Understanding Immunisation Controversies

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ABSTRACT

Background

Mass childhood vaccination has had a profound impact on reducing morbidity and mortality from a number of infectious diseases. Ironically, as vaccine preventable diseases become less common and so less visible to the public, greater attention is afforded to vaccine risks. In the UK, Japan, France and the USA, controversies about the safety of vaccines have led to declining public confidence in the practice which, at times, has lowered immunisation rates, leading to disease outbreaks and deaths. Public health workers are often perplexed at how to respond in such situations. In order to plan effective communication strategies it is necessary to understand how controversies about vaccine safety escalate. This thesis describes the nature of public controversies about vaccine safety by examining the discourses of the anti-vaccination lobby, the mass media, parents and health professionals.

The anti-vaccination movement

This thesis first explores the activities of the anti-vaccination movement and their efforts to disseminate their core messages to the wider public. In Australia, the anti-vaccination lobby are a largely unseen force in sustaining controversies about vaccine safety. This small but vocal movement are well organised and strategic. A description of their activities in Australia demonstrates the comprehensiveness of their efforts to oppose vaccination at the political, community and mass media level.

The news media

The news media have the potential to influence public perceptions about childhood vaccination. To complement previous research on the nature of anti-vaccination reportage, this thesis examines positive coverage from four and a half years of newsprint articles about immunisation published in Australian newspapers. Located at the core of
anti-vaccination discourse is an appeal to an individualistic ideology that upholds vigilance against the erosion of civil liberties, suspicion of authority figures and the back-to-nature idyll. By contrast, pro-vaccination rhetoric is centred on notions of threat from personified and malevolent infectious disease and vaccines as saviours and modern medical miracles.

Parents and vaccine safety

Focus groups with new mothers explore how they deconstruct competing messages about vaccine safety, using vignettes from broadcast media. Results suggest that anti-vaccination claims are most potent when they come from medical sources and/or include stories and images of allegedly vaccine-damaged children. Mothers apply complex assessments of risk and benefit in their decision-making and draw on analogies to explain their position. Trust in vaccine providers, personal experiences with vaccine preventable diseases, the advice of family and friends, and scepticism about the media as a source of information are important in decision making.

Implicit in attempts to counter negative publicity are assumptions that factual information about disease and vaccines will alone reassure parents. However, when their support for vaccination is challenged, mothers are more likely to mobilise images of children with vaccine preventable diseases than numerical assessments of risk and benefit. More generally, parental support of vaccination is sustained by recourse to normative beliefs and the desire to follow convention. Parents also have an underlying desire to actively protect their children from diseases that are dreaded.

Vaccination providers

Their encounter with vaccine providers is fundamental to parental decision making and negotiation of conflicting messages about vaccination. An interview study with doctors incorporating simulated scenarios explores how doctors address parental concerns about vaccination in the clinical encounter. In this study, doctors acknowledge a mother’s
concerns, tailor their discussion to the individual circumstance of the mother and convey the notion of choice. They attempt to compare vaccine and disease risks using mainly qualitative estimates of disease and adverse event incidence.

Possibly less helpful aspects of the encounters are when doctors became adversarial, discredit a mother’s source of information, ask hypothetical “how would you feel if…” questions, over-use scientific language, enter into games of scientific ping pong or give bland “you’re wrong” statements. Doctors face difficulty when communicating with patients whose paradigms are diametrically opposed to their own. Influencing these encounters is their underlying relationship with the patient, messages from the mass media and theories that help guide the doctor’s communication efforts.

The model

This thesis proposes a model for how vaccine controversies can lead to sustained declines in vaccination rates. This is achieved through highlighting the above perspectives and examining the current controversy over the combined measles, mumps, rubella vaccine and it’s unsupported link to autism. It suggests that vaccine safety concerns ‘catch fire’ when the source of a controversy is trusted, seen as expert and coming from a prestigious body or publication. Greater potency is gained when vaccines are implicated as the cause of a dreaded condition and when the link has some biological plausibility face value. Moving personal testimony about allegedly vaccine-damaged children can eclipse official attempts to provide factual reassurances which, by comparison, appear bland and uncompelling. Finally, a less acknowledged but possibly more important factor is the erosion of confidence among health professionals and confusion at the level of service delivery where upstream changes can have exponential effects.
Conclusion

