of many vaccine-hesitant parents had the potential to leave them feeling deviant and pushed them to the fringe of society through exposure to cyberbullying, mockery, fear and aggression. Online trolling or cyberbullying has become a significant problem in Australia, and laws exist to prevent the use of the internet in a way that is harassing or offensive. Cyberbullying has been described as bullying that takes place online and can include racial slurs and gay bashing, and was observed in this research as vaccine choice bashing (Cherian, 2019). Additionally,

significant amounts of misinformation and conspiracy theories were present with the potential to impact information seeking and create doubt and anxiety around decision-making. These findings extend knowledge in the field regarding the impact of social media on vaccine decision-making. This study provides further evidence that social media has the potential to negatively impact vaccine uptake and confirms the findings of previous research (Broadbent, 2019; Clark et al., 2022; Court et al., 2021; Rozbroj et al., 2022; Wilson & Wiysonge, 2020). However, only one study, by Bradshaw et al. (2021), could be located that investigated the influences on parents from within a social networking site. The research by Bradshaw et al. (2021) used discourse analysis of an anti-vaccination social networking site to measure the impact on vaccine choices and found that anti-vaccination advocates controlled the information fed to the vaccine hesitant. However, Bradshaw's study was conducted within a closed anti-vaccination social networking site under non-pandemic conditions, therefore cannot truly reflect current pandemic conditions .

The global pandemic and subsequent introduction of COVID-19 vaccines in 2021 focused anti-vaccination sentiment, both online and in the print media (Australian Government Department of Health, 2021b). This explosion of vitriolic commentary from both pro-vaccination and anti-vaccination groups was described by participants in all aspects of this research but has not previously been reported to this extent in academic literature. The COVID-19 pandemic has been described by the United Nations as the most severe global health disaster of modern times (Renstrom & Back, 2021). Hence, it is not unreasonable to expect extreme responses to individuals who may be different and less socially acceptable to the dominant culture group who are pro-vaccination. A further contributer to the alienation and marginalisation of vacine hesitant parents was the introduction of compulsory COVID-19 immunisation by some workplaces. Whilst these new requirements did not impact all workplaces, the concept of mandated vaccines created further distrust among the hesitant, and increased the vitriole on the social networking site by the immunised majority. Whilst this has not previously been addressed in academic literature, the media and social media have reflected considerable anger from both pro and anti-vaccination advocates and would benefit from further research.

The internet and social media have previously been thought to have a negative influence on vaccine decision-making (Tustin et al., 2018). Misinformation and conspiracy theories were prevalent on the purpose-designed social networking site. Much of this content was focused on the risks associated with vaccines and the safety and credibility of the pharmaceutical industry. This misinformation had a focus on the safety of pregnancy vaccines including COVID-19 vaccines,

and posts were accompanied by highly emotive, inaccurate and persuasive discourses with no evidence of research to back the claims. These posts included the inference that pregnancy vaccines were unsafe with insufficient testing, resulting in miscarriage and death. This was often presented in a highly credible way and with the intention to instil fear and doubt in the vaccine hesitant. These posts had the potential to cause doubt in the undecided and confirm the beliefs of the vaccine hesitant. Data obtained in this research confirms current knowledge about the negative impact of social media on the perception of vaccine risk (Bradshaw et al., 2021). This is despite a British study finding that the internet had a positive impact on vaccine uptake (Clarke, Sirota, et al., 2019). Providing immunisation information early in pregnancy may reduce parental need to seek information from non-traditional sources such as the internet and social media, thereby avoiding exposure to conspiracy theories and misinformation. This recognition of the potential negative impact of social media on vaccine decision-making reinforces the importance of providing timely and accurate antenatal immunisation education before it is sought elsewhere.

Vaccine hesitancy has been reported to be increasing in middle-to high-income countries (WHO, 2019d). This study sought to develop an understanding of the experiences of vaccine-hesitant parents and pregnant women, and this objective was the focus of all phases of this research. The online exploratory survey and semi-structured interviews explored the experiences of vaccine-hesitant parents and pregnant women through open- and closed-ended questions and providing opportunities for parents and pregnant women to share their experiences. Whilst the netnographic study explored the online experience of vaccine-hesitant parents. Through observation and subtle participation, the researcher was able to gain a deeper understanding of the online influences on vaccine-hesitant parents as conveyed in the findings in this section. A vaccine-hesitant or undecided parent using social media could potentially be exposed to misinformation and conspiracy theories, as well as aggression, mockery and vitriol from social media users.. The dominant pro-vaccination culture group used aggression and mockery to affirm and define social norms and subsequently reinforce the alienation and ostracism of vaccine-hesitant participants, whilst the antivaccination contributors used misinformation and conspiracy theories to support their viewpoint.

8.5 The critical point – the timing of immunisation education provision

This research confirms the importance of timely information provision by healthcare professionals. Participants in both the online survey, semi-structured interview phase and the netnography

phase of this research reported seeking information from non-traditional sources when the information from healthcare professionals was inadequate or insufficient. These sources included allied health sources such as homeopaths, friends and family, social media and other sources including anti-vaccination literature. Participants in this research also reported incidences of perceived bullying and having care refused by healthcare professionals, thus demonstrating a knowledge gap in this area of how to provide timely evidence-based information to those who are vaccine hesitant. Previous research has also shown that healthcare professionals need to take a more active and sensitive role in educating and informing parents and pregnant women at critical points of information seeking (Tustin et al., 2018; Ward et al., 2017).

Pregnancy has been shown by previous Australian studies, and confirmed in this research, to be a time when vaccine decision-making begins (Danchin et al., 2018). This study confirmed that over 70% of survey participants began thinking about immunisation during their pregnancy which is in line with Danchin et al. (2018) who also found that vaccine decision-making commences in pregnancy. This knowledge has important implications for the timing of immunisation education and information provision. The declaration of a global pandemic in 2020, as well as the development of COVID-19 vaccines, have also focused the timing of vaccine decision-making on whether to accept immunisation (The Royal Australian and New Zealand College of Obstetricians and Gynaecologists, 2021b; WHO, 2020a). Research has demonstrated that there is a perception that COVID-19 vaccines may have been rushed, resulting in a desire to delay acceptance (Kennedy et al., 2021). This body of research demonstrates that pregnant women are confronted by the decision to accept or reject vaccines in pregnancy, thereby confirming other current research (Gencer et al., 2021). However, the lack of reliable and accurate data on antenatal immunisation uptake in Australia and information provided by healthcare professionals means that this theory cannot be tested. ‘

This research demonstrated that many participants begin immunisation decision-making in pregnancy which is consistent with the work of (Danchin et al., 2018). Those who did not begin the decision-making process in pregnancy reported being confronted by the first vaccine on the Australian schedule, the Hep B vaccine, given in the first week of an infant’s life (National Health and Medical Research Council, 2013). Participants stated that they were confronted by the nature of the first vaccine, which many wrongfully believed provided protection against a sexually transmitted disease. Participants were of the mistaken belief that their infant was not at risk of acquiring Hep B and therefore did not need the vaccine. These findings conflict with results of a

German study that found that parents' vaccine decision-making was influenced by the pain inflicted at the first immunisation encounter (Betsch et al., 2018). The perception that the Hep B vaccine was unnecessary demonstrates a lack of knowledge that may be attributed to inadequate education by healthcare professionals. The early postnatal period is the optimal time to reinforce immunisation education on childhood vaccines. Midwives are best placed to provide this information. South Australian postnatal procedures currently include the recommendation to educate parents about immunisation in this period; however, time is often limited and the depth of discussion can be dependent upon staffing levels and the commitment of the staff member (South Australian Perinatal Practce Guidelines, 2021).

Findings from this research show that midwives, nurses, and general practitioners provided 65% of immunisation education to parents and pregnant women, which corroborates previous studies that support these findings (Charron et al., 2020; Danchin et al., 2018; Helps et al., 2021; Helps et al., 2019). However, 35% of participants stated that they received no advice about immunisation. A common thread reported in this research was the inability to have questions answered to their satisfaction by healthcare professionals. This extends the results of contemporary research in the area which stated that healthcare professionals felt underprepared for their role (Berry et al., 2017; Helps et al., 2021; Nair et al., 2021; Smith et al., 2021). Failure to meet the needs of vaccine-hesitant parents can result in the breakdown of the therapeutic relationship and force parents to look elsewhere for information that may be unreliable. Additionally, this research also demonstrates that healthcare professionals are not always knowledgeable nor respectful of vaccine-hesitant parents and pregnant women, confirming that healthcare professionals can be unhelpful, dismissive, hindering and unhelpful (Helps et al., 2019). Participants also reported being bullied and refused access to healthcare because of their immunisation choices, which is of concern and places both pregnant women and young children at risk.

Pregnancy was shown to be a time of high information needs. This study confirms other research finding that pregnancy is the optimal time to provide information about both pregnancy and childhood immunisation (Diaz Crescitelli et al., 2020). However, this research found that only a small proportion of participants received a recommendation to seek immunisation from a healthcare professional, despite a previously shown association between a healthcare professionals' recommendation and vaccine uptake (Ben Natan et al., 2017). Parents who do not receive a recommendation or information from a healthcare professional have reported looking elsewhere for information, and this may be online and inaccurate (Gao et al., 2013; Sayakhot &

Carolan-Olah, 2016). Of those who did receive advice, this research found that nurses and midwives were the most trusted source of immunisation information in pregnancy (96%) who, and along with general practitioners, midwives and nurses, played a significant role in the provision of antenatal immunisations. Despite this, the research shows that sensitivity was often lacking. Additionally, nurses and midwives currently receive minimal undergraduate immunisation education, especially on how to communicate and approach vaccine-hesitant parents or pregnant women. A previous study reported that Australian midwives receive on average, less than four hours of immunisation education in a three-year degree with many reporting inadequate preparation for their role (Attwell et al., 2019; Smith et al., 2021). Participants in this research identified that healthcare professionals demonstrated a significant knowledge deficit and limited understanding of the use of counselling in motivating vaccine-hesitant people to accept vaccines. This finding is consistent with other research that recommends enhanced education for healthcare professionals (Diaz Crescitelli et al., 2020; Giambi et al., 2018). These results suggest a need for an enhanced national syllabus across nursing, midwifery and medical undergraduate courses as well a contuous professional development in immunisation. Additionally, consideration must be given to including this education in both general practice education and in professional development across the public health sector. Motivational counselling is an approach to counselling aimed at eliciting a change in behaviour, and is a recognised intervention to illicit behaviour change in a health setting (Lim et al., 2019). Motivational interviewing techniques were recently used in an antenatal setting to increase vaccine uptake, however, more research may be needed in this space to confirm the efficacy of this technique (Brewer et al., 2017; Frost et al., 2018).

Pregnancy and early parenting are times when support networks are vital for parents' emotional and mental health (McLeish & Redshaw, 2017). This research confirms the importance of social and health support at this time, especially from peers, nurses, and midwives. Participants in this study discussed the implication of being socially isolated at a time when social support is vital for feeling accepted as a mother. Given the polarising nature of vaccine hesitancy, this research demonstrates that healthcare professionals must be aware of the impact of social isolation on mental health and maternal and infant outcomes. Additionally, the deviant nature of vaccine hesitancy can result in increased conformity amongst those who react to it, resulting in further marginalisation. This research also confirms that pregnancy is a critical point when most families begin to investigate immunisation, which corroborates previous Australian research. The implications of receiving a hostile reception, no information, recommendation or opportunity to

discuss their concerns led to vaccine-hesitant parents seeking information from non-traditional sources. These sources are often not evidence-based and focus on emotional decisions regarding safety and risk. This suggests that pregnant women need to be the focus for immunisation education and information provision early in pregnancy, before non-traditional and unreliable sources of information are sought. Additionally, healthcare professionals who traditionally provide this information, including nurses, midwives and general practitioners, must be appropriately prepared for their role in effectively communicating with vaccine-hesitant parents and not further marginalising them. This research demonstrates a clear need for timely immunisation education and these findings are supported by other research in the field of vaccine hesitancy calling for the integration of immunisation competencies in the nursing curricula (Mossey et al., 2019).

This research demonstrates that when information was not provided by healthcare professionals at critical times, parents and pregnant women looked to non-traditional sources, especially online. This confirms the importance of timely information provision by healthcare professionals. Participants in all phases of this research reported seeking immunisation information from non-traditional sources when the information received from healthcare professionals was inadequate or insufficient. These sources included homeopaths, friends and family, social media sites and other sources including anti-vaccination literature. Participants in this research also reported incidences of perceived bullying and were refused care by healthcare professionals who were identified as having knowledge gaps in this area. Previous research and findings from this study confirmed, that healthcare professionals need to take a more active and sensitive role in educating and informing parents and pregnant women at critical points of information seeking. This research demonstrates a clear need for timely immunisation education and motivational counselling education for general practitioners, nurses and midwives.

8.6 Limitations

All research has limitations, and the limitations that impact this research are discussed at length in Chapter 9. The initial literature search conducted in 2020 identified only 31 papers with a focus on vaccine decision-making, with only 12 more added in 2022 (Appendix 1). The small number of participants recruited to the interview phase of this research is also a limitation. Similarly, conducting this research during a global pandemic could be seen as both a limitation and an advantage.

8.7 Chapter summary

The main findings from this research have been discussed under the following points: weighing up the risks and safety concerning anxieties surrounding vaccine safety, being pushed to the fringe of society, false narratives and the cyberculture effect, and the critical point concerning the timing of immunisation education provision. Many factors were identified that influenced vaccine choices and anxiety surrounding vaccine safety as one of the main finding of this research. Through evaluating vaccine risks and incorrectly believing vaccines were more dangerous than disease, parents and pregnant women were inadvertently marginalising themselves, as well as being marginalised by others. Once marginalised this culture group reported feeling pushed to the fringe of society, victimised by the dominant culture, ignored and mistreated by some healthcare professionals. This social isolation combined with information seeking from non-traditional sources subsequently exposed vaccine-hesitant parents to false narratives, cyberbullying and further marginalisation. This research demonstrates that pregnancy is a critical point for immunisation information provision. Pregnancy has been shown to coincide with a time of high information needs and is an opportunity for healthcare providers to respond to concerns and questions about pregnancy and childhood immunisation. This research confirms and extends contemporary research that found that pregnant women are very likely to seek information online if their needs are not met by healthcare professionals. Pregnancy has been shown to be a time when prospective parents actively seek information, which if not met by traditional sources such as midwives, nurses and general practitioners, will be sought from non-traditional sources such as the internet, social media, friends or family whose information may be neither evidence-based nor accurate.

The inability of healthcare professionals to address concerns and demonstrate respect has been attributed to inadequate education in the undergraduate space and in ongoing professional development. Both healthcare professionals and parents have expressed dissatisfaction with healthcare professionals' level of knowledge and ability to address the concerns of vaccine-hesitant parents. This research extends current knowledge in this field by confirming that a knowledge deficit exists in immunisation education across nursing, midwifery and general practice. Focusing provider education on the undergraduate space, as well as professional development, is likely to have a greater impact on both knowledge and performance of healthcare professionals in addressing the concerns of vaccine-hesitant parents.

This chapter presented and critically examined the main findings of this research with consideration to Durkheim's deviance theory and the cultural aspects of the vaccine-hesitant cohort. It compared this research with contemporary research and demonstrated why these findings are important to professional practice, education policy and research. The following concluding chapter revisits the aims and objectives of the research, the discussion points, implications, recommendations and limitations.

Chapter 9: Pushed to the Fringe: Conclusion and Recommendations

> People do not like to think. If one thinks, one must reach conclusions. Conclusions are not always pleasant. Helen Keller (n.d.)