This thesis concludes that parents and experts are often speaking different risk languages. While personal experiences, value systems and level of trust in health professionals might be fundamental to parental decision making, experts tend to rely on population-based and empirical estimates of risk. Health professionals need to recognise the competing discourses in which vaccine controversies operate. Those making responses in the mass-media, should re-frame debates away from powerful discourses appropriated by opponents of vaccination and develop their own discourse which is not reactive but centres on child health and the need for disease prevention. Lessons from the field of risk communication are also applied.
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PREFACE

Candidate’s contribution

The studies reported in chapters 4, 5 and 6 were designed as a follow-up to the candidate’s MPH treatise (“An attempt to swindle nature”: Press reportage of anti-immunisation, Australia 1993-97.) These studies were funded by a National Health and Medical Research Council project grant. Professors Simon Chapman, Penelope Hawe and Margaret Burgess were Chief Investigators. They contributed to the original study conception and design. During the data collection phases, this research team provided input into decisions about recruitment and overall structure of the interviews. Within this broad structure, the candidate made all methodological decisions, undertook the literature review, all recruitment, interviewing, analysis and writing. For the study reported in chapter 3, the candidate was responsible for designing the study, analysing the material and writing the results. For the study reported in chapter 4, three people assisted in the coding of data.
PUBLICATIONS

Publications arising from the studies reported in this thesis are as follows:


Leask J, Hawe P, Chapman S. Focus group composition: a comparison between natural and constructed groups. *Aust N Z J Public Health* 2001;25(2):152-4. (This paper expands on the methodological decisions reported in chapter 5)


*The following article has been submitted to a journal for peer review:*

# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACKNOWLEDGEMENTS</td>
<td>vi</td>
</tr>
<tr>
<td>PREFACE</td>
<td>vii</td>
</tr>
<tr>
<td>PUBLICATIONS</td>
<td>viii</td>
</tr>
<tr>
<td>TABLE OF CONTENTS</td>
<td>ix</td>
</tr>
<tr>
<td>LIST OF TABLES AND BOXES</td>
<td>xiii</td>
</tr>
<tr>
<td>LIST OF FIGURES</td>
<td>xiii</td>
</tr>
<tr>
<td>ABBREVIATIONS</td>
<td>xiv</td>
</tr>
</tbody>
</table>

## CHAPTER 1 INTRODUCTION: PART I

THE IMPORTANCE OF VACCINATION

1.1 VACCINE EFFECTIVENESS                                     | 1   |
1.2 VACCINE ADVERSE EVENTS                                    | 3   |
1.3 NARROWING RISK BENEFIT RATIOS                              | 4   |
1.4 AUSTRALIA’S CHILDHOOD IMMUNISATION RATES                   | 8   |
1.5 DETERMINANTS OF UPTAKE                                     | 8   |
1.6 INTERVENTIONS TO INCREASE IMMUNISATION UPTAKE              | 12  |
1.7 STRONG CONFIDENCE IN VACCINATION                          | 12  |
1.8 CHAPTER OUTLINES                                           | 13  |
1.9 CONCLUSION                                                 | 15  |

## CHAPTER 2 INTRODUCTION: PART II

PARENTAL ATTITUDES TO VACCINATION: A REVIEW OF THEORIES AND STUDIES

2.1 AIM                                                       | 17  |
2.2 THEORETICAL APPROACHES TO UNDERSTANDING ATTITUDES AND BEHAVIOUR | 17  |
2.3 REASONS FOR PARTIAL VACCINATION ..................................................18
2.4 VACCINE RISK PERCEPTION – HEURISTICS AND BIASES ............21
2.5 SOCIAL MODIFIERS OF RISK RESPONSE ........................................24
2.6 LIMITATIONS WITH THEORIES OF RATIONAL BEHAVIOUR ............25
2.7 THE COMPLEXITY OF VACCINATION DECISIONS .........................27
2.8 CONSCIENTIOUS OBJECTORS TO VACCINATION ..........................28
2.9 WIDER SOCIAL INFLUENCES ..........................................................31
2.10 OVERSEAS EXPERIENCE WITH VACCINE CONTROVERSIES .........33
2.11 CORE AIMS OF THIS THESIS ..........................................................35
2.12 RISK COMMUNICATION ...............................................................35
2.13 SUMMARY .....................................................................................36

CHAPTER 3 THE ANTI-VACCINATION LOBBY

3.1 AIM .................................................................................................37
3.2 INTRODUCTION ................................................................................37
3.3 PART I: THE AUSTRALIAN VACCINATION NETWORK ....................40
3.4 PART II: “ALL MANNER OF ILLS”: THE ATTRIBUTION OF SERIOUS
DISEASES TO VACCINATION ...............................................................53
3.5 SUMMARY .....................................................................................69

CHAPTER 4 THE MEDIA ON IMMUNISATION

4.1 AIM .................................................................................................71
4.2 INTRODUCTION ................................................................................71
4.3 METHODS ......................................................................................73
4.4 RESULTS ........................................................................................75
4.5 DISCUSSION ...................................................................................90
4.6 SUMMARY .....................................................................................95
7.6 SUMMARY .......................................................................................................................... 223

CHAPTER 8

CONCLUSION .......................................................................................................................... 225

REFERENCES .......................................................................................................................... 227

APPENDICES

After page

APPENDIX 1 .......................................................................................................................... 253

APPENDIX 2 SUMMARY OF AUSTRALIAN VACCINATION NETWORK NEWSLETTER “VACCINATION? THE CHOICE IS YOURS!”, 1997 TO 2001 .... 255

APPENDIX 3 EXPlicit CLAIMS MADE IN OPPOSITION TO VACCINATION AUSTRALIAN NEWSPAPERS 1993 TO 1997 .................................................. 269

APPENDIX 4 IMMUNISATION QUESTIONNAIRE .................................................................. 271

APPENDIX 5 PARTICIPANT INFORMATION SHEET ......................................................... 273

APPENDIX 6 PARTICIPANT CONSENT FORM ................................................................. 275

APPENDIX 7 .......................................................................................................................... 277

APPENDIX 8 SURVEY OF FOCUS GROUP PARTICIPANTS ........................................... 279

APPENDIX 9 FOCUS GROUP INTERVIEW GUIDE ......................................................... 281

APPENDIX 10 GENERAL PRACTITIONER SURVEY ...................................................... 283

APPENDIX 11 LETTER TO GENERAL PRACTITIONERS ........................................... 285

APPENDIX 12 INFORMATION SHEET FOR GENERAL PRACTITIONERS .............. 287

APPENDIX 13 CONSENT FORM FOR GENERAL PRACTITIONERS .......................... 289

APPENDIX 14 .......................................................................................................................... 291
LIST OF TABLES AND BOXES

Table 1.1 Notifications and deaths from vaccine preventable diseases on the Australian schedule .................................................................................................................................................. 2
Table 3.1 AVN lobbying ............................................................................................................................................................................................................................. 45
Table 3.2 Diseases or conditions attributed to vaccination in anti-vaccination writings .................................................................................................................................................. 59
Table 3.3 Fright factor applicability to immunisation .................................................................................................................................................................................. 68
Table 4.1: Who is blamed for low vaccination rates? ......................................................................................................................................................................................... 81
Table 4.2 Spokespersons quoted or referred to in articles by professional grouping ............................................................................................................................................................. 90
Box 5.1 Video 1 .......................................................................................................................................................................................................................................................... 102
Box 5.2 Video 2 .......................................................................................................................................................................................................................................................... 103
Box 5.3 Video 3 .......................................................................................................................................................................................................................................................... 104
Table 5.1 Demographic characteristics of focus group participants ........................................................................................................................................................................... 106
Box 6.1 Role play scenarios .................................................................................................................................................................................................................. 146
Table 7.1 Framing both sides of the vaccination debate .................................................................................................................................................................................. 192

LIST OF FIGURES

Figure 1.1 Vaccine risk benefit reversal .......................................................................................................................................................................................... 5
Figure 7.1 Escalation of a vaccine controversy .................................................................................................................................................................................. 208
ABBREVIATIONS

Hib  Haemophilus influenzae type b
NSW  New South Wales, Australia
UK   United Kingdom
USA  United States of America
IOM  United States Institute of Medicine
DT   diphtheria-tetanus vaccine
DTP  diphtheria-tetanus-whole cell pertussis vaccine
SIDS sudden infant death syndrome
OPV  oral polio vaccine
MMR  measles-mumps-rubella vaccine
SSPE subacute sclerosing panencephalitis
VAPP vaccine-associated paralytic poliomyelitis
GP   general practitioner
ACIR Australian Childhood Immunisation Register
GPII General Practice Incentive Initiative
AVN  Australian Vaccination Network
HBM  Health Belief Model
ABS  Australian Bureau of Statistics
SWEP South Wales Evening Post
CJD  Creutzfeldt-Jakob Disease
VIS  Vaccination Information Statement
MenC meningococcal disease serogroup C vaccine
AAP  American Academy of Pediatrics
Chapter 1 Introduction: Part I
The importance of vaccination