This body of research explored the values, beliefs and choices made by pregnant women and parents regarding their decision not to vaccinate their child or children, to determine the factors that influence decision-making and to give a voice to vaccine-hesitant parents. Chapters 5–7 presented the findings from the three phases of the overarching research project that, whilst having the same aim, employed a variety of predominantly qualitative methodologies to answer the research question: "What factors influence pregnant women and parents to become vaccine hesitant?" These phases included an exploratory online survey utilising both closed- and open-ended questions (*n* = 106) (see Chapter 5), semi-structured in-depth interviews (*n* = 12) (see Chapter 6) and a netnographic investigation, via a purpose-designed social media site as well as the "Overheard at Flinders" site (see Chapter 7).

The exploratory online survey sought to gain a beginning understanding of the problem whilst gathering demographic data as well as the answers to open-ended questions designed to address the research objectives. The interview phase further explored these issues with a view to gaining a deeper understanding of the beliefs and experiences of this culture group. Finally, the netnographic study sought to gain an understanding of the cyberculture and its potential effect on vaccine-hesitant parents and pregnant women. These methodologies were chosen as they were the most appropriate to answer the research question and to explore the underlying cultural aspect of vaccine hesitancy.

Chapter 8 presented and critically examined the main findings from this research, developed meaning and understanding through deviance theory, and compared the results with contemporary research. This chapter summarises the main findings, describes the implications of this research, makes recommendations for future research and presents the limitations. The recommendations include changes to policy, practice, education and research. In addition, this chapter acts as a conclusion to this thesis by highlighting how the key research objectives were met and how this body of research contributes to new knowledge.

This thesis contributes to new knowledge that will be of benefit to healthcare professions such as general practitioners, nurses and midwives through providing insights into the beliefs, experiences and decision-making of vaccine-hesitant parents. New knowledge was created through developing a deeper understanding of the sociocultural aspects of vaccine hesitancy, including what it is like being vaccine hesitant and marginalised in a predominantly pro-vaccination world, and by gaining an understanding of the influences on the decision-making of parents. Through gaining an enhanced insight into vaccine hesitancy, healthcare professionals will be better able to understand the culture of vaccine hesitancy, communicate with vaccine-hesitant parents, and meet their needs for evidence-based information. Additionally, this new knowledge has the potential to increase vaccine uptake and vaccine confidence in those who may be hesitant.

9.1 Revisiting the aim and objectives

The aim of this research project was to explore the values, beliefs and choices made by pregnant women and parents regarding their decision not to vaccinate their child or children, to determine the factors that influence this decision-making and to give a voice to vaccine-hesitant parents. The research objectives were to:

i) explore when vaccine-hesitant parents and pregnant women make immunisation decisions,
ii) discover from whom vaccine-hesitant parents and pregnant women obtain the bulk of their immunisation information and education,
iii) explore the factors that influence the vaccine choices that vaccine-hesitant parents and pregnant women make, and to
iv) gain an understanding of the experiences of vaccine-hesitant pregnant women and parents.

This aim and objectives of this research were fulfilled through using multiple methods under an ethnographic/netnographic methodology to drive data acquisition including an online survey (*n* = 106), in-depth semi-structured interviews with 12 vaccine-hesitant parents and pregnant women as well as a netnographic study conducted on a purpose-designed social media platform as well as on the “Overheard at Flinders” page. This research offers insights into the decision-making of vaccine-hesitant parents and pregnant women, and what influences their choice around vaccination. Additionally, it has deepened awareness of the sociocultural influences on the decision-making of vaccine-hesitant parents and pregnant women.

9.2 Summary of main points

The main findings of this thesis are summarised below.

9.2.1 Weighing up the risks

This research confirms contemporary studies that have found that one of the greatest concerns affecting the decision-making of vaccine-hesitant parents and pregnant women is fear associated with vaccine safety. This research found vaccine safety, including concern about vaccine content, doubt about the severity of some vaccine preventable diseases and distrust in the pharmaceutical industry were significant factors associated with vaccine hesitancy and refusal. Concerns also existed about the number of vaccines on the Australian schedule, including the number of multivalent vaccines. This is the first study to identify parental concerns regarding the use of multivalent vaccines, which is important new knowledge to be considered when educating parents and pregnant women on the benefits of immunisation. A further area of concern for participants was whether the first vaccine on the Australian schedule, the Hep B vaccine, is necessary or safe. Whilst this conflicts with other research in this space, it is an area that must be addressed when educating parents.

9.2.2 Pushed to the fringe

Throughout all aspects of this research, vaccine-hesitant parents and pregnant women reported feeling isolated, marginalised and pushed to the fringe of society. This research shows that the No Jab No Pay and No Jab No Play legislation had the greatest impact on parents of lower socioeconomic status. Participants in this research believed that the legislation placed financial, social and legislative pressures on them, as well as contributing to their deviance and defining legally and morally what is the appropriate choice. Parents and pregnant women also reported that healthcare professionals contributed to their feelings of marginalisation through bullying, refusing care and through their inability to respond appropriately to vaccine-hesitant parents. This included the need to “go into battle” to achieve appropriate care for themselves and their children. The impact this had on families and children is of concern.

9.2.3 False narratives and the cyberculture effect

The declaration of a global pandemic in 2020 had a significant impact on access to participants with an anti-vaccination stance for the netnographic phase of this research. Many websites were

forcibly shut down to reduce the negative impact on COVID-19 vaccine confidence and uptake. Despite this, access to anti-vaccination information was still available, but to a much lesser extent than in a non-COVID-19 environment, and access to these sites became increasingly difficult. Therefore, the method of recruiting participants to this research was via a purpose-designed Facebook page where participants could gain access to the online survey, volunteer for interviews and take part in discussion threads on Facebook. This familiar and comfortable social media participation resulted in commentary from people with both pro-vaccination and anti-vaccination beliefs. Discussion threads rapidly increased in both volume and level of emotion, resulting in the page becoming a source of vitriol, aggression, conspiracy theories and misinformation, requiring both site and administrator moderation at times. Content on social media was shown to have a negative impact on parents who sought immunisation information online. Social media exposed individuals to vaccine safety misinformation and conspiracy theories about COVID-19, as well as an online culture that was aggressive, mocking and deliberately alienating for vaccine-hesitant individuals. However, despite the unnatural nature of a purpose-designed page, the data obtained provided a valuable insight into life as a vaccine-hesitant parent.

9.2.4 The critical point – timing of immunisation education provision

Pregnancy has been shown to be a time of high information needs and as such, immunisation education should commence early in pregnancy to prevent the search for, and acquisition of, misinformation. However, this research has demonstrated that as many as 31% of participants received no information or recommendation to seek immunisation. This is a lost opportunity to discuss concerns and provide education at a time when information needs are high. This lack of reliable information provision has resulted in a situation where parents and pregnant women seek information from less reliable sources, leading to the subsequent gathering of misinformation, and acquisition of conspiracy theories as well as other misinformation. Appendix 17 provides the outline of an educational program designed to meet the needs of healthcare professionals enrolled in undergraduate programs).

9.3 Limitations

The literature exploring the decision-making of vaccine-hesitant parents was initially limited to 31 articles and only nine had an Australian focus. The number of studies with a vaccine decision-making focus in pregnancy and parenting increased over the course of this research and was incorporated throughout. A further 12 papers were added on a subsequent search. There are

strengths and limitations to this research. A significant strength was the use of multiple methodologies and data sources, which provided an opportunity for triangulation. Additionally, the use of netnography provided the opportunity to access geographically diverse participants and participants who would rarely participate in research. Additionally, the social media site attracted participants with both pro- and anti-vaccination perspectives, thereby adding depth to the research. The online environment combined with the use of in-depth qualitative interviews provided rich data. Although the findings cannot be generalised, it may be transferable to vaccine-hesitant parents worldwide – especially to those who have access to social media.

The small number of participants in the interview phase was a potential limitation of this research and affects the transferability of these findings, although qualitative research is not concerned with the number of participants and a small number can provide rich data that can be analysed qualitatively. A further limitation of the research was the use of telephone interviews, which affected the researcher's ability to observe facial expressions and other nuances. Additionally, the lack of fathers recruited may have resulted in bias due to the all-female participants. A further limitation was the timing of data collection, which took place during a global pandemic, thereby resulting in the need to artificially create a social media site due to the restrictions placed on sites with anti-vaccination sentiments. As a result, the findings of this research cannot be extended to a non-pandemic environment, but some findings may be transferable.

The author's background as a midwife/maternal child health nurse and immunisation provider could be seen as introducing bias into this research. However, through researcher reflexivity, positionality and deliberately addressing beliefs that are pro-vaccination, the researcher was able to critique assumptions and interpretations. There was a genuine desire to accurately present the beliefs of participants who held views that were not in line with the researcher, and this study was conducted with an open mind and a genuine desire to understand vaccine hesitancy.

The netnographic study conducted as part of this body of research also had limitations, including the pandemic conditions under which it was conducted. Whilst this research included content from both pro- and anti-vaccination participants and accurately represented the online environment under pandemic conditions, further research with a focus on vaccine decision-making, under non-pandemic conditions, should be conducted to confirm the results.

9.4 Roadmap for solving issues and recommendations

This section details the recommendations for changes to policy development, tertiary education, professional practice and research, to ensure that vaccine hesitancy and any subsequent vaccine refusal is addressed with a view to increase vaccine confidence and uptake. Pregnancy has been shown to be a critical point when most families begin to investigate immunisation, and it is also a time of high information needs. As such, immunisation education should commence early in pregnancy and parenting to prevent the search for, and acquisition of, misinformation. However, this research has confirmed that many parents and pregnant women received no recommendations regarding antenatal immunisation. There is evidence to suggest that a recommendation from a healthcare professional may be a predicter or influence in vaccine uptake. The first page of the discussion paper published in the *Journal of children and young peoples' health,* "Communicating with vaccine hesitant parents" is attached at Appendix 15.

9.4.1 Recommendations for policy development

This research demonstrates the importance of providing timely information on both antenatal and childhood immunisation, early in pregnancy, as well as the opportunity to discuss concerns and assistance to weigh up the risks of refusing immunisation.

Recommendation 1

Inclusion of a reminder in the Pregnancy Handbook of all Australian states and territories to discuss both pregnancy and childhood immunisation at the first pregnancy visit (Government of South Australia, 2021b): The Pregnancy Handbook is available to all healthcare professionals who provide care for pregnant women, and a reminder in this useful record may encourage healthcare professionals to discuss immunisation and provide information at a critical point.

Recommendation 2

The development of postnatal procedures to educate new parents on the importance and safety of immunisation in the first week of life: Midwives are the most likely healthcare professionals to have access to peri and postnatal women, and prior to the Hep B vaccine is the optimal time to discuss childhood immunisation.

Recommendation 3

Immunisation education to be included in all antenatal education: Many first-time parents attend antenatal classes, and this is an ideal time to provide accurate and timely immunisation information.

Recommendation 4

Immunisation education and promotion must be universal but should also target families from middle- to high-income regions for greatest effect: Whilst the findings of this research cannot be generalised, there was an indication that many parents from high income regions may be more financially able to bare the financial pressures of vaccine refusal and loss of the subsequent taxation benefits.

Recommendation 5

Include pregnancy as a reason for immunisation in the Australian Immunisation Register (Services Australia, 2019) to ensure access to accurate data: The Australian Immunisation Register is a whole-of-life register that acts as a valuable source of data for research and program development. Whilst pregnancy is not currently included as a reason for receiving antenatal immunisation in the Australian Immunisation Register, the register has the capacity to record Aboriginal and Torres Strait Islander status as a reason for receiving some immunisations. Therefore, despite the age of the database, there is the potential to include pregnancy in the data recorded. Additionally, the inclusion of pregnancy as a reason for immunisation must be considered a priority for any replacement to the Australian Immunisation Register system to ensure accuracy of data collection.

Recommendation 6

Prioritise the collection of immunisation status and include in perinatal outcome statistics across all states and territories: South Australia began collecting immunisation data for inclusion in the perinatal outcome statistics in 2020. These will soon be available to researchers; however, there is currently only 1 year of data available, which contains statistics from around half of the women birthing in the state. These data are available from some other states; however, this needs to be a national priority to ensure accuracy of data for both research and program planning.

Recommendation 7

Consideration could be given to the inclusion of more information on government websites regarding vaccine safety and vaccine content to allow parents to accurately weigh up the risks and benefits of immunisation: This needs to be presented in a way that facilitates interpretation of risk. Participants in this research revealed considerable concerns about vaccine safety, as well as concerns about the potential for adverse reactions to vaccines. Official Australian websites produced by the Australian Government and the National Immunisation Program contain minimal information on this topic.

9.4.2 Recommendation for education

This research has also confirmed the importance of effective and empathetic communication and rapport building to elicit behaviour change. However, the ability to provide information, answer questions and be empathetic was questioned by the participants in this study. When appropriate care and information were not readily available, parents and pregnant women were more likely to seek this elsewhere. Findings also demonstrated that communication difficulties persist between vaccine-hesitant parents and healthcare professionals. Many of these were highlighted by the vaccine-hesitant parents and pregnant women who participated in both the online survey and semi-structured interviews, as well as the social networking site. Additionally, general practitioners and obstetricians received considerable criticism from the participants for lacking the ability to either answer questions or provide information in an empathetic manner. The implications are that all healthcare professionals would benefit from education at both the undergraduate level and in the form of professional development in motivational counselling and immunisation knowledge, as well as effective communication skills with vaccine-hesitant parents and pregnant women. Additionally, there is a need to identify evidence-based strategies to encourage healthcare professionals to approach vaccine-hesitant individuals in empathetic way, even when contrary to their own values or beliefs. Therefore, education would not merely include facts but involve the changing of attitudes of healthcare professionals. These findings confirm a need for improved immunisation education in both the undergraduate space and professional development across all healthcare professions involved in educating or providing immunisations.

As healthcare professionals are generally part of the dominant pro-vaccination group, discrimination against the deviant minority cannot be ruled out, and further education for healthcare professionals (information about the efficacy and need for vaccines) that does not

address discrimination and marginalisation, may further cement pro-vaccination views of vaccine hesitancy. Healthcare professional education must include information designed to change attitudes and communication, as well as knowledge. Additionally, policy in healthcare settings could include ongoing professional development in immunisation and motivational counselling. Research into healthcare professional immunisation education and knowledge was also found to be minimal if at all. There are few studies that have evaluated tertiary immunisation education or assessed the role of nurses, midwives and general practitioners in relation to immunisation. Apart from the lack of information provided by healthcare professionals, participants in this research raised concerns about the number and type of vaccines on the Australian schedule. A proposed immunology program is attached at Appendix 17.

Recommendation 8

Tertiary education providers must assume responsibility for including immunisation in the curricula to adequately prepare new practitioners for this vital role: There is a need for the development of an enhanced syllabus to support nursing, midwifery and medicine undergraduate immunisation education across Australian universities. This syllabus should include motivational counselling, as well as an overview of the factors influencing vaccine-hesitant parents and pregnant women.

Recommendation 9

Inclusion of immunisation education and motivational counselling for doctors attending general practice training: This syllabus should include motivational counselling, as well as an overview of the factors influencing vaccine-hesitant parents and pregnant women.

Recommendation 10

The inclusion of immunisation and motivational counselling in professional development for all healthcare professionals including general practitioners, nurses and midwives.

9.4.3 Recommendations for research

Further research is needed into the effects of social media on vaccine decision-making. The internet has previously been thought to have a negative influence on vaccine decision-making. This research has extended this knowledge. Misinformation and conspiracy theories were prevalent and had a strong focus on vaccine safety, particularly associated with pregnancy immunisation, and posts were accompanied by highly emotive, inaccurate and persuasive

discourses. The misinformation included the suggestion that pregnancy vaccines are unsafe, with insufficient testing resulting in miscarriage and death. This was often presented in a highly credible way and with the intention to instil fear and doubt in the vaccine hesitant. The findings of this thesis demonstrate the effect of social media on vaccine decision-making in a COVID-19 environment. This research should be repeated in a non-COVID-19 environment for comparison.