Along with better public hygiene, nutrition, water supplies, sewage disposal, and provision of medical treatment, childhood immunisation has made a significant contribution to reducing morbidity and mortality from a growing number of infectious diseases. Smallpox devastated populations for more than three thousand years. The declaration of its global eradication in 1980 rendered this disease no longer a threat, apart from the possibility of germ warfare arising from malevolent appropriation of stored viral stocks.\textsuperscript{1,2} After an intensive mass polio vaccination campaign that began in many nations including Australia in the 1950s, this country reported its last wild polio case in 1978.\textsuperscript{3} The Western Pacific Region was declared free of indigenous polio transmission in 2000,\textsuperscript{4} and worldwide eradication is aimed for 2005. Before measles vaccine licensure in the USA in 1963, the country reported over half a million cases annually which had declined to just 54 by 1998.\textsuperscript{5} Worldwide measles eradication is anticipated although a target date has not been set.\textsuperscript{6}

1.1 Vaccine effectiveness

Population data and epidemiological studies demonstrate the effectiveness of vaccination in reducing disease incidence. Since its introduction childhood vaccination has significantly reduced morbidity and mortality from diphtheria, mumps, tetanus, rubella, pertussis, hepatitis B, \textit{Haemophilus influenzae} type b (Hib) (see Table 1.1). Like polio, Australian parents and health professionals no longer see the acute effects of diphtheria with no notifications recorded since 1992.\textsuperscript{7} Mass childhood vaccination also promises to reduce the incidence of varicella,\textsuperscript{8} invasive pneumococcal disease\textsuperscript{9} and meningococcal group C disease.\textsuperscript{10} Invasive pneumococcal disease places a disproportionate burden on Australia’s indigenous people.
Table 1.1 Notifications and deaths from vaccine preventable diseases on the Australian schedule* (Source, Communicable Disease Network. *Vaccine preventable diseases and vaccination coverage in Australia, 1993-1998. Canberra: Department of Health and Aged Care, 2000.)

<table>
<thead>
<tr>
<th>Disease</th>
<th>Hib#</th>
<th>Measles</th>
<th>Mumps</th>
<th>Pertussis</th>
<th>Rubella</th>
<th>Tetanus</th>
<th>Acute hepatitis B</th>
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<tr>
<td>Notifications (1993-1998)</td>
<td>634</td>
<td>12404</td>
<td>760</td>
<td>34848</td>
<td>15790</td>
<td>47</td>
<td>1645</td>
</tr>
<tr>
<td>Deaths (1993-1997)</td>
<td>15</td>
<td>7</td>
<td>2</td>
<td>9</td>
<td>0</td>
<td>7</td>
<td>239</td>
</tr>
</tbody>
</table>

* There were no notifications or deaths from polio and diphtheria.

# Notifications for children aged 0 to 14 years only

Surveillance data show sharp declines in disease incidence after the introduction of mass vaccination.\(^1\)\(^1\) For example, since Hib vaccination commenced in the early 1990s, notifications of invasive Hib disease in Australian children have reduced by 95 per cent in the absence of any other putative factors.\(^9\)

Randomised controlled trials also confirm vaccine effectiveness. In a large Swedish trial, infants were randomised to receive either the diphtheria-tetanus vaccine (n=1726), or the diphtheria-tetanus-pertussis vaccine (n=1724). The researchers found that of the 312 cases of pertussis, 240 (77%) occurred in the diphtheria-tetanus group and those vaccinated again pertussis who contracted the disease had clinically milder cases.\(^12\)

Conversely, low vaccination rates have left communities vulnerable to outbreaks. In the 1970s and early 1980s, the United Kingdom (UK) experienced a drop in pertussis vaccination rates from 80 per cent to 30 per cent, with 300,000 subsequent notifications and 70 deaths.\(^13\)\(^14\) These falls, and subsequent rises, in vaccination rates demonstrate a clear inverse relationship with disease incidence.\(^15\) Analytical epidemiological studies support such a relationship. In one recent United States (US) study of those who receive philosophical exemptions from immunisation, non-vaccinated children were 22.2 times
more likely to acquire measles and 5.9 times more likely to acquire pertussis that their vaccinated counterparts.\textsuperscript{16}

1.2 Vaccine adverse events

Sustaining these successes requires maintenance of high vaccination rates. However, like any other medical intervention, vaccines are not risk free. Minor side effects such as injection site inflammation, fever, discomfort, rash, drowsiness and specific vaccine related effects can occur. More serious adverse events are rare. \textit{The Australian Immunisation Handbook} lists 31 serious adverse events following immunisation which providers should report. However, it stresses that their occurrence after vaccination does not imply causality,\textsuperscript{17} a claim requiring more rigorous epidemiological studies.

Due to their rareness, limitations with reporting systems, and inherent methodological problems, establishing causality between a vaccine and an adverse event following vaccination is challenging but important.\textsuperscript{18} In 1993, the US Institute of Medicine (IOM) conducted an extensive review of vaccine adverse events and evidence bearing on causality.\textsuperscript{19}

The committee rejected a causal relationship between diphtheria-tetanus (DT) and diphtheria-tetanus-whole cell pertussis (DTP) vaccination and sudden infant death syndrome (SIDS) and between DT and encephalopathy. They found evidence favouring or establishing a causal relationship for Hepatitis B vaccine and anaphylaxis (established); DTP and encephalopathy (favoured); DT and Guillain-Barré Syndrome and brachial neuritis (favoured) and anaphylaxis (established); oral polio vaccine (OPV) and Guillain-Barré Syndrome (favoured) and poliomyelitis (established); measles vaccine and anaphylaxis (favoured); measles-mumps-rubella (MMR) vaccine and thrombocytopenia and anaphylaxis (established); and rubella vaccine and chronic arthritis (favoured) and acute arthritis (established).\textsuperscript{19} Finally, the Committee found inadequate evidence to accept or reject a causal relationship between specific vaccines and a number of serious adverse events and called for further studies.\textsuperscript{19}
Serious adverse reactions to vaccination are rare. Anaphylaxis is thought to occur once in 600,000 Hepatitis B vaccine recipients and mild encephalitis can occur once in every 3 million recipients of the Jeryll-Lynn strain of the mumps vaccine.\textsuperscript{20} Guillain-Barré Syndrome can occur once in every million influenza vaccine recipients.\textsuperscript{21}

A marked difference emerges when comparing relative risks between vaccine and disease effects. For example, measles causes encephalitis in 1 in every 1000 reported cases.\textsuperscript{22} Death occurs in 1 to 2 of every 1000 reported cases. Subacute sclerosing panencephalitis is always fatal for the one in 25,000 measles cases who develop it.\textsuperscript{17} Comparably serious adverse events from the measles vaccine are rare. One in every 30,500 vaccinated cases will develop thrombocytopenia while encephalitis is thought to occur once in every million vaccine doses although a causal relationship is uncertain.\textsuperscript{23}

Chen et al. recently reviewed the current evidence for associations between vaccines and auto-immune disease.\textsuperscript{24} The best available evidence has not supported associations between Hepatitis B vaccination and multiple sclerosis,\textsuperscript{25,26} or vaccines and type 1 diabetes.\textsuperscript{27} Ongoing research, improvements in reporting, active surveillance systems and database linkage will hopefully shed light on other hypothesised associations.\textsuperscript{24,28}

1.3 **Narrowing risk benefit ratios**

Parent information leaflets distributed today commonly frame the benefits and risks of vaccination in relative terms, that is, they compare adverse event incidence against incidence of sequela when a vaccine preventable disease is contracted. It is uncommon to see such comparisons account for the incidence of the disease itself. In an era of low disease incidence and high vaccination rates, the absolute risk reduction for an individual is less impressive. For some diseases, risk-benefit margins could continue to narrow until they eventually reverse, making the risk posed by the vaccine higher than for the disease. In Australia, a risk-benefit reversal has occurred under the current oral polio vaccination programme. Polio vaccination has been so successful that indigenous
poliomyelitis no longer occurs in Australia. However, the oral vaccine carries a risk of vaccine-associated paralytic poliomyelitis (VAPP) once in every 2.5 to 2.6 million doses.\(^3\) When the risk posed by a vaccine is greater than that of the disease, fully informed and rational parents might question the wisdom of subjecting their children to oral polio vaccination. If all individuals acted on this concern and ceased vaccination, the population would be vulnerable to re-importation of the disease, outbreaks would ensue and the public would again seek vaccination. Chen and Hibbs\(^{18}\) (1998) diagrammatically represented this scenario, demonstrating the cyclic nature of vaccination and disease rates as eradication is achieved (see figure 1.1).