Recommendation 11

Further research is needed into the effects of social media, in a post COVID-19 world, to confirm and extend knowledge about the impact of social media on vaccine decision-making.

Recommendation 12

Further research on the No Jab No Pay and No Jab No Play legislation could be undertaken to fully evaluate its impact on vaccine-hesitant families and particularly the learning outcomes of children who are excluded from early education. This research has suggested that the Australian No Jab No Pay and No Jab No Play legislation had considerable social and financial impact on families in lower- to middle-income areas, however more research to confirm these results is needed. This is an under researched area and one that would benefit from further investigation into the social and educational impact on under-immunised children who are excluded from preschool education, as well as the impact on parental wellbeing.

9.4.4 Recommendation for practitioners

Healthcare professionals have not been free of criticism from the participants in this research and would benefit from further education. Participants in this research have identified many communication failings amongst healthcare practitioners. These included episodes of being bullied and abused, the inability of healthcare professionals to answer questions or address concerns and being refused care for unrelated medical conditions due to their immunisation status or having an unimmunised child. Participants reported having to go into battle to achieve their basic right for healthcare as well as experiencing considerable emotional manipulation, bullying and coercion to give consent for the Hep B vaccine at birth. This suggests that healthcare professionals may be lacking knowledge and the ability to effectively communicate with vaccine-hesitant parents and pregnant women.

Recommendation 13

Healthcare professionals should seek education on both immunisation in general as well as motivational counselling. Uninformed healthcare professionals may unintentionally contribute to vaccine hesitancy.

9.5 Study impact

The research underpinning this thesis makes a significant and original contribution to knowledge of the sociocultural influences on vaccine-hesitant pregnant women and parents. From a methodological perspective, the use of multiple methodologies has expanded on the suite of qualitative approaches to research in this area. Similarly, the use of deviance theory as theoretical underpinning for this research has resulted in a unique understanding of the impact of being considered a social deviant as vaccine-hesitant parents and pregnant women. In addition to a methodological and theoretically unique approach, the primary contribution of this research is to increase and further the understanding of what it is like to be a vaccine-hesitant parent, and provides insight into the lives, experiences and voices of this cultural group.

These findings corroborate and extend knowledge presented in the literature review (Chapter 2). This research confirms that concerns about vaccine safety is an important factor in the refusal of vaccines. Additionally, this research confirms that vaccine decision-making begins in pregnancy. However, this research has also shown that parents who are undecided during pregnancy may be confronted by the nature of the first childhood vaccine (Hep B) and this could contribute to vaccine hesitancy. Additionally, this research has extended knowledge on the effect of the No Jab No Pay legislation on vaccine-hesitant parents and demonstrates that there is a trend for vaccine-hesitant parents to reside in areas of middle to high income, however, further work is needed to confirm this.

This research has demonstrated that a key factor in vaccine decision-making is the perception of the source and quality of information received. Through missed opportunities to provide timely and accurate information and education, parents may rely on other non-traditional sources. Parents who receive no or inadequate immunisation information are likely to use social media as an information source. This medium has the potential to provide misinformation, conspiracy theories, aggression and bullying, which is likely to influence vaccine decision-making. This research has extended knowledge and understanding of the multifactorial influences on vaccine-hesitant parents. This was achieved through using differing methods and methodologies with a

view to collecting rich data and gaining more of an understanding of the influences on vaccine choices in parents and pregnant women and how they experience their marginalisation and discrimination.

9.6 Concluding statement

Immunisation remains the single most significant public health initiative in recent times. However, a small proportion of the Australian population remain vaccine hesitant. This body of research explored the values, beliefs, experiences and choices of vaccine-hesitant pregnant women and parents. Additionally, this research sought to determine the factors that influenced the decision-making and also enable the voices of vaccine-hesitant parents to have primacy of place. This thesis was conducted with the theoretical underpinning of Durkheim's deviance theory and found that vaccine-hesitant parents can be marginalised and discriminated against. Key findings demonstrate a culture of fear and defensiveness surrounding the decision-making process, influenced by concerns about vaccine safety and a distrust of the pharmaceutical industry, influenced in the main by social media and unfounded and unreliable information.

Parents and pregnant women experienced feelings of being marginalised and pushed to the fringe of society through their decision to refuse vaccines. Additionally, cyberculture was shown to have a potential impact on the decision-making of vaccine-hesitant parents, reinforcing their beliefs about safety concerns. Finally, this research identified two critical points when immunisation education is most effectively provided to parents and pregnant women. If professional practice and immunisation confidence is to improve, tertiary educators and policymakers need to see this a priority inclusion in both undergraduate and postgraduate courses, as well as staff development. As healthcare professionals are generally part of the dominant pro-vaccination majority, discrimination against the deviant minority cannot be ruled out, and further education for healthcare professionals (information about the efficacy and need for vaccines) that does not address discrimination and marginalisation, may further cement pro-vaccination views and marginalise vaccine-hesitant parents. Healthcare professional education will ideally include information designed to change attitudes of healthcare professionals, as well as increasing knowledge around side effects and content of vaccines. Additionally, policy in healthcare settings needs to include ongoing professional development in immunisation and motivational counselling. Research into healthcare professional immunisation education and knowledge was found to be minimal. There are few studies that have evaluated tertiary immunisation education or assessed

the role of nurses, midwives and general practitioners in relation to immunisation. Apart from the lack of information provided by healthcare professionals, participants in this research raised concerns about the number and type of vaccines on the Australian schedule. Finally, marginalisation and discrimination will not help the drive for improved immunisation uptake but may have the opposite effect, whereby vaccine-hesitant parents may become more adamant and defensive of the choice they have made.

Parents and pregnant women who are vaccine hesitant require support, understanding and reliable information, and deserve to be listened to. If the culture of discrimination as described in this study becomes entrenched in both the vaccine-hesitant population and the healthcare professions, then the marginalisation and discrimination may continue. Additionally, if the only source of information that is trusted by vaccine-hesitant parents is social media, then vaccine hesitancy will continue to be a problem.. Education of healthcare professionals, as well as policy adjustments, may contribute to a greater uptake of vaccines in pregnancy and childhood with the potential to improve the health of our population and reduce stigmatisation associated with not being vaccinated. Labelling and name-calling vaccine-hesitant parents and pregnant women and pushing them to the fringes of society has not worked in the past and only serves to further marginalise them.

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Appendices

Appendix 1 – Summary of literature review articles

Author, Date	Country	Aim	Methodology, Method, sample, setting.	Findings	Limitations
(Attwell, Ward, et al., 2018)(Attwell, Ward, et al., 2018).	Australia	The aim was to address the knowledge gap by exploring how vaccine rejecting and hesitant parents present their use of complementary and alternative medicine (CAM) vis a vie their decision-making (*n* = 29.	This study used qualitative semi-structured interviews with parents of children under five years who were not vaccinating, were partially vaccinating, or had delayed some vaccinations. Parents of children under five.	Parents in this study approached CAM as a set of practices of health care and body maintenance. Parents saw homeopathy as an alternative to immunisation which is safer. Parents stated that homeopathy provided protection without being full of rubbish. Only one participant had used homeopathic immunisation, but most saw it as a regimen to guide living rather than an alternative to immunisation. CAM providers were sources of information and guidance. Personal research and reliance upon friends for information formed part of the participants' decision-making process. Some CAM providers had indirectly influenced participants vaccine choices by introducing a different way of thinking. The participants of this study saw CAM as part of an expert system running counter to Western medicine but was not seen as a replacement for immunisation, rather a buttress for child health and wellbeing. Parents perceived CAM as natural but, in this study, it did not influence or cause vaccine hesitancy, rather it was associated with the decision.	Findings cannot be generalised to the entire vaccine hesitant and rejecting population in Australia. Other limitations relate to the design and conduct of the studies which were not conducted with CAM in focus.

Author, Date	Country	Aim	Methodology, Method, sample, setting.	Findings	Limitations
(Ben Natan et al., 2017)(Ben Natan et al., 2017)	Israel	To identify factors associated with the intention to receive pertussis vaccine in pregnancy (*n* = 220).	Pregnant women native born in the former Soviet Union resident in Israel (*n* = 220).	Healthcare professionals (HCP) need to take a more active role in educating pregnant women on the risks of pertussis. Perceived risks and benefits of vaccines predicted intention to immunise.	Snowball sampling method can limit generalizability of study. Most participants were primigravida with academic education.

Author, Date	Country	Aim	Methodology, Method, sample, setting.	Findings	Limitations
(Betsch et al., 2018)(Betsch et al., 2018).	Germany	The aim was to assess how and why vaccine attitudes change over time and influences this change (*n* = 351) (*n* = 204 (*n* = 173.	A prospective cohort study was conducted during pregnancy, +3/12, +6/12 and +14/12. Cross sectional control groups were also recruited (*n* = 351, *n* = 204, *n* = 215 and (*n* = 173) to identify knowledge distortion. This was a web-based study with participants randomly assigned to the longitudinal cohort. Randomly assigned web-based study.	At recruitment all their personal experiences of immunisation as being positive. Maternal attitudes towards immunisation are critical factors in the uptake of vaccines. Attitudes during pregnancy are not correlated to a child's vaccination status at 14/12. A negative experience with babies first vaccine can impact subsequent vaccine choices. Information received and the first childhood vaccine experience are critical to vaccine choices throughout a child's life. This event may lead to vaccine risk perception increase and concerns about vaccine safety Even though the initial attitude was positive, negative experiences may lead to subsequent under-vaccination of the child. The role of healthcare professionals in introducing the topic in pregnancy is vital. Vaccination must be made as pleasant as possible to ensure maternal attitudes remain positive. Pregnancy is an optimal time to provide childhood vaccine information.	Selection bias is a potential limitation as only women with an interest in health were recruited.

Author, Date	Country	Aim	Methodology, Method, sample, setting.	Findings	Limitations
(Bradshaw et al., 2021)(Bradshaw et al., 2021).	USA	To analyse social media content to determine how first-time pregnant and new mothers were treated and influenced by anti-vaccine advocates in a closed face-book group.	Qualitative discourse analysis was employed to gain an understand of the behaviour, attitudes, and impact of "thought influencers" in this medium. A Facebook group with more than 100,000 members was the focus of this study.	Pregnant women and parents of young children (*n* = 22) posted on this site during the study period. Many of these posters expressed vaccine hesitancy whilst some were already delaying recommended vaccines. There was frequent sharing of misinformation on this site. Other arguments raised included the focus on natural solutions including organic food, vitamin supplements, use of essential oils, sunshine sleep, and exercise. Fear based responses were used to sway decision-making. Group discussion demonstrated significant turmoil involved in the decision-making process. On this page undecided posters received infinitely more support than tentative advice seekers. Additionally, those who expressed doubt or were pro-vaxers received harsh replies, were belittled, or deemed to be "trolls".	Paraphrasing of posts may be limitation. Also, study cannot be generalised as any qualitative study.
(Clarke, Sirota, et al., 2019)(Clarke, Sirota, et al., 2019)	UK	To investigate the vaccine decision-making process throughout pregnancy (*n* = 182).	Quantitative online study. Pregnant women. during early and late pregnancy (*n* = 182).	88% reported seeking additional information about pertussis during pregnancy. Risk associated with pertussis vaccine decreased as pregnancy progressed.	Self-selection bias relating to participation in this study with higher than national average immunisation rate among participants.

Author, Date	Country	Aim	Methodology, Method, sample, setting.	Findings	Limitations
(Costa-Pinto et al., 2018)(Costa-Pinto et al., 2018).	Australia	The aim of this study was to determine the prevalence of vaccine concerns, socio-economic status, and vaccine uptake. This study also assessed the resources and parents' satisfaction with these resources (*n* = 311) (*n* = 391).	A quantitative survey of parents of children under five years attending general paediatric out-patients department and maternal child health centres in two Australian states.	Nearly half of Australian parents have some vaccine concerns and a quarter lack decision-making confidence. Parental concerns included: too many vaccines in the first two years of life; fear of vaccines causing autism; concerns about the effects of vaccines on the immune system; and fear that vaccines may weaken the immune system. Some parents felt that because other children were vaccinated there was no need to immunise. Parents found GP's to be the most trusted source of information. Other sources were nurses, paediatricians, the internet and family or friends. Some used anti-vaccination and complementary and allied medical practitioners as information sources.	Exclusion of non-English speaking parents may limit generalisability. Also limited access to vaccine hesitant parents is a limitation.

Author, Date	Country	Aim	Methodology, Method, sample, setting.	Findings	Limitations
Danchin et al., 2018	Australia	To ascertain vaccine information received, maternal immunisation uptake and attitudes and concerns regarding childhood immunisation in Australia (*n* = 490, *n* = 295, *n* = 399 and *n* = 231).	Quantitative survey. Pregnant women attending antenatal appointments at four public hospitals across four Australian states (*n* = 490, *n* = 295, *n* = 399 and *n* = 231).	First time mothers are more vaccine hesitant and only 2/3 of mothers believed they received enough information during pregnancy.	Only 43% of mother agreed to follow up. Only English-speaking mothers and low levels of Indigenous mothers were included in the study.

Author, Date	Country	Aim	Methodology, Method, sample, setting.	Findings	Limitations
(Diaz Crescitelli et al., 2020)(Diaz Crescitelli et al., 2020).	Italy, UK.	The aim of this paper was to conduct a systematic review and meta-synthesis of qualitative studies to identify key elements involved in childhood vaccine hesitancy.	A meta-synthesis was conducted on 27 qualitative papers from eight countries.	Parents reported anxiety and apprehension about vaccines and agonized over the decision to vaccinate and reported fear associated with toxic effects of vaccines. Parents reported fear of damage to their child in the form of vaccine-induced conditions. Some parents believed that a good diet and healthy lifestyle prevented diseases rendering vaccines unnecessary. Some hesitant parents saw some vaccines as unnecessary, i.e., measles. Parents believed vaccine preventable diseases were of a low risk and immunity acquired from the disease to be natural and hence better. Parents expressed distrust in pharmaceutical companies, healthcare practitioners and media. Parents also voiced a distrust of Government Institutions. Parents demonstrated doubts about scientific research and official vaccine information. Parents expressed concerns about overloading a child's immune system.	Many studies from Western settings were included and none from Asian settings making the results more relevant to a Western setting.
(Dube, Vivion, et al., 2016)(Dube, Vivion, et al., 2016)	Canada	To better understand why mothers, choose to vaccinate – or not – their newborns in Canada (*n* = 56).	Qualitative interview. Pre- and post-natal, of women (*n* = 56) were purposively recruited to achieve a balance of vaccine hesitant, vaccine refusers and vaccine accepters.	Many factors influence vaccine decision-making with many parents ambivalent about immunisation and continuing to question their decision.	Selection bias may exist as participants were voluntary. Generalizability is limited due to the nature of the study and the settings.

Author, Date	Country	Aim	Methodology, Method, sample, setting.	Findings	Limitations
(Dube et al., 2018)(Dube et al., 2018).	Canada	The aim of this paper was to explore vaccine hesitancy among Canadian parents and to examine factors associated with parents' intention to vaccinate (*n* = 2013).	An online quantitative survey of Canadian parents informed by the Theory of Planned Behaviour (TBT) study. (*N* = 2013) parents of under five-year-old children were eligible for this study.	82.5% of children were immunised according to the provincial recommendations. parents who intended to vaccinate considered their immunisation knowledge to be good compared to parents with no or low intentions to vaccinate. 68.1% of parents reported having to ask for or seek vaccine information. 69.7% of parents believed that it was their role to question vaccines, higher in parents with little or no intention to immunise. Trust in the media and pharmaceutical industry was low in all parents. There were differing levels of trust in health authorities and academic researchers between parents who strongly intended to vaccinate and those with a weaker intention. Overall, parental intention to vaccinate was associated with the TPB model.	Selection bias due to participants having certain characteristics. Some study design issues including timing of participation.

(Duchsherer et al., 2020.	USA	The aim of this study was to evaluate testimonials on a film entitled VAXXED, an anti-vaccination film.	This paper is a qualitative content analysis of testimonials on a film entitled VAXXED, an anti-vaccination film.	Mothers know their child's health best and are best placed to make vaccination decisions for them. Distrust of doctors was evident. Mothers sought to establish themselves as trusted sources. Self-diagnosis of supposed vaccine injuries were evident. Community building is central to the growth of the anti-vaccination movement and vaccine hesitant parents connect through social media platforms like Facebook. Mothers sought to establish themselves as trustworthy sources Analysis limited to spoken word videos and testimonials. Findings cannot be generalized due to sampling and design of the study. of information. Advocacy was evident in many testimonials. Self-diagnosis of supposed vaccine injuries were evident. Using only science to combat vaccine hesitancy is recognised as ineffective. The community with which parents associate can have a significant effect on vaccine beliefs. Parents who were vaccine hesitant were more likely to know someone who was also vaccine hesitant. Online sources and communities play an increasing role in vaccine decision-making. Parents have demonstrated a preference for sources that provide strong social support rather than credible information. Parents recognized medical sites as most trustworthy, they maintained a more active presence on popular blogs and less credible sites. Instead of scientific evidence, many communities rely upon narrative, storytelling, and personal experience. Narratives have been shown to increase recall, aid comprehension and shorten reading time.	Analysis limited to spoken word videos and testimonials. Findings cannot be generalized due to sampling and design of the study.
(Giambi et al.,	Italy	The aim of this study was to	A quantitative cross-sectional online survey	Vaccine hesitant parents made up 16% whilst anti0vaccination parents were 1%. Safety concerns were the main reason for	Families residing in the north of

Author, Date	Country	Aim	Methodology, Method, sample, setting.	Findings	Limitations
2018)(Giambi et al., 2018).		conduct a survey to estimate vaccine hesitancy and its determinants (*n* = 3130).	was conducted (*n* = 3130) on parents to evaluate parents' attitudes and beliefs in relation to tetanus and measles vaccines. Parents were then categorised as pro-vaccine, vaccine hesitant or anti-vaccine.	refusing vaccines. Hesitant and anti-vaccination parents demonstrated more doubts about the safety of the vaccines. They demonstrated more concerns about combined and co-administered vaccines. 21% of parents still believe that vaccines can cause autism. 44% of parents believe that many vaccines contain mercury. Having a recommendation by a family physician was a predictor for uptake but only 84% received a recommendation. Hesitant parents and pro-vaccination parents share a similar perception of the usefulness of vaccines, but more hesitant parents were aware that rare diseases may resurge without immunisation.	Italy were over-sampled. Hesitancy rate could be over or under-estimated.
(Gidengil et al., 2019)(Gidengil et al., 2019).	USA	The aim of this study was to conduct a systematic review of the literature to identify the range of beliefs around childhood vaccines (*n* = 32).	Of the 1727 studies identified 71 were included in this review using the PRISMA checklist. Studies using open ended question only were included in the final review.	Seven themes emerged from the literature. Fear of adverse events. Mistrust in governments, doctors, pharmaceutical companies, and profit motive. Lack of necessity, i.e., natural remedies, natural immunity, diseases not severe, healthy lifestyle. Pro-vaccine options included: child deserves protection, vaccines therapeutic, vaccines protective, doctors have bet interests in mind. Scepticism about effectiveness of vaccines, disbelief in herd immunity, schedule not effective. Desire for autonomy, parents right to choose. Morality concerns, some ingredients are derived from foetuses.	The studies included in this review focussed on identifying barriers to immunisation. Findings are likely to be biased to negative findings about immunisation.

Author, Date	Country	Aim	Methodology, Method, sample, setting.	Findings	Limitations
(Helps et al., 2018)(Helps et al., 2018).	Australia	The aim of this study was to interview vaccine hesitant parents to ascertain the impact of legislation aimed to enhance vaccine compliance (*n* = 31).	Semi-structured face to face interviews were conducted of vaccine hesitant parents' resident in the Byron Shire, a northern NSW coastal area with a high proportion of vaccine hesitant parents.	Three main themes emerged including: Questioning policy integrity; minimising impact; and holding my ground. A suite of behaviours accompanied vaccine refusal, specifically salutogenic parenting. Herd immunity was not a motivating factor. Parents questioned the legislation and saw it as coercion. Parents stated that no government measure would influence their choice to refuse vaccines. Autonomy in health decisions have strengthened with the advent of No Jab no Pay. Parents valued the notion of informed consent.	Interviews occurred in geographical clusters, Byron Shire. Study not generalizable.
(Helps et al., 2019)(Helps et al., 2019).	Australia	The aim of this study was to explain vaccine refusal in a sample of Australian parents (*n* = 32).	Qualitative study using Charmaz version of Grounded Theory. Semi-structured interviews were conducted on parents and one pregnant woman.	Elevated parental anxiety detected in sample and need to justify decision. Vaccine refusers were adversely affected by societal animosity. Need of HCP to recognise complex and diverse nature of decision-making. Overall concerns of community declining health. Parents decision was not final, and they conducted ongoing risk assessments. Therapeutic roadblock present when HCP do not listen. Parents expressed limited faith in studies debunking autism/MMR link. Parents expressed desire to receive information and ask questions. Parents have experience of being judged. Decision not to immunise can be intuitive but remains difficult and fraught. Increased importance on organic food, prolonged breastfeeding, exercise, and fresh air. Parental doubts often surface in pregnancy.	Interviews occurred in geographical cluster, Byron Shire. Study not generalizable.

Author, Date	Country	Aim	Methodology, Method, sample, setting.	Findings	Limitations
(Jenkins & Moreno, 2020)(Jenkins & Moreno, 2020).	USA	The purpose of this study was to analyse how parent vaccination opinions are expressed online.	Content analysis was conducted to evaluate comments on parenting blogs related to vaccination. Nine blogs were included from 244 comments.	Parents involved in the vaccine discourse were both pro and anti-vaccines. Three main findings included the following. Both pro and anti-vaccines bloggers demonstrated that they believed their rhetoric to be based in science. The blogs on this platform were mainly giving information not requesting it. Pro- vaccination comments were more likely to take on an aggressive tone.	Comments on blog favoured pro-vaccination stance. Sample size small and aimed at most popular blogs, not anti-vaccination blogs.
(Koski & Holst, 2017)(Koski & Holst, 2017).	Finland	The aim of this study was to explore vaccine hesitancy through an artist-scientist collaboration to better understand health beliefs and the influences of decision-making (*n* = 6).	Qualitative study including interviews conducted with parents' resident in either Finland or Netherlands who identified as vaccine hesitant. This study uses visual narrative to gain a better understanding of parent's health beliefs.	Four main health beliefs were explored in this study: perceived benefit of illness; belief in the bodies self-healing; belief about the inside-outside flow of substances; and the view of death as a natural part of life. Parents saw illness as a process, beneficial to the child's growth and development and not something to be prevented and did not discriminate between vaccine preventable diseases and the common cold. Parents expressed a desire for a more natural way of living with a more intuitive approach. Diagrams and narratives merged to reveal health beliefs behind vaccine hesitancy.	Recruitment of vaccine hesitant parents through authors own social network was a limitation to the study.

Author, Date	Country	Aim	Methodology, Method, sample, setting.	Findings	Limitations
(Lama et al., 2020)(Lama et al., 2020).	USA	The aim of this study is to explore the predictors of childhood influenza status based on adult status (*n* = 328) and to examine the factors contributing to concordance or otherwise.	Quantitative study. Data were collected from a previously conducted national survey of non-Hispanic black and white parents. Classification trees were used to identify drivers of parental decision-making.	The main influence on parents' decision to immunise their children were physician recommendation, knowledge of influenza recommendations for children, influenza vaccine confidence and perception of disease risk. Reasons not to vaccinate were hesitancy about vaccines in general; low perception of disease risk; poor knowledge of recommendation to vaccinate, and low confidence in the vaccine. Predictors of children's influenza vaccination varied between vaccinated and unvaccinated parents.	Limitations exist in the sampling and the nature of the cross-sectional survey which provides only a snapshot in time of vaccine decision-making.

Author, Date	Country	Aim	Methodology, Method, sample, setting.	Findings	Limitations
(Peretti-Watel et al., 2019)(Peretti-Watel et al., 2019).	France	The aim of this study was to compare two populations with contrasting socio-economic profiles to evaluate vaccine hesitancy. In-depth interviews (*n* = 25) were conducted.	Qualitative study. Semi-structured interviews of French parents (*n* = 25) of young children. were conducted in the spirit of grounded theory using a guide designed to investigate child vaccination issues including physician interactions, sources of information, and involvement in the decision-making process.	Most participants searched the internet for vaccine-related information, but it was not the basis of decision-making. Parents struggle with overwhelming and ambiguous vaccination related information. The internet is a factor in decision-making but widely consulted and deeply mistrusted, not obviously linked to vaccine hesitancy. Peers and significant others have an enduring influence on vaccination related attitudes and decisions. Vaccine refusal is a difficult decision. Parents who refused believed that they were doing the right thing. Vaccine refusing parents look to compensate with other ways to boost immunity such as homeopathy, healthy feeding, limiting access to toxins in food and other products. Vaccine acceptors often have enduring doubts about their choice, and this may lead to later rejection of vaccines. Choosing the "right" physician with whom to establish a trysting relationship was a way to opt out of the decision-making process. Decision-making in this study was largely a gendered issue involving mothers and their network of female relatives. Vaccine hesitancy was not obviously related to socioeconomic status.	Recall bias and social desirability bias are limitations in this study.

Author, Date	Country	Aim	Methodology, Method, sample, setting.	Findings	Limitations
(Romijnders et al., 2019)(Romijnders et al., 2019).	Netherlands	The aim of this study was to investigate factors at play in informed vaccine decision-making of childhood immunisation (*n* = 12).	This qualitative study used three focus group interviews across the Netherlands with vaccine acceptors, refusers, and partial acceptors.	Vaccine acceptors perceived decision-making as self-evident. Vaccine refusers relied mostly on anecdotal evidence. Partial acceptors described an elaborate deliberation of weighing up the pros and cons of each vaccine and disease. All parents felt uninformed and stated that they received inadequate information on vaccine safety. Vaccine refusers believed that vaccine side-effects were more serious than diseases. Vaccine refusers preferred to receive anecdotal evidence from vaccine-critical websites and social-media platforms. Using search engines to gather information about childhood vaccination leads to selection bias due to previously used search terms and ranking of websites by search engines. Partial acceptors lost trust in vaccine providers when their questions were ignored. This led to increased decisional conflict. Partial acceptors reported a lack of social support from friends, family, and vaccine providers. Many participants expressed a need for more information about childhood vaccination. Vaccine providers find it difficult to discuss alternative vaccine decisions with parents.	Selection bias with high proportion (96%) highly educated.

Author, Date	Country	Aim	Methodology, Method, sample, setting.	Findings	Limitations
(Rossen et al., 2019)(Rossen et al., 2019).	Australia	The aim of this study was to examine the structure and roots of anti-vaccination attitudes, intentions, and moral preferences (*n* = 296).	This study used a quantitative online survey. Parents or caregivers (*n* = 296) who were visitors to parenting websites and Facebook pages completed an online questionnaire. A combination of questions based on the Vaccine Confidence Inventory, Vaccine behavioural intentions scale and the Moral Foundation Questionnaire.	This study confirmed the emergent profiles of three groups of parents, these are: Vaccine accepters, fence sitters and rejecters. Vaccine accepters displayed a high intention to vaccinate, are confident in the safety of vaccines. This group is unaffected by anti-vaccination rhetoric. The fence-sitters mostly supported vaccination but strongly supported the right to decide whether to vaccinate or not. The rejectors showed low intentions to vaccinate and demonstrated strong endorsement of the anti-vaccination rhetoric. They were strongly opposed to restrictions of liberty and scored low on endorsement of authority and high on the concept of purity i.e., concerns about toxins entering a child's body.	Australian parenting website data may not generalise to a broader population. Sample is self-selected and subject to bias.

Author, Date	Country	Aim	Methodology, Method, sample, setting.	Findings	Limitations
(Rosso et al., 2020)(Rosso et al., 2020)	Italy	To conduct a systematic review of studies that assessed the knowledge and attitudes of pregnant women to paediatric vaccinations.	Systematic review. Sixteen primary source articles were reviewed.	Pregnant women overall believe vaccines are important to protect their children. Vaccine safety concerns persist which reduce trust in vaccines.	Limitation are the nature of vaccine hesitancy itself which has been described as a context specific phenomenon. Survey may not be generalizable.
(Rozbroj et al., 2020)(Rozbroj et al., 2020).	Australia	The aim of this study was to gain a deeper insight into the way having children influences vaccine beliefs of parents (*n* = 904).	This qualitative study drew participants from a subset of parents surveyed in a previous study. Only those participants who were parents and indicated that they had changed their attitude to vaccination after having children.	Five themes were identified in the analysis. All parents felt that parenthood was a time to learn more about vaccination. In the groups with some concerns, parents expressed distrust in pharmaceutical companies. Hesitant and refusing parents feared vaccine risks and thought the efficacy was overstated. Hesitant parents were concerned about the scheduling of vaccines believing that too many vaccines are recommended at too young an age. Parents who did not support full immunisation believed that their child was harmed by vaccines. All groups reported researching vaccines when they had children. Parents with low vaccination confidence viewed information through a lens of broader beliefs related to distrust of vaccine oversight, disapproval of the schedule and concerns over side effects.	Paper focussed mainly on parents whose vaccine attitude remained unchanged by having children.

Author, Date	Country	Aim	Methodology, Method, sample, setting.	Findings	Limitations
(Rumetta et al., 2020)(Rumetta et al., 2020).	Malaysia	The aim of this study was to explore Malaysian parents' reasons for vaccine refusal and to report their views on recommendations on discussing vaccine-related concerns (*n* = 14)	This qualitative study used face to face and online in-depth interviews of parents who had refused any childhood vaccine and lived within the study area. A topic guide was developed using the Health Belief Model.	The reasons for vaccine refusal included: Lack of confidence in modern medicine and distrust of health care personnel. Distrust in the motives of the pharmaceutical companies. A preference for a natural approach including using natural products and gaining immunity through disease rather than vaccine. Religious beliefs, i.e., "if God provided an immune system, then vaccines were unnecessary". Instincts, i.e., a gut feeling. Concerns about the negative effects of vaccines and the contents of the vaccine. Insufficient knowledge information and understanding of vaccines. Most anti-vaccination information came from peers, the internet, and online groups	Participants had a background of tertiary education and lacked representation of lower educated parents. These findings are not generalisable as sample was small.

Author, Date	Country	Aim	Methodology, Method, sample, setting.	Findings	Limitations
(Saada et al., 2015)(Saada et al., 2015).	USA	The aim of this study was to gain a better understanding of parents' rationales for their vaccine choices (*n* = 24).	This qualitative study used semi-structured interviews of parents attending a health centre. Participants were stratified into "on-time", "late" and "missing", dependent upon the child's vaccination status.	This study included five alternative vaccination schedules. Parents who fit the "on-time" category had a belief in the importance and effectiveness of vaccines. Parents who followed alternative schedules or classified as "missing", expressed concerns about vaccine safety, concerns of immune system burden and fear of autism. Some parents preferred fewer vaccines given at once. Parents expressed the desire for more control over the schedule. Parents also valued participation and engagement in the vaccine decision-making process. Many parents were unsatisfied with the depth and scope of vaccine information including parents who choose non-conforming schedules. Parents expressed a desire for vaccine info in the antenatal period. who choose non-conforming schedules? Parents expressed a desire for vaccine info in the antenatal period.	Sample was small and select and included only insured members of a health organization. Results cannot be generalised.