**Figure 1.1** Vaccine risk benefit reversal (Source: Chen RT, Hibbs B. Vaccine safety: current and future challenges. *Pediatric Annals* 1998;27(7):445-55.\(^{18}\)
1.3.1 The “prevention paradox”

In theoretical terms, maintaining mass childhood vaccination in an era of low disease incidence creates a prevention paradox; “a measure that brings large benefits to the community offers little to each participating individual”.\(^{29}\) When individuals respond to this paradox by refusing to adopt the measure, Hardin’s “tragedy of the commons” may result.\(^{30}\) That is, the effect of an individual’s action could hold little consequence for them but the aggregation of individual behaviours could become a burden to the wider society. In a seminal paper, Hardin (1968) used the metaphor of the commons to describe this dilemma. The commons is a pasture open to all where herdsmen keep their cattle. One herdsman might add another animal to the commons in order to benefit from its later sale. This practice continues until the cattle overgraze the commons. The herdsman gains the entire benefit from the sale of extra cattle but everyone shares the burden of overuse. If other herdsmen, rational and seeking to maximise their utility, purchase extra cattle too, then the commons eventually becomes unusable and a tragedy of the commons results.

Over-fishing, industrial pollution of rivers, use of fossil fuels and unsustainable population growth also create a scenario where the aggregate costs of individual actions threaten populations, the environment and future generations. Similarly, the decision not to vaccinate a child may bear little consequence for those who “free ride”\(^{31}\) on the immunity of others but when enough individuals choose this action, they threaten population or “herd” immunity and epidemics occur.\(^{32}\) \(^{33}\)

1.3.2 Population protection

Therefore, vaccine programmes need to continue in order to prevent epidemics and potentially eradicate a disease so that future populations bear neither disease nor vaccine risk. Mass oral polio vaccination in Australia now implicitly asks parents to put their children at very small risk of serious harm for the benefit of society and future generations who might live in a world free of polio. In response to the polio situation, the Australian government is considering the adoption of the inactivated polio vaccine
which does not pose a risk of VAPP. The estimated cost of such a policy is $115 million per case of VAPP prevented by the use of inactivated polio vaccine. This would reduce to $10 million when using multivalent vaccines incorporating inactivated polio vaccine. The government’s willingness to consider paying this cost is perhaps a reflection of the degree to which the individual-population trade-off is seen as unacceptable.

Population immunity from mass childhood vaccination also benefits individuals at high risk. For example, pertussis vaccination provides the greatest benefit to infants too young to be immunised but who are most severely affected by the illness. In Australia from 1993 to 1997, all nine deaths from pertussis occurred in children aged under 12 months. For their protection, infants require very low levels of pertussis circulation within the community. This is achieved by high vaccination rates.

Rubella vaccination affords a similar style of protection. For most, rubella is a mild and inconsequential disease but if contracted in-utero, it can cause congenital rubella syndrome with associated multiple defects including deafness, blindness, brain and heart damage.

The development of new vaccines for diseases with lower rates of morbidity and mortality highlight the tension created when benefit from vaccination is less visible. For example, most parents see varicella (chickenpox) as a trivial almost normal disease of childhood. Its seriousness in older persons, the foetus and the immuno-compromised is not readily recognised. If mass vaccination is deemed beneficial because it can reduce economic burden and lead to disease eradication, efforts to communicate its importance in an environment of heightened public awareness about vaccine risk will prove challenging.

With high vaccination rates necessary to maintain population protection, the tensions between individual and community based risk assessments will increase. Such tensions often arise in public health. Implicit in policies that regulate drink driving, nutrient
fortification of food, or decisions to forgo universal screening for prostate cancer, are values which place benefit to the population ahead of risks or inconvenience to some individuals.

This thesis upholds the value of placing population benefit ahead of risk to some individuals. It considers population benefit in terms of minimising premature deaths, morbidity, and costs to society. To date, the benefits of mass childhood vaccination have been framed primarily in terms of individual protection. However, public health workers will be required to address the challenges of communicating the importance of societal benefit. It is hoped that by exploring the ways that consumers and providers negotiate individual-community tensions in this thesis, an enhanced understanding might guide these efforts.