Author, Date	Country	Aim	Methodology, Method, sample, setting.	Findings	Limitations
(Swaney & Burns, 2019)(Swaney & Burns, 2019).	Australia	The aim of this study was to explore reasons for vaccine hesitancy among higher socioeconomic parents in Pert WA (*n* = 18).	A qualitative approach using grounded theory was taken for this study. Face to face interviews using open ended questions were conducted. Sampling was via snowballing after postings on Facebook pages. High income parents in WA who had concerns about vaccinating their children.	Four main themes emerged from the data. We are educated; parents felt that higher levels of education supported and enhanced vaccination decision-making abilities. Some parents wanted better quality vaccine information We control our health by eating organically, breastfeeding, exercise and limiting contact with others. This group believed that natural was better. What we want, parents were dissatisfied with the quality of the vaccination information available. Some expressed a desire for more narrative style of information. Safe from disease but at risk from vaccines. Parents felt less likely to contract vaccine preventable diseases because they live in Australia Some sought vaccine contents disclosure. Parents with a higher education were more likely to be vaccine hesitant and were confident that better education informed vaccine decision-making.	No limitations to this study were reported however, this research is not generalizable due to the nature of qualitative research.
(Syiroj et al., 2019)(Syiroj et al., 2019).	Indonesia	The aim of this study was to explore parents underlying reasons for their child's incomplete immunisation (*n* = 16).	Qualitative semi structured interviews were conducted with parents of under immunised children in Banten Province. Sampling was purposive.	Three themes were identified. Beliefs, (Wang et al., 2015)(Wang et al., 2015) barriers driven by Islamic beliefs and preference for natural immunity and belief in alternative medicine. Trust issues and misinformation including distrust in government and trust in social networks exacerbated by misinformation and lack of knowledge. Concerns about vaccine safety, adverse events, and anxiety about components of vaccines including belief that they contained pork products which is not allowed for Muslim people.	Limitations include generalisability. The views of vaccine hesitant parents who subsequently vaccinate their children are not represented.

Author, Date	Country	Aim	Methodology, Method, sample, setting.	Findings	Limitations
(Tomljenovic et al., 2020)(Tomljenovic et al., 2020).	Croatia	The aim of this study was to explore factors that contribute to parental vaccine conspiracy theories (*n* = 823).	A quantitative cross-sectional correlation design conducted online (*n* = 823) with a focus on analytically rational and experientially intuitive styles. This study used the Rational-experiential inventory instrument. Explore parents (*n* = 823) reasons for incomplete immunization of their child.	The results indicate a strong association between vaccine conspiracy beliefs and vaccine uptake. Conspiracy beliefs and vaccine uptake were associated with unpleasant emotions such as anger, fear, disgust, anxiety, repulsiveness, and worry. These unpleasant emotions directly motivate the action of avoiding vaccination. These parents are more likely to ignore objective probabilities and information and focus on the fear of adverse events, regardless of how improbable. Faith in intuition and not the need for cognition predicted vaccine conspiracy beliefs and uptake. Conspiracy beliefs were not predicted by age, gender, marital status, or political ideology. Vaccine conspiracy beliefs do not stem from lack of motivation to engage in rational and analytical thinking but in strong unpleasant emotions. Results suggest the primary importance of emotions and intuitive thinking in relation to vaccine decision-making.	The data obtained were correlational and cannot be linked to any causal effect. A biased sample of mostly female participants from similar background also infer bias.

Author, Date	Country	Aim	Methodology, Method, sample, setting.	Findings	Limitations
(Tustin et al., 2018)(Tustin et al., 2018).	Canada	The aim of this study was to investigate the link between parental perceptions of vaccine risk with seeking information from the internet(*n* = 966) (*n* = 951).	A quantitative web-based convenience sample survey on Facebook was compared with data obtained from random digit dialling of Canadian parents by telephone survey.	The internet is an important source of vaccine information for parents. The use of internet sources for vaccine information resulted in the perception of vaccines being unsafe. The use of internet sources is significantly associated with negative perceptions of vaccine risks. This study has shown the need for more internet-based health information in the form of stories and testimonials to positively influence parents' vaccine risk perception. The internet has become an important risk factor for vaccine hesitancy with exposure nearly doubling the risk that parents will question the risk of childhood vaccination.	The method of Randomised digit dialling is a limitation in this study as fewer people retain a landline thus compromising the samples representativeness.
(Wang et al., 2015)(Wang et al., 2015).	USA	The aim of this study was to examine how attitudes and beliefs are developed and contribute to immunisation decisions(*n* = 23).	A qualitative study using grounded theory and employing open-ended in-depth interviews was conducted on parents claiming to be pro-vaccine. Convenience sampling was used to recruit parents in upper middle-class neighbourhoods in Philadelphia.	Parents reported feeling frustrated by overwhelming and conflicting information presented by various sources. Parent's decision-making was informed by palpable tensions between the scientific and non-scientific approach to decision-making. This study found that high immunisation rates do not imply high vaccine confidence. Provider acceptance of an altered schedule because of parental request or child illness may be endorsing parental concerns. Pro-vaccine parents exhibit vaccine hesitancy which results in non-science-based vaccine decision-making. The decision-making experience in the context of over-whelming vaccine information may be the mechanism that generates and perpetuates vaccine hesitancy.	Sample populations were already interested in vaccination issues. The sample were also predominantly pro-vaccine and results cannot be generalised.

Author, Date	Country	Aim	Methodology, Method, sample, setting.	Findings	Limitations
(Ward et al., 2017)(Ward et al., 2017).	Australia	This paper aimed to explore the ways parents talked about perceived risks and benefits of vaccination (*n* = 29).	A qualitative study using interviews of vaccine hesitant parents in Australia. Interviews focussed on factors that shaped their decisions.	Capacity - a conscious and logical choice not to vaccinate their children. Questioning science and shifting evidence. Salutogenic parenting – comprehensive health promoting and illness prevention.	Data were analysed from two separate studies undertaken by two different researchers in two cities. Results are not generalisable due to nature of qualitative research.

Appendix 2 – CASP – Qualitative Appraisal Tool

Author, date	Clear statement of aim	Research design appropriate to aim	Recruitment strategy appropriate	Data collected in a way that addressed aim	Relationship between researcher and participant considered	Ethical issues identified	Data analysis sufficiently rigorous	Clear statement of findings	Research Valuable
(Attwell, Ward, et al., 2018)(Attwell, Ward, et al., 2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
(Bradshaw et al., 2021)(Bradshaw et al., 2021)	No	yes	yes	yes	yes	yes	yes	yes	yes
(Dube, Vivion, et al., 2016)(Dube, Vivion, et al., 2016)	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes
(Dube et al., 2018)(Dube et al., 2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
(Duchsherer et al., 2020)(Duchsherer et al., 2020)	Yes	Yes	Yes	Yes	N/A	N/A	Yes	Yes	Yes
(Helps et al., 2019)(Helps et al., 2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
(Helps et al., 2018)(Helps et al., 2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
(Jenkins & Moreno, 2020)(Jenkins & Moreno, 2020)	Yes	Yes	Yes	Yes	N/A	N/A	Yes	Yes	Yes
(Koski & Holst, 2017)(Koski & Holst, 2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Not clear	Yes
(Peretti-Watel et al., 2019	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
(Romijnders et al.,	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Author, date	Clear statement of aim	Research design appropriate to aim	Recruitment strategy appropriate	Data collected in a way that addressed aim	Relationship between researcher and participant considered	Ethical issues identified	Data analysis sufficiently rigorous	Clear statement of findings	Research Valuable
2019)(Romijnders et al., 2019)									
(Rozbroj et al., 2020)(Rozbroj et al., 2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
(Rumetta et al., 2020)(Rumetta et al., 2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
(Saada et al., 2015)(Saada et al., 2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
(Syiroj et al., 2019)(Syiroj et al., 2019)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
(Wang et al., 2015)(Wang et al., 2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
(Ward et al., 2017)(Ward et al., 2017)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Appendix 3 – CASP Quantitative Studies

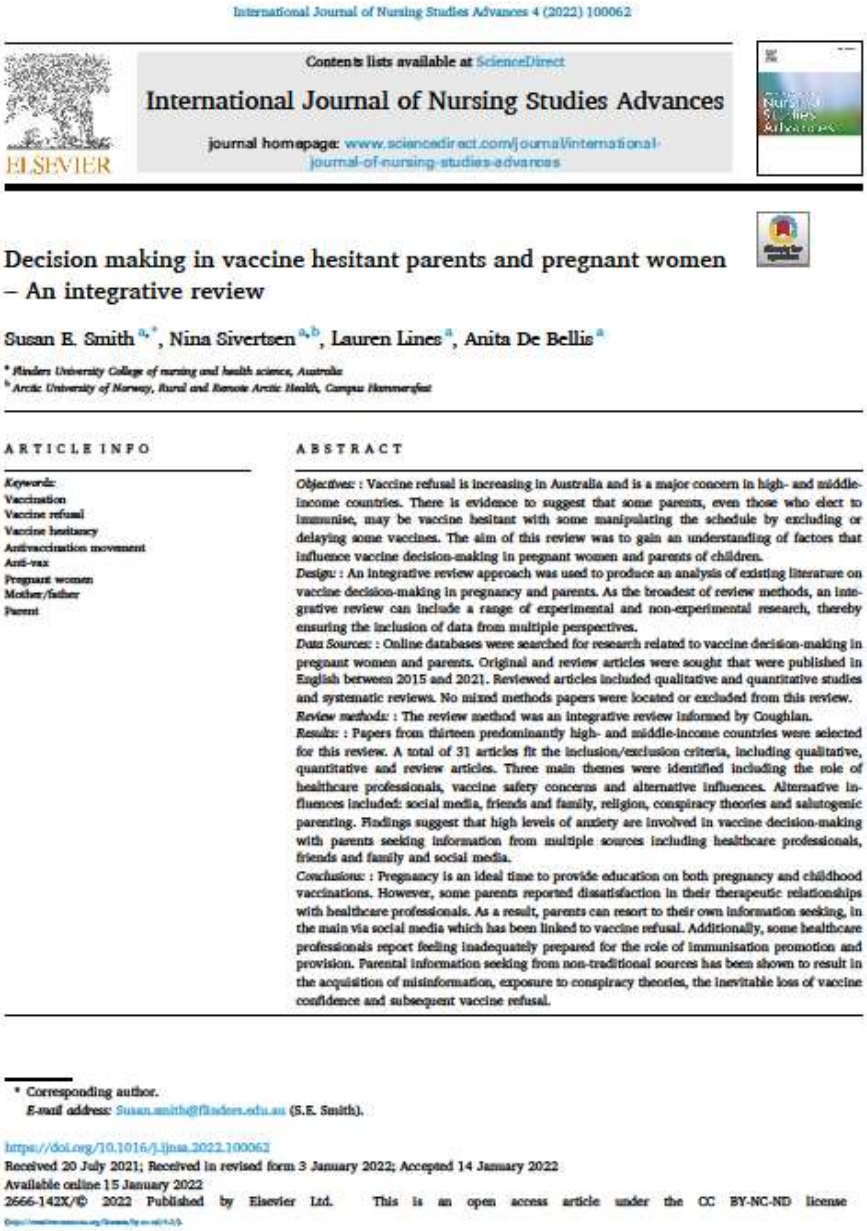
Author, date	The study addresses a clearly focused issue	The method appropriate to research question	Sample size and recruitment appropriate	Outcomes accurately measured	Ethical issues considered	Confounding factors identified	Results clearly presented and precise	Findings believable	Results can be replicated and generalised to another setting
(Ben Natan et al., 2017)(Ben Natan et al., 2017)	yes	yes	yes	yes	yes	yes	yes	yes	yes
(Betsch et al., 2018)(Betsch et al., 2018).	yes	yes	yes	yes	yes	yes	yes	yes	yes
(Clarke, Sirota, et al., 2019)(Clarke, Sirota, et al., 2019)	yes	yes	yes	yes	yes	yes	yes	yes	yes
(Costa-Pinto et al., 2018)(Costa-Pinto et al., 2018)	yes	yes	yes	yes	yes	yes	yes	yes	yes
Danchin et. al., 2017	yes	yes	yes	yes	yes	yes	yes	yes	yes
(Giambi et al., 2018)(Giambi et al., 2018)	yes	yes	yes	yes	yes	yes	yes	yes	yes
(Lama et al., 2020)(Lama et al., 2020)	yes	yes	yes	yes	yes	yes	yes	yes	yes
(Rossen et al., 2019)(Rossen et al., 2019)	yes	yes	yes	yes	yes	yes	yes	yes	yes
(Tomljenovic et al., 2020)(Tomljenovic et al., 2020)	yes	yes	yes	yes	yes	yes	yes	yes	yes
(Tustin et al., 2018)(Tustin et al., 2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Appendix 4 – Systematic Reviews

Author	Focused Question	Papers Appropriate	All relevant studies included	Sufficient Quality Assessment	Results Appropriately combined	Results combined	Precise Results	Results can be applied to local settings	Important outcomes considered
(Rosso et al., 2020)(Rosso et al., 2020)	Yes. To assess knowledge and attitudes towards paediatric vaccines.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
(Diaz Crescitelli et al., 2020)(Diaz Crescitelli et al., 2020)	Yes. To summarise the evidence surrounding vaccine hesitancy from a prenatal perspective.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
(Gidengil et al., 2019)(Gidengil et al., 2019)	Yes. To identify and summarise the range of beliefs around childhood vaccines.	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Appendix 5 – Publication from this thesis

The first page of a version of the data included in Chapter 2. This article, an integrative review of the literature, was reprinted from the *International Journal of Nursing Studies Advances*.



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Decision making in vaccine hesitant parents and pregnant women – An integrative review

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ABSTRACT

Objectives: : Vaccine refusal is increasing in Australia and is a major concern in high- and middle-income countries. There is evidence to suggest that some parents, even those who elect to immunise, may be vaccine hesitant with some manipulating the schedule by excluding or delaying some vaccines. The aim of this review was to gain an understanding of factors that influence vaccine decision-making in pregnant women and parents of children.
Design: : An integrative review approach was used to produce an analysis of existing literature on vaccine decision-making in pregnancy and parents. As the broadest of review methods, an integrative review can include a range of experimental and non-experimental research, thereby ensuring the inclusion of data from multiple perspectives.
Data Sources: : Online databases were searched for research related to vaccine decision-making in pregnant women and parents. Original and review articles were sought that were published in English between 2015 and 2021. Reviewed articles included qualitative and quantitative studies and systematic reviews. No mixed methods papers were located or excluded from this review.
Review methods: : The review method was an integrative review informed by Coughlan.
Results: : Papers from thirteen predominantly high- and middle-income countries were selected for this review. A total of 31 articles fit the inclusion/exclusion criteria, including qualitative, quantitative and review articles. Three main themes were identified including the role of healthcare professionals, vaccine safety concerns and alternative influences. Alternative influences included: social media, friends and family, religion, conspiracy theories and salutogenic parenting. Findings suggest that high levels of anxiety are involved in vaccine decision-making with parents seeking information from multiple sources including healthcare professionals, friends and family and social media.
Conclusions: : Pregnancy is an ideal time to provide education on both pregnancy and childhood vaccinations. However, some parents reported dissatisfaction in their therapeutic relationships with healthcare professionals. As a result, parents can resort to their own information seeking, in the main via social media which has been linked to vaccine refusal. Additionally, some healthcare professionals report feeling inadequately prepared for the role of immunisation promotion and provision. Parental information seeking from non-traditional sources has been shown to result in the acquisition of misinformation, exposure to conspiracy theories, the inevitable loss of vaccine confidence and subsequent vaccine refusal.