1.4 Australia’s childhood immunisation rates

Given that high vaccination rates are necessary for disease control, studies have attempted to quantify coverage among Australian children. In 1995, a large national sample survey used parental self report and verification of written records to determine immunisation status. The survey found that only 52 per cent of children under 5 years were fully vaccinated for their age. When partially vaccinated children were included, this figure rose to 98.1 per cent. A more recent study of vaccination coverage based on the Australian Childhood Immunisation Register (ACIR) data estimated that at September 2001, 94 per cent of children aged 12 months and 90 per cent of children aged 24 months were fully vaccinated. For these age groups, these rates meet the National Health and Medical Research Council’s target of 90 per cent vaccination coverage.

1.5 Determinants of uptake

A complex, interdependent web of factors influence vaccination uptake in populations. These can be defined broadly as structural and individual influences. Structural
influences relate to government vaccine policies and provision of services. Individual influences include the dispositions, knowledge, attitudes and behaviour of providers and parents about vaccines. These two main influences are not mutually exclusive. For example, systematic deficits in the knowledge of individual parents or providers (an individual issue) probably reflect the need for improved education and in-service training (a structural issue).

1.5.1 Government

Political commitment, which provides the funding and infrastructure to support vaccination programmes, is central to their success. Situations where political commitment was compromised demonstrate the sensitivity of vaccination programmes to changing political support. In Japan during the mid 1970s, political commitment for pertussis vaccination was so eroded by safety concerns that the Ministry of Health temporarily suspended the vaccine for infants. Soon after, the minimum vaccination age increased from 3 months to 2 years. Pertussis vaccination rates fell from 80 per cent to 10 per cent by 1976 and an epidemic resulted in 1979 with 41 deaths.\(^{15}\)

The importance of other structural factors becomes most apparent in systematic reviews of interventions to improve vaccine coverage. Strefer and colleagues (1999) reviewed 95 intervention studies conducted in industrialised countries.\(^{39}\) They emphasised the impact of legislating for vaccination at school entry. They also outlined strategies to improve service delivery such as reducing parental out-of-pocket costs and expanded access through a variety of health care settings. Other important aspects of service delivery include primary health care provider reminder systems and the maintenance of the storage cold chain to ensure vaccine efficacy.\(^{40}\)

The importance of a positive interaction between political will and service delivery was seen in Australia during the early 1990s. At this time, a lack of clarity between state and federal responsibility for childhood immunisation caused fragmented service delivery
and declining vaccination rates. Some providers asserted that such multiple levels of administration contributed to provider confusion.\textsuperscript{41}

Surveys of parents and providers reflect system constraints in a secondary fashion. For example, the 1995 Australian Children’s Immunisation survey showed that 30 per cent of those parents whose children were not vaccinated against measles falsely believed they were too young to receive the vaccine.\textsuperscript{35} This misconception arises from a lack of consistent information and the failure of providers to suggest vaccination during other health service encounters (opportunistic vaccination).

1.5.2 Providers

Providers are essential to the success of immunisation programmes since they form the focal point of the immunisation encounter. Providers can be supported through reminder/recall systems, education and incentive schemes. Opportunistic vaccination during other health service encounters also improves vaccine uptake.\textsuperscript{42,43} Provider incentive schemes have been associated with increased vaccination uptake in the UK\textsuperscript{44} and the USA.\textsuperscript{45,46} However, they have produced no effect in some contexts.\textsuperscript{47} The General Practice Incentive Initiative (GPII) established in Australia in 1998 offers financial incentives to general practitioners for immunising children. This initiative will require ongoing evaluation to determine its effectiveness.

Provider knowledge and beliefs can influence their behaviour. Studies have identified common provider misconceptions about contraindications to vaccination as a barrier to timely vaccination.\textsuperscript{48-50} One recent Australian study of general practitioners found that 43 per cent incorrectly withheld vaccines due to an upper respiratory tract infection and 50 per cent due to concurrent antibiotic use.\textsuperscript{51} US research of physicians found that 32 per cent overestimated the risk of serious adverse effects from the pertussis vaccine.\textsuperscript{52} Members of this group were also more likely to fear litigation which in turn affected whether they vaccinated a child during a fever. These and other studies highlighted the need for education and continued in-service training for providers.\textsuperscript{53}
1.5.3 Parents

A substantial volume of literature focuses on parental factors affecting immunisation rates. Surveys have identified low income, education, migrant status, single parent families, household transience, family size, age and birth order of the child as important socio-economic predictors of low rates. Research has also elucidated the practical, knowledge and attitudinal barriers that exist for parents. Practical barriers relate to infrastructure problems such as inconvenient clinic hours or the ‘busy lives’ factor of parents simply not finding time. Parents are less likely to have second and subsequent children fully vaccinated. This trend has been linked to increased confidence in child rearing and the difficulty in finding time with the demands of more children.