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Available online 15 January 2022

Appendix 6 – Exploratory Survey

Description of the study

This project will investigate the vaccine decision-making process of pregnant women and parents of pre-school aged children and the influences upon them. This project is supported by Flinders University, College of Nursing and Health Science and has ethics approval (2464).

Purpose of the study

The purpose of this study is to explore vaccine decision-making and the influences on vaccine hesitant parents.

Benefits of the study

The sharing of your experiences will help to gain a deeper understanding of what influences your decision-making including who you rely on for vaccine information.

The research

This study will take place in two parts, an online survey and interview, you may consent to take part in one or both parts of this study. If you do not wish to complete the survey and would like to participate only in the interview phase of this study, please contact the Principal Investigator on 0466 848853.

If you do not wish to answer a question in the survey, simply leave that question blank and move onto the next question. If you change or mind about completing the survey, simply close the browser. There is no need to send a withdrawal text as the data you have entered to that point will not be saved. If you have already completed the survey, it will not be possible to remove your data as it will no longer be identifiable.

By clicking on the button below you acknowledge that your participation in this survey is voluntary, you are over the age of 18 years and are aware that you may terminate your participation at any time and for any reason. If you chose to participate in the interview phase of this study, you will be asked to sign a consent form which will be provided prior to participation.

The results of this study will be used in research which has ethics approval from Flinders University. You are assured anonymity and no identifying information will be applied to your submission. By

continuing, you are providing consent to participation in the survey only and to the information you provide being used in research. This survey should take around 8 minutes of your valuable time.

Confidentiality and privacy

Only researchers listed on this form have access to the individual information provided by you. Privacy and confidentiality will be assured at all times. The research outcomes may be presented at conferences, written up for publication or used for other research purposes as described in this information form. However, the privacy and confidentiality of individuals will be protected. You will not be named, and your individual information will not be identifiable in any research products without our explicit consent. No data, including identifiable, non-identifiable and de-identified datasets, will be shared or used in future research projects without your explicit consent.

Data storage

The information collected may be stored securely on a password protected computer and/or Flinders University server throughout the study. Any identifiable data will be de-identified for data storage purposes unless indicated otherwise. All data will be securely transferred to and stored at

Flinders University for at least five years after publication of the results. Following the required data storage period, all data will be securely destroyed according to university protocols.

Ethics Committee approval

The project has been approved by Flinders University's Human Research Ethics Committee No.2464.

Queries and concerns

Queries or concerns regarding the research can be directed to the research team on +61 466 848 853 or email susan.smith@flinders.edu.au. If you have any complaints or reservations about the ethical conduct of this study, you may contact the Flinders University's Research Ethics & Compliance Office team via telephone 08 8201 3116 or email human.researchethics@flinders.edu.au.

The researchers do not expect the questions to cause any harm or discomfort to you. However, if you experience feelings of distress as a result of participation in this study, please let the research

team know immediately. You can also contact the following services for support: Counselling services Lifeline – 13 11 14, www.lifeline.org.au Beyond Blue – 1300 22 4636, www.beyondblue.org.au "BetterHelp" – www.betterhelp.com

Do you consent to take part in only this survey? Yes/No

Are you over 18 years? Yes/No

Please select your age range.

- ○ 18-29 years (1)
- ○ 30-39 years (2)
- ○ 40-49 years (3)
- ○ 50+ years (4)

Where do you live?

- ○ Country (4) _____
- ○ Postcode/Zip code (5) _____

Are you fully immunised? Yes/No/Unsure

Is your partner fully immunised? Yes/No/Unsure

Are you in favour of vaccination? Yes/No (can you tell us why?/Unsure

Are you currently pregnant? Yes/No

Were you advised to have vaccinations during your pregnancy? Yes/No/Unsure

Who gave you information about immunisation? (Please select all relevant)

- ☐ General Practitioner (8)

- [ ] Obstetrician (9)
- [ ] Midwife (10)
- [ ] Nurse (11)
- [ ] Friends or family (12)
- [ ] Other, please tell us who. (13)

_____

What vaccines would you accept in pregnancy? (Please select all relevant)

- [ ] Influenza (10)
- [ ] Whooping cough (11)
- [ ] Unsure (12)
- [ ] None, please tell us why. (13)

_____

Did you receive any information from a health professional about childhood immunisations during your pregnancy? Yes/No/Unsure/ Did you start thinking about your child's/children's immunisation during your pregnancy?

During your pregnancy did you seek different opinions on the risks and benefits of immunization?

- ○ Yes, what was the source of this information? (1)

_____

- ○ No (2)
- ○ Unsure (4)

This section is for parents of pre-school aged children.

Are you the parent or caregiver of a child aged under five years?

- ○ Yes (1)
- ○ No (2)

What ages are your children?

- ○ Birth-1 year (4)
- ○ 1 year - 2 years (5)
- ○ 2 years - 3 years (6)
- ○ 3 years to 5 years. (7)

Are any of your children not immunised?

- ○ Yes (1)
- ○ No (2)

Are any of your children partially immunised?

- ○ Yes (1)
- ○ No (2)

Are you considering immunising your children but delaying it?

- ○ Yes, can you tell us which vaccines you will delay? (1) _____
- ○ No (2)
- ○ Unsure (4)

I believe that I know enough about the risks and benefits of immunisation.

- ○ Strongly Agree (1)
- ○ Agree (2)
- ○ Unsure (3)
- ○ Disagree (4)
- ○ Strongly Disagree (5)

Do you believe that vaccines against childhood diseases are more dangerous than the childhood diseases?

- ○ Yes, which vaccines are you concerned about? (1) _____
- ○ No (2)
- ○ Unsure (3)

What were the sources of immunisation information that you received? (Please select all relevant)

- ☐ General Practitioner (1)
- ☐ Midwife (2)
- ☐ Nurse (3)
- ☐ Internet (4)
- ☐ Social Media (5)
- ☐ Friends/family (6)
- ☐ Scientific evidence (7)

☐ Other (8)

☐ If you used a website or social media page or blog, can you tell us which one you rely on for immunisation information? (9)

_____

What were your sources of information not to vaccinate?

_____

Can you tell us why you chose this information?

_____

Have you or someone you know had a negative experience during or after an immunisation which may have affected your decision to not vaccinate?

○ Yes, can you tell us about this? (1)

_____

No (2)

What alternative practices, if any, do you use in place of vaccination?
Please describe?

_____

Do you believe that the current COVID pandemic is a risk to your children?

○ Yes (3)

○ No, can you tell us why you believe this? (4)

_____

○ Unsure (5)

If there was a COVID vaccine for children, would you choose to have your children vaccinated?

○ Yes (1)

○ No, can you tell us why? (2) _____

○ Unsure (3)

Thank you for taking part in this survey. Would you consider also being interviewed? Or would you consider providing a written description of your decision not to vaccinate your children? Be assured that this further participation would be confidential and anonymous.

If you would like to participate in an interview or by writing a short story, please enter your first name and contact details (Phone and/or email address) in the box below. Alternatively, you could contact the researcher directly on 0466 848 853 or email susan.smith@flinders.edu.au. A researcher will call or email you to make any arrangements. We value your participation and giving you a voice.

Thank you.

Appendix 7 – Participant information sheet and consent form

PARTICIPANT INFORMATION SHEET AND CONSENT FORM

Vaccine hesitancy in pregnancy and early childhood

Title: Vaccine hesitancy

Chief Investigator

Mrs. Susan E. Smith RN, RM, Master of Midwifery.

College of Nursing and Health Science

Flinders University

Tel: xxxx xxxx

Supervisor

Dr. Anita De Bellis

College of Nursing and Health Science

Flinders University

Tel: 8201 3441

Supervisor

D. Nina Sivertsen

College of Nursing and Health Science

Flinders University

Tel: 8201 3911

Description of the study

This project will investigate the vaccine decision making process of pregnant women and parents of pre-school aged children and the influences upon them. This project is supported by Flinders University, College of Nursing and Health Science.

Purpose of the study

The purpose of this study is to explore vaccine decision-making and the influences on vaccine hesitant parents.

Benefits of the study

The sharing of your experiences will help to gain a deeper understanding of what influences your decision making including who you rely on for vaccine information.

Participant involvement and potential risks

If you agree to participate in the research study, you will be asked to:

Attend a one-on-one interview with a researcher that will be audio recorded.

Respond to questions regarding your views about vaccine decision making.

Interviews may be conducted either online or by phone at your request.

If you prefer, you may provide written information in either the form or a diary or journal or a short paper. This can be done by emailing the Principal Investigator

(Susan.smith@flinders.edu.au) and including the information in the email body or by adding the written information as an attachment.

The interview will take about 50 minutes and participation is entirely voluntary.

The researchers do not expect the questions to cause any harm or discomfort to you. However, if you experience feelings of distress as a result of participation in this study, please let the research team know immediately. You can also contact the following services for support:

- Lifeline – 13 11 14, www.lifeline.org.au
- Beyond Blue – 1300 22 4636, www.beyondblue.org.au
- "Betterhelp" – www.betterhelp.com

Withdrawal Rights

You may, without any penalty, decline to take part in this research study. If you decide to take part and later change your mind, you may, without any penalty, withdraw at any time without providing an explanation. To withdraw, please contact the Chief Investigator or you may just refuse to answer any questions / close the internet browser and leave the online survey / leave Focus Group discussions / not participate in exercises at any time. Any data collected up to the point of your withdrawal will be securely destroyed.

Confidentiality and Privacy

Only researchers listed on this form have access to the individual information provided by you. Privacy and confidentiality will be assured at all times. The research outcomes may be presented at conferences, written up for publication or used for other research purposes as described in this information form. However, the privacy and confidentiality of individuals will be protected at all times. You will not be named, and your individual information will not be identifiable in any research products without your explicit consent.

No data, including identifiable, non-identifiable and de-identified datasets, will be shared or used in future research projects without your explicit consent.

Data Storage

The information collected may be stored securely on a password protected computer and/or Flinders University server throughout the study. Any identifiable data will be de-identified for data storage purposes unless indicated otherwise. All data will be securely transferred to and stored at Flinders University for at least five years after publication of the results. Following the required data storage period, all data will be securely destroyed according to university protocols.

Recognition of Contribution / Time / Travel costs

If you would like to participate, in recognition of your contribution and participation time, you will be provided with a $30.00 voucher. This voucher will be provided to you face-to-face on completion of the interview.

How will I receive feedback?

On project completion, a short summary of the outcomes will be provided to all participants via email or published on Flinders University's website.

Ethics Committee Approval

The project has been approved by Flinders University's Human Research Ethics Committee Project No. 2464.

Queries and Concerns

Queries or concerns regarding the research can be directed to the research team. If you have any complaints or reservations about the ethical conduct of this study, you may contact the Flinders University's Research Ethics & Compliance Office team via telephone 08 8201 3116 or email human.researchethics@flinders.edu.au.

Thank you for taking the time to read this information sheet which is yours to keep. If you accept our invitation to be involved, please sign the enclosed Consent Form.

CONSENT FORM

Consent Statement

☐ I have read and understood the information about the research, and I understand I am being asked to provide informed consent to participate in this research study. I understand that I can contact the research team if I have further questions about this research study.

☐ I am not aware of any condition that would prevent my participation, and I agree to participate in this project.

☐ I understand that I am free to withdraw at any time during the study.

☐ I understand that I can contact Flinders University's Research Ethics & Compliance Office if I have any complaints or reservations about the ethical conduct of this study.

☐ I understand that my involvement is confidential, and that the information collected may be published. I understand that I will not be identified in any research products.

I further consent to:

☐ completing a questionnaire

☐ participating in an interview

☐ having my information audio recorded

☐ sharing my de-identified data with other researchers

☐ my data and information being used in this project and other related projects for an extended period of time (no more than 10 years after publication of the data)

Signed:

Name:

Date:

Appendix 8 – Weighing up the risks – Vaccine decision-making in pregnancy and parenting

The following is the first page of a version of the data included in Chapter 5. This article, an exploratory survey, is reproduced with permission from *Women and Birth Journal*.

ARTICLE IN PRESS

Women and Birth xxx (xxxx) xxx

Contents lists available at ScienceDirect

Women and Birth

journal homepage: www.sciencedirect.com/journal/women-and-birth

Weighing up the risks — Vaccine decision-making in pregnancy and parenting

Susan E. Smith [a,*], Nina Sivertsen [a,b], Lauren Lines [a], Anita De Bellis [a]

[a] CNHS, Flinders University, Australia
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ARTICLE INFO

Keywords:
Vaccine
Vaccination
Decision-making
Pregnancy
Parents

ABSTRACT

Background: Immunisation is universally accepted as one of the most significant health initiatives in recent times. However, vaccine hesitancy is increasing in Australia and other high- and middle-income countries. There is evidence to suggest that many parents, even those who elect to immunise, may have a degree of vaccine hesitancy. The recommendation of a healthcare professional is a predictor for vaccine uptake.
Aim: The purpose of this study was to explore the values, beliefs and choices made by vaccine hesitant parents and pregnant women, regarding their decision not to vaccinate their child or children. The aim being to determine the factors that influence this decision making and to give a voice to vaccine hesitant parents.
Method: A qualitative exploratory online survey of 106 vaccine hesitant parents and pregnant women was conducted in 2021. The survey utilised closed and open-ended questions.
Findings: Pregnant women and parents obtained most of their immunisation education from nurses, midwives, and general practitioners. Vaccine decision-making was however, influenced by multiple factors including vaccine safety concerns, the sources of information accessed, and a previous negative immunisation experience. Other influential factors included the use of alternative therapies, diet, and lifestyle factors.
Discussion: Along with general practitioners, nurses and midwives are a popular, respected and a vital source in the provision of accurate and timely immunisation education. However, further education is required at an undergraduate level to adequately prepare them for their role of listening to and educating vaccine hesitant pregnant women and parents.

Statement of significance

Problem

Vaccine hesitancy in parents and pregnant women.

What is known

Vaccine hesitancy is increasing in middle- and high-income counties.

Maintaining high levels of immunisation is vital for herd immunity.

There is no reliable way to measure uptake of pregnancy vaccines including COVID-19 which is currently suboptimal.

The recommendation of a healthcare professional is a predictor for vaccine uptake.

What this paper adds

Pregnant women and parents receive most of their immunisation information from midwives, nurses and general practitioners who are a trusted source of immunisation information.

Vaccine safety concerns are a major factor in vaccine compliance by parents and pregnant women including anxiety about vaccine contents.

Vaccine decision-making is influenced by multiple factors including information sources, vaccine safety concerns, previous negative experiences and are often accompanied by alternative lifestyle factors.

Vaccine hesitant pregnant women and parents are unlikely to accept a COVID-19 vaccine in pregnancy or for their child under 12 years.

Vaccine hesitant parents reject the expression "vaccine hesitant" in favour of "Pro-Choice".

;1;

1. Introduction

Immunisation is universally accepted as one of the most significant public health initiatives in recent times. Childhood vaccines alone have been credited with saving 2–3 million lives annually [1]. However, vaccine hesitancy is a growing problem in middle- and high-income countries and has recently overtaken vaccine access as the primary

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E-mail address: susan.smith@flinders.edu.au (S.E. Smith).

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Please cite this article as: Susan E. Smith, *Women and Birth*, https://doi.org/10.1016/j.wombi.2022.02.007

Appendix 9 – Qualitative interview schedule

Audio recorded informed consent

Interview Pseudonym: _____

Demographics

Gender: Male Female Age in years:

Marital Status: Married Single Partner

Employment: Employed as Unemployed Home Duties

Currently pregnant: Yes No

Number of children and ages: _____

Number of Children not vaccinated: _____

Are any of your children vaccinated? _____

Number of children partially vaccinated? _____

Describe vaccination history for each child: _____

Postcode of home address: _____

QUESTIONS

1. Can we start by you telling me about your child/children/pregnancy?

2. Can you describe your personal beliefs about immunisation?

3. Does the father/mother of your children have similar views? If not, what are their views?

4. Can you tell me when you began to think about immunisation?

5. What was your main source of immunisation information?

6. Did you discuss your choice with anyone else e.g. family, friends, partner? And what sort of reaction did you get and from whom?

7. How did you feel about the information given? Were all your questions answered?

8. What if any unanswered questions do you have?

9. What was important to you in making this choice not to vaccinate your child or children?

10. Can you tell me which childhood vaccines concern you the most? Why?

11. What was helpful and what was not helpful for you in making the decision not to vaccinate your child?

12. Can you tell me which childhood vaccines concern you the most? Why?

13. How do you feel about that decision and is it likely to change in the future?

14. If your child or children are partially vaccinated, what was the reason for this?

15. What are your thoughts on complementary therapies such as naturopathy, chiropractic, natural medicines and/or herbs as far as immunisation is concerned?

16. What are your thoughts about COVID 19 and any vaccinations that may become available for your children?

17. Do you have any other comments you would like to make?

18. Would you like a transcript of this interview sent to you? If so, can you give me your email address (recognising that this is not a secure medium) or home address.

_____

Thank you for your time. Here is your voucher/your voucher will be sent to you by email or post.

Extra Questions

Can you give me more detail? Could you describe that more? Can you give me an example? When, where, how, why, and what?

Appendix 10 - Ethics Approval Letter

1 December 2020

HUMAN RESEARCH ETHICS COMMITTEE

APPROVAL NOTICE

Dear Mrs Susan Smith,

The below proposed project has been **approved** on the basis of the information contained in the application and its attachments.

Project No: 2464

Project Title: Vaccine decision-making in pregnancy and early childhood.

Primary Researcher: Mrs Susan Smith

Approval Date: 01/12/2020

Expiry Date: 31/03/2023

Please note: Due to the current COVID-19 situation, researchers are strongly advised to develop a research design that aligns with the University's

COVID-19 research protocol involving human studies. Where possible, avoid face-to-face testing and consider rescheduling face-to-face testing or

undertaking alternative distance/online data or interview collection means. For further information, please go to https://staff.flinders.edu.au/coronavirusinformation/

research-updates.

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. Participant Documentation

Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept

any responsibility for the above mentioned errors.

the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent

forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders

University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should

be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be

conducted overseas.

the HREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

This research project has been approved by the Flinders University Human Research Ethics Committee (Project Number 2464). For more information

Regarding ethics approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by

email human.researchethics@flinders.edu.au.

2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the National Statement on Ethical Conduct in Human Research 2007 (updated 2018) an annual progress report must be submitted each year on the anniversary of the approval date for the duration of the ethics approval using the HREC Annual/Final Report Form available online via the ResearchNow Ethics & Biosafety system.

Please note that no data collection can be undertaken after the ethics approval expiry date listed at the top of this notice. If data is collected after expiry, it will not be covered in terms of ethics. It is the responsibility of the researcher to ensure that annual progress reports are submitted on time; and that no data is collected after ethics has expired.

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please either submit (1) a final report; or (2) an extension of time request (using the HREC Modification Form).

For student projects, the Low Risk Panel recommends that current ethics approval is maintained until a student's thesis has been submitted, assessed and finalised. This is to protect the student in the event that reviewers recommend that additional data be collected from participants.

3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes /modifications include:

change of project title;

change to research team (e.g., additions, removals, researchers and supervisors)

changes to research objectives;

changes to research protocol;

changes to participant recruitment methods;

changes / additions to source(s) of participants;

changes of procedures used to seek informed consent;

changes to participant remuneration;

changes to information / documents to be given to potential participants;

changes to research instruments (e.g., survey, interview questions etc);

extensions of time (i.e. to extend the period of ethics approval past current expiry date).

To notify the Committee of any proposed modifications to the project please submit a Modification Request Form available online via the ResearchNow Ethics & Biosafety system. Please open the project, then select the 'Create Sub-Form' tile in the grey Action Menu, and then select the relevant Modification Request Form. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.au immediately if: any complaints regarding the research are received; a serious or unexpected adverse event occurs that effects participants; an unforeseen event occurs that may affect the ethical acceptability of the project.

Yours sincerely,

Hendryk Flaegel

on behalf of

Human Research Ethics Committee

Research Development and Support

human.researchethics@flinders.edu.au

Flinders University

Sturt Road, Bedford Park, South Australia, 5042

GPO Box 2100, Adelaide, South Australia, 5001

http://www.flinders.edu.au/research/researcher-support/ebi/human-ethics/human-ethics_home.cfm

Appendix 11 – Annual Ethics Report

Dear Susan Smith,

The Annual Report outlined below has been approved.

Project ID: 2464

Project Title: Vaccine decision-making in pregnancy and early childhood.

Primary Applicant: Vaccine decision-making in pregnancy and early chi Susan Smith

Application Link: https://researchnow-ethics-forms.flinders.edu.au/Project/Index/4931

You can access the Annual Report in the *ResearchNow Ethics & Biosafety* system via the Application Link above.

Please do not hesitate to contact the Research Ethics Office if you have any questions.

Regards,

_____

Hendryk Flaegel

Appendix 12 – Publication

The following is a version of the data included in Chapter 6. This article is currently under peer review with the *Journal of primary health*.

Understanding the impact of vaccine hesitancy on parents and pregnant women.

RUNNING TITLE: Pushed to the fringe.

Authors

***Susan E. SMITH RN, RM, PhD Candidate, Flinders University, College of Nursing and Health Science. ***

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Nina SIVERTSEN RN, PhD, Flinders University and Arctic University of Norway, Rural and Remote Arctic health, Campus Hammersfest.

Lauren LINES RN, PhD, Flinders University.

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Susan E Smith @susan_miffy

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Appendix 13 – Examples of Facebook posts

17/08/2021 15:12	With SPC and Alliance Airlines, amongst other Australian companies requiring staff be immunised against COVID-19, can you share your thoughts on the topic?	Status	Public	166 1.9K 560
13/08/2021 14:35	How do you feel about COVID-19 vaccines being a condition of employment in some workplaces?	Status	Public	22 77 11
01/08/2021 08:43	Many are anxious about receiving a COVID vaccine. If this is you, has that changed your views on people who refuse other vaccines?	Status	Public	10 103 9
19/07/2021 10:56	Vaccine hesitancy in pregnancy and early childhood. added a button to help you learn more about them.	Link	Public	6 61 0
13/07/2021 13:50	If you are in favour of vaccines, can you tell me what concerns you about people who elect not to vaccinate?	Status	Public	125 1.4K 579
26/06/2021 09:45	I am commencing data analysis and want to thank you all again for the wonderful data you provided.	Status	Public	9 88 9
25/05/2021 08:00	I have closed my survey after 135 completed. Thank you all so much for contributing to this important research. I would now like to know what concerns or threatens you about people who choose not to vaccinate?	Status	Public	6 69 3
17/04/2021 08:42	I will be ceasing my data collection at the end of June and would like to thank everyone who has completed my survey and taken part in an interview. I would also like to thank everyone who has posted thoughts and comments. You have made my PhD journey a pleasure.	Status	Public	2 62 6

26/03/2021 13:54	With Easter and school holidays in a few days this page wants to wish everyone a safe and pleasant break. I am still hoping to hear your thoughts on vaccines and would value and respect your opinions. I am still available.	Status Public	58	0 1
23/03/2021 10:18	I am getting to the end of my data collection and want to thank everyone who has commented, posted memes, completed my survey and volunteered for an interview. I love your passion and know there are a few of you out there who still want to have your say and I want to hear your views. Please take this chance to include your thoughts in my thesis and potentially make a difference for our children.	Status Public	61	3 2
20/03/2021 09:19	Saturday is a great day to take a survey or volunteer for an interview. Please consider it as I come to the end of my data collection. I still want to hear your opinions.	Status Public	54	0 1
11/03/2021 12:22	I am loving reading your commentary on this page including the pros and cons of vaccination but would like to remind everyone to share their opinions on my survey or volunteer for an interview or both. It is only through your input that this important research will come to fruition. I can't make it up or do it on my own. Follow the link to the survey. https://tinyurl.com/yywq2xcf	Status Public	62	4 2
10/03/2021 07:32	I am still keen to interview women and parents who are undecided about immunisation or who have decided not to immunise. Please respond to this ad if you would like to take part. I will not try and change your mind and your opinions will be respected.	Status Public	669	33 55

25/02/2021 18:08	Recruiting for interviews now. Please contact me if you would like to share your thoughts.	Status	Public	77	4 3
11/02/2021 16:20	I appreciate the amount of interest this page is attracting but would prefer if we could respect each other's views without name calling. This is exactly why I am fascinated by this divisive topic.	Status	Public	113	6 3
29/01/2021 09:44	Hello, I have attempted to contact a few people who have volunteered to take part in my study but sadly the email addresses are incorrect or the phones unanswered. I really want to contact you but have run out of options.	Status	Public	200	36 14
29/01/2021 09:12	Good morning, I want to say to anyone who has concerns about participating in this study that the researchers will not attempt to influence your decisions on immunisation and will respect you right to decide. This is purely a research project into the decision-making process and the influences upon it. Whether you have elected to refuse vaccines or receive only specific vaccines or accept the entire schedule is your choice and will be respected. This is NOT a means of vaccine promotion.	Status	Public	193	3 6
22/01/2021 16:29	My data collection is now under way very slowly, so this is where I ask you all to like and share this page again. Thanks in advance for helping my recruitment.	Status	Public	169	0 3
18/01/2021 19:25		Photo	Public	406	61 53
16/01/2021 12:26	This study is now live, and I would appreciate your support by sharing this page with all your friends. Click the learn more button to complete the survey.	Status	Public	189	11 2

14/12/2020 09:07	Good morning, you are invited to like and follow this page. For those of you who don't know, I am doing a PhD at Flinders University and this Meta (Facebook) page will be part of that journey. I will send irregular updates on the progress of my study and will not fill your pages full of "stuff". I am not quite ready to promote my survey, but when I am you will be asked to kindly share it with your own Meta (Facebook) family. I really appreciate your support by simply sharing my page and eventually my survey. Thank you for your support and Merry Christmas and happy New Year.	Status Public 232	2 16
13/12/2020 09:00	This research study now has Ethics Approval from Flinders University HREC.	Status Public 145	1 1
	Hello and welcome to this page. The purpose of this page is to promote my research study and to act a conduit between researchers, supporters and study participants. This is a safe space where differing opinions will be valued, and the research is the focus.		3 1
13/12/2020 08:43		Status Public 118	

Appendix 14 – Cyberculture influences on vaccine decision-making in parents – a netnography

The following is a version of the data included in Chapter 7. This paper is currently under peer review with *Vaccine journal*.

Cyberculture influences on vaccine decision-making in parents – A netnography.

ABSTRACT

Background

Immunisation is universally accepted as one of the most significant health initiatives of recent times. However, vaccine hesitancy is increasing and was declared to be one of the top ten threats to global health by the World Health Organisation in 2019. A major factor associated with vaccine hesitancy, is thought to be the viral spread of misinformation by a small but active anti-vaccination movement. This movement relies heavily on social media to influence the decision-making of parents.

Aims

The purpose of this study was to gain a deeper understanding of the influences of social media on vaccine decision-making in parents.

Methods

This study is part of a larger body of research which explored vaccine decision-making in parents and pregnant women. Netnography was chosen as the methodology for this aspect of the study. Netnography is a form of qualitative inquiry which explores online culture and life, with its roots in ethnography. A research specific Business Meta (Facebook) page was established and provided a medium for open discussions on vaccine choices.

Findings

The three key themes identified in this study were vaccine safety concerns, the emotional debate, and COVID-19 issues. Vaccine safety concerns, including the perception that vaccines were both unsafe and unnecessary was a major theme identified in this research. Significant distrust was

demonstrated in pregnancy specific vaccines and the proliferation of misinformation and conspiracy theories prevailed. Concerns also existed about COVID-19 vaccines, and the mandating of vaccines.

Appendix 15 – A discussion paper on how to communicate with vaccine hesitant parents - Top ten tips for effective communication.

This article is a version of the information included in Chapter 9 and is reprinted with permission of the *Journal of children and young peoples' health.*

A discussion paper on how to communicate with vaccine hesitant

parents: top 10 tips for effective communication

Abstract

Vaccine hesitancy is an increasing problem in middle- to high-income countries. Australia currently has high levels of childhood immunisation uptake; however, COVID-19 vaccine uptake during pregnancy remains sub-optimal. This paper acknowledges the important role of nurses and midwives in the promotion and provision of immunisation and recognises that many feel under-prepared for encounters with vaccine hesitant parents and pregnant women. The aim of this paper is to discuss the current literature on vaccine hesitancy, conduct a balanced discussion, and provide the top ten tips for effectively communicating with vaccine hesitant parents.

Keywords vaccine hesitant, vaccination, vaccine refusal, parent

For referencing Smith SE et al. A discussion paper on how to communicate with vaccine hesitant parents: top 10 tips for effective communication. Journal of Children and Young People's Health 2022; 3(1):4-7

DOI https://doi.org/10.33235/jcyph.3.1.4-7

Submitted 26 November 2021, Accepted 11 April 2022

Introduction

The role of nurses and midwives in the promotion and provision of immunisation is well recognised.[1–3] Healthcare professionals have a vital role to play in education, information provision, and responding to the concerns of vaccine hesitant parents.[4] Despite this important role in immunisation, many healthcare professionals feel underprepared for addressing vaccine hesitancy.[1,2,5] However, the quality of interactions between parents and healthcare professionals

has been shown to be pivotal in shaping future vaccine decisions.[5] An encounter, poorly handled, can result in the breakdown of a therapeutic relationship, thereby effecting future health and wellbeing. Therefore, the aim of this paper is to discuss the current literature on vaccine hesitancy in pregnancy and parenting, with a focus on influences affecting vaccine decision-making.

Appendix 16 – Co-authorship approvals

Office of Graduate Research
Room 003, Registry Building
Bedford Park, SA 5042
GPO Box 2100, Adelaide 5001 Australia
Email: hdrexams@flinders.edu.au
Phone: (08) 8201 5961
Website: https://students.flinders.edu.au/my-course/hdr
CRICOS Provider: 00114A

CO-AUTHORSHIP APPROVALS FOR HDR THESIS FOR EXAMINATIONS

In accordance with Clause 5, 7 and 8 in the HDR Thesis Rules, a student must sign a declaration that the thesis does not contain any material previously published or written by another person except where due reference is made in the text or footnotes. There can be no exception to this rule.

a. Publications or significant sections of publications (whether accepted, submitted or in manuscript form) arising out of work conducted during candidature may be included in the body of the thesis, or submitted as additional evidence as an appendix, on the following conditions:
   I. they contribute to the overall theme of the work, are conceptually linked to the chapters before and after, and follow a logical sequence
   II. they are formatted in the same way as the other chapters (i.e. not presented as reprints unless as an appendix), whether included as separate chapters or integrated into chapters
   III. they are in the same typeface as the rest of the thesis (except for reprints included as an appendix)
   IV. published and unpublished sections of a chapter are clearly differentiated with appropriate referencing or footnotes, and
   V. unnecessary repetition in the general introduction and conclusion, and the introductions and conclusions of each published chapter, is avoided.

b. Multi-author papers may be included within a thesis, provided:
   I. the student is the primary author
   II. there is a clear statement in prose for each publication at the front of each chapter, recording the percentage contribution of each author to the paper, from conceptualisation to realisation and documentation.
   III. The publication adheres to Flinders Authorship of Research Output Procedures, and
   IV. each of the other authors provides permission for use of their work to be included in the thesis on the Submission of Thesis Form below.

c. Papers where the student is not the primary author may be included within a thesis if a clear justification for the paper's inclusion is provided, including the circumstances relating to production of the paper and the student's position in the list of authors. However, it is preferable to include such papers as appendices, rather than in the main body of the thesis.

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Student ID	9505553
College	College of Nursing and Health Sciences
Degree	PhD
Title of Thesis	Pushed to the fringe – vaccine hesitancy in parents and pregnant women

CO-AUTHORSHIP APPROVALS FOR HDR THESIS EXAMINATION

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Full Publication Details	Smith, SE, Sivertsen, N., Lines, L., De Bellis A., (2022) Decision-making in vaccine hesitant parents and pregnant women – An integrative review. International journal of nursing studies - advances
Section of thesis where publication is referred to	Chapter 4 – Literature Review

Student's contribution to the publication

80	%	Research design
80	%	Data collection and analysis
80	%	Writing and editing

Outline your (the student's) contribution to the publication:

The literature review was designed predominantly by the research student. Data collection was undertaken by the research student and analysis was supported by the academic supervisory team. Writing was undertaken by the research student with editing and support from the academic supervisory team.

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Name of Co-Author 2	Nina Sivertsen	Signed		Date	30/11/2022
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CO-AUTHORSHIP APPROVALS FOR HDR THESIS EXAMINATION

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Full Publication Details	Smith SE, Sivertsen, N., Lines, L., De Bellis, A., (2022) Weighing up the risks – vaccine decision-making in pregnancy and parenting. Women and Birth.
Section of thesis where publication is referred to	Chapter 5 – Exploratory survey

Student's contribution to the publication

80	%	Research design
80	%	Data collection and analysis
80	%	Writing and editing

Outline your (the student's) contribution to the publication:

The exploratory survey was designed predominantly by the research student on advice received from the academic supervisory team. The Facebook page was established and maintained by the research student and data collection was undertaken by the student. Analysis was supported by the academic supervisory team. Writing was undertaken by the research student with editing and support from the academic supervisory team.

APPROVALS

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Full Publication Details	Smith, SE, Sivertsen N., Lines, L., De Bellis A., (2022) A discussion paper on how to communicate with vaccine hesitant parents: Top ten tips for effective communication. Journal of Children and Young Peoples health 3 (1); 4-7.
Section of thesis where publication is referred to	Chapter 8 and 9 – Discussion and Conclusion

Student's contribution to the publication

80	%	Research design
80	%	Data collection and analysis
80	%	Writing and editing

Outline your (the student's) contribution to the publication:

This paper was written on request from a new journal. The design, writing and editing were supported by the academic supervisory team.

APPROVALS

By signing the section below, you confirm that the details above are an accurate record of the students contribution to the work.

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Full Publication Details	Cyberculture influences on vaccine decision-making in parents- A netnography. Smith, SE., Sivertsen S., Lines, L., De Bellis, A., (2022) A paper currently under peer-review with Vaccine Journal.
Section of thesis where publication is referred to	Chapter 7 - Netnography

Student's contribution to the publication

80	%	Research design
80	%	Data collection and analysis
80	%	Writing and editing

Outline your (the student's) contribution to the publication:

The Facebook page was established and maintained by the research student and data collection was undertaken by the student. Analysis was supported by the academic supervisory team. Writing was undertaken by the research student with editing and support from the academic supervisory team.

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Full Publication Details	Understanding the impact of vaccine hesitancy – Pushed to the fringe. Smith SE., Sivertsen, N., Lines L., De Bellis, A., (2022) A paper currently under peer-review with the Australian Journal of primary health.
Section of thesis where publication is referred to	Chapter 6 - Interviews

Student's contribution to the publication

80	%	Research design
80	%	Data collection and analysis
80	%	Writing and editing

Outline your (the student's) contribution to the publication:

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Full Publication Details	Smith, SE, Sivertsen, N., Lines, L., De Bellis A., (2022) Netnography – A novel methodology for investigating vaccine-hesitancy. A paper currently in the final stages of development for submission to the Journal of qualitative methods.
Section of thesis where publication is referred to	Chapter 4 - Methodology

Student's contribution to the publication

80	%	Research design
80	%	Data collection and analysis
80	%	Writing and editing

Outline your (the student's) contribution to the publication:

This paper was drafted by the research student with editing and support from the academic supervisory team.

APPROVALS

By signing the section below, you confirm that the details above are an accurate record of the students contribution to the work.

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Appendix 17 – Immunisation for healthcare professionals

This course is designed for undergraduate (3rd year) and postgraduate level, for both online and attendance. It incorporates eight learning modules and a final assessment).

Knowledge translation: Major and minor findings from this research.	**Numbers**	**Module title**	**Description**	**Rationale**
WEIGHING UP THE RISKS: This research has demonstrated that vaccine-hesitant parents are distrustful of the safety of vaccines, vaccine contents and vaccine development.	Module 1- Online	Introduction to immunisation	Introduces the learner to immunisation from a public and primary healthcare perspective. Discusses the risks and benefits of immunisation programs. The National Immunisation Program is introduced including childhood, pregnancy, and adult schedules. Specific contents of vaccines will be introduced including myths and realities about mercury and other concerns.	This research has demonstrated that some HCPS have reported having inadequate knowledge about the risks and benefits of immunisation including the rationale behind immunisation programs.
	Module 2- Online	Microbiology basics – the risks and benefits of vaccines	This module provides information on the basics of microbiology including the difference between viruses and bacteria etc. It also provides an understanding of the disease process, the chain of infection, vaccine development and testing, as well as how they work. It will discuss each disease included on the immunisation schedule, how each vaccine preventable disease is spread, the severity of the illnesses and potential sequelae.	Throughout this research, vaccine-hesitant parents have reported that HCP's lack knowledge. HCPS have stated that they feel unable to address parental concerns in this area. This module will include tips on how to communicate knowledge effectively.

Knowledge translation: Major and minor findings from this research.	Numbers	Module title	Description	Rationale
	Module 3 – Attendance required	Vaccine management	This module will discuss the requirements for vaccine transport and storage. It will address the national recommendations for practice that ensure the patency of vaccines. It will introduce immunisation technique, the importance of appropriate documentation and provide education on the Australian Immunisation Register.	This research has demonstrated the importance of accurate and timely data which is currently not available. The AIR is central to collecting immunisation data however, pregnancy immunisation data is not yet available for researchers.
PUSHED TO THE FRINGE: This research has identified the degree of isolation and bullying vaccine-hesitant parents are exposed to. This includes the No Jab No Pay legislation which has been shown to have the greatest impact on families from middle- to low-income areas.	Module 4 - Online	High-risk groups and legislation	This module will introduce the concept of vaccine hesitancy and discuss some of the factors that contribute to feelings of social isolation. It will discuss ways to minimise the impact of vaccine preventable disease on children and encourage uptake of vaccines, even if only in a modified schedule. This module will also introduce the learner to groups that are at a higher risk of suffering serious sequelae to some diseases. This will include Aboriginal people, pregnant women, preterm babies, immunocompromised individuals, those at risk occupationally and refugees.	Throughout this research vaccine-hesitant parents have reported feeling isolated and bullied including by the pro-immunisation majority. They also believe that governmental policies like No Jab No Pay etc. contribute to their marginalisation. This knowledge is vital in the promotion of immunisation generally.

Knowledge translation: Major and minor findings from this research.	Numbers	Module title	Description	Rationale
FALSE NARRATIVES AND THE CYBERCULTURE EFFECT: This research has demonstrated the role of social media in the acquisition of misinformation, as well as the exposure to bullying and aggression.	Module 5- Online	False narratives and cyberculture	This module will discuss the sources and types of misinformation which influence vaccine decision-making It will also discuss the myths and realities of immunisation and the appropriate way to respond to misinformation. It will introduce the concept of motivational counselling.	Throughout this research, vaccine-hesitant parents have been critical of HCP knowledge and have relied on alternative sources to answer difficult questions.
CRITICAL POINT: This research has identified the critical timing for information provision which is early in pregnancy and the first days of parenthood.	Module 6- Attendance required	Motivational counselling	This module will introduce the concept of motivational counselling. It will discuss optimal ways of communicating with vaccine-hesitant people as well as the optimal timing of information and education provision. It will also stress the importance of maintaining a therapeutic relationship.	This research has identified the need for knowledge of motivational counselling to assist communication with vaccine-hesitant parents.
MINOR FINDING: Responding to adverse reactions.	Module – 7 Online	Adverse events	This module will discuss the potential for adverse events, discuss the difference between anaphylaxis and vasovagal and administration of adrenaline and other emergency responses. It will also introduce adverse event management as well as how they are investigated. It will discuss the need for healthcare professionals to be aware of the potential for an adverse event and emphasise the need to acknowledge that these do occur.	This research has revealed that a previous adverse event is influential in subsequent vaccine decision-making. This is another critical time when a knowledgeable and balanced response is vital. The ability to professionally manage and acknowledge adverse events, no matter how minor, is vital to future vaccine decision-making.

Knowledge translation: Major and minor findings from this research.	Numbers	Module title	Description	Rationale
	Module 8-Online	Assessment	Assessment will be in the form of multiple-choice questions.	

Appendix 18 – Netnography: a novel methodology for qualitative research

The following is a version of the data included in Chapter 4. This methodology paper is currently in the final stages of drafting for possible submission to the *Journal of qualitative research methods*.

ABSTRACT

Aims

This aim of this paper is to discuss the benefits of netnography as a research methodology with an application for nursing research.

Background

Vaccine-hesitant parents and pregnant women have traditionally been difficult to recruit to research studies, they are marginalised, isolated, and bullied by the pro-vaccination majority. This paper discusses the benefits of netnography to a study which not only involved a population which is typically hard to recruit, vaccine parents and pregnant women, but also took place during a global pandemic when social distancing and work from home rules were in place. Netnography is a relatively new methodology which, in combination with minable online data is an ideal methodology for nursing research. This paper utilises data obtained from a previous study which used multiple methods and a combination of netnography and ethnography as methodology to explore vaccine hesitancy in parents. It will discuss the benefits of this methodology when taking a humanistic approach, in this case, the factors that influence decision-making in vaccine-hesitant parents. Additionally, this paper will discuss the benefits of using social networking sites for recruitment and proved to be cost effective and provided a timely and minable source of quality data.

Design

Discussion paper.

Data sources

English language literature was sourced from databases where predominantly nursing research can be located including: CINAHL, SCOPUS and Google Scholar including data from 2000-2022.

Discussion

Netnography is a relatively recent methodological innovation which involves the study of networked society through a variety of tools and paying particular attention to the cultural insights and conditions that are determined by the varieties of human experience. As a methodology with a humanist approach, there are clear benefits in its application for nursing research.

Conclusion

The use of netnography as methodology and a social networking site as a recruiting tool, had significant advantages in this research. Netnography, like ethnography, allows the researcher to get close to research participants and cultures with the added convenience of the research field accessible 24 hours a day. Additionally, the research method of data mining from online platforms provided large volumes of quality data. Social networking sites provide an opportunity for information seeking and sharing. Additionally, the researcher can elect to participate or to simply observe the online interactions. This strategy also ensured the engagement of a hard-to-reach population, in this case, vaccine-hesitant parents and pregnant women.

Appendix 19 – Australian childhood immunisation schedule

Australian Government
Department of Health and Ageing

National Immunisation Program Schedule

(VALID FROM 1 JULY 2007)

Age	Vaccine
Birth	• Hepatitis B (hepB) [a]
2 months	• Hepatitis B (hepB) [b] • Diphtheria, tetanus and acellular pertussis (DTPa) • *Haemophilus influenzae type b (Hib)* [c,d] • Inactivated poliomyelitis (IPV) • Pneumococcal conjugate (7vPCV) • Rotavirus
4 months	• Hepatitis B (hepB) [b] • Diphtheria, tetanus and acellular pertussis (DTPa) • *Haemophilus influenzae type b (Hib)* [c,d] • Inactivated poliomyelitis (IPV) • Pneumococcal conjugate (7vPCV) • Rotavirus
6 months	• Hepatitis B (hepB) [b] • Diphtheria, tetanus and acellular pertussis (DTPa) • *Haemophilus influenzae type b (Hib)* [c] • Inactivated poliomyelitis (IPV) • Pneumococcal conjugate (7vPCV) [e] • Rotavirus [j]
12 months	• Hepatitis B (hepB) [b] • *Haemophilus influenzae type b (Hib)* [d] • Measles, mumps and rubella (MMR) • Meningococcal C (MenCCV)
12-24 months	• Hepatitis A (Aboriginal and Torres Strait Islander children in high risk areas) [f]
18 months	• Varicella (VZV)
18-24 months	• Pneumococcal polysaccharide (23vPPV) (Aboriginal and Torres Strait Islander children in high risk areas) [g] • Hepatitis A (Aboriginal and Torres Strait Islander children in high risk areas)
4 years	• Diphtheria, tetanus and acellular pertussis (DTPa) • Measles, mumps and rubella (MMR) • Inactivated poliomyelitis (IPV)
10-13 years [h]	• Hepatitis B (hepB) • Varicella (VZV)
12-13 years [i]	• Human Papillomavirus (HPV)
15-17 years [i]	• Diphtheria, tetanus and acellular pertussis (dTpa)
15-49 years	• Influenza (Aboriginal and Torres Strait Islander people medically at-risk) • Pneumococcal polysaccharide (23vPPV) (Aboriginal and Torres Strait Islander people medically at-risk)
50 years and over	• Influenza (Aboriginal and Torres Strait Islander people) • Pneumococcal polysaccharide (23vPPV) (Aboriginal and Torres Strait Islander people)
65 years and over	• Influenza • Pneumococcal polysaccharide (23vPPV)

* Please refer to reverse for footnotes

IMMUNISATION

Immunisation schedules vary from State to State with some vaccines funded by State specific Health departments. Vaccine schedules change frequently to meet the needs of the population. For these reasons, links to the state schedules can be found at the following websites.

Queensland: https://www.health.qld.gov.au/__data/assets/pdf_file/0032/989114/qld-immunisation-schedule-children.pdf

New South Wales: **https://www.health.nsw.gov.au/immunisation/publications/nsw-immunisation-schedule.pdf**

Australian Capital Territory: **https://health.act.gov.au/sites/default/files/2020-04/Immunisation-Schedule.pdf**

Victoria: **file:///C:/Users/smit0515/AppData/Local/Downloads/immunisation-schedule-february-2023.pdf**

Tasmania: **https://www.health.tas.gov.au/sites/default/files/2021-11/Free_Vaccines_Supplied_DoHTasmania2020.pdf**

South Australia:
https://www.sahealth.sa.gov.au/wps/wcm/connect/867a5f004dda2d17a7dcff6d722e1562/20063.1+National+Immunisation+Schedule-FINAL.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-867a5f004dda2d17a7dcff6d722e1562-oeePxt

Western Australia:
https://ww2.health.wa.gov.au/~/media/Files/Corporate/general%20documents/Immunisation/PDF/WA-Immunisation-Schedule.pdf

Northern Territory:
https://digitallibrary.health.nt.gov.au/prodjspui/bitstream/10137/776/4/NT%20Imms%20Children_2021_08_with%20COVID-19_Final_Approved.pdf