Many children are not fully vaccinated because parents are not sure when a vaccine is due or because of misconceptions about when a vaccine should be withheld. Indeed false contraindications held by both parents and providers are thought to account for a significant percentage of children not being fully immunised. The ABS survey identified that of those children not immunised against rubella, one third of the parents mistakenly believed the vaccine was only for girls and 8.3 per cent claimed to have been advised against it.

Many studies emphasise the importance of provider- and service-related interventions to address the above barriers. In particular, they recommend that services should target specific groups such as those listed above. They also recommend service expansion and flexibility to meet the needs of working parents. Parent incentives and reminder systems can be effective in promoting timely vaccination. In one study, parents most commonly recommended reminder systems to improve rates.
1.6  **Interventions to increase immunisation uptake**

In recent years, measures implemented in Australia to improve vaccine coverage have been directed at the levels of service delivery and provider support, addressing socio-demographic barriers and knowledge deficits. One measure is the provision of financial incentives for general practitioners. Parental incentives include the linking of vaccination status to maternity allowance and the provision of child care benefits, and a mailed reminder scheme operating from the Australian Childhood Immunisation Register (ACIR) established in 1996. In terms of their relative significance, some researchers believe that interventions at the level of services and providers are more important than addressing parental knowledge and attitudes. Recent increases in Australian immunisation rates correspond with improved political commitment, coordination and multi-factorial interventions thus reflecting their significance.

1.7  **Strong confidence in vaccination**

In terms of parental attitudes, large-scale surveys of parents repeatedly demonstrate wide support for vaccination. In their survey of 759 UK parents, Sutton and Gill found that 92 per cent of non-completers thought it was important to have their children immunised. A recent national US study found that 87 per cent of parents agreed immunisation was extremely important. Results from the 1995 ABS study suggested that at least 94 per cent of parents support vaccination.

Australia currently enjoys high vaccination rates and declining disease incidence. Ironically, this climate of low disease incidence and a largely unchallenged confidence in vaccination provides the greatest potential for vaccine controversies to take hold. New generations of parents and providers have decreasing awareness of vaccine preventable diseases while society has more awareness and possibly less tolerance of vaccine risk. Wider social changes are also occurring including a greater public willingness to question medical authority and intervention, increased consumerism, a broadening interest in alternative health practices, and the apparent rise of the anti-vaccination movement.
When these elements combine, catastrophic reductions in vaccination rates can occur as experienced in countries like the UK during the 1970s pertussis vaccine controversy.

This thesis sets out to understand the responses of different participants in controversies about vaccine safety. It examines the perspectives of four players: the anti-vaccination lobby; the mass media; parents; and health professionals.

### 1.8 Chapter outlines

Chapter 2 reviews the literature on parental attitudes and perceptions about vaccination. This provides a background for understanding how parents respond to conflicting messages about vaccine safety. The chapter briefly outlines the theories most commonly used to study vaccination behaviour and introduces potentially useful theories from the field of risk perception and media studies. It also reviews studies that explore the reasons for full, partial and non-vaccination to highlight the complex nature of decisions. It then discusses the interplay between wider social changes and specific attitudes and beliefs about vaccination.

The anti-vaccination movement actively participates in public controversies about vaccination. Parents, some health professionals, and others who believe vaccination is dangerous and ineffective comprise this movement. It is found in most developed countries including Australia. Concern has been expressed at the potential for opponents of vaccination to have a disproportionate influence on parents’ decision making but little research has explored this movement in detail. Part 1 of chapter 3 outlines the lobbying efforts of the anti-vaccination movement using the Australian Vaccination Network (AVN) as an exemplar. The section thematically analyses three years of AVN newsletters to show the comprehensiveness of their efforts at media, community and political lobbying. Of interest is not only how they advance their messages but the subtexts of their claims. Accordingly, part 2 of the chapter elaborates on earlier research by the candidate and examines the wider social discourses embedded in the claim that
vaccination is the cause of many unacknowledged and serious idiopathic ills.\textsuperscript{76} (A copy of this paper can be found in Appendix 1.)

While attempts by anti-vaccination groups to circulate their claims in local communities are significant, their reach does not compare with that attained by mainstream broadcast and print media.\textsuperscript{76} More generally, the media are a significant source of immunisation information for parents. In order to describe the dominant media messages that audiences receive about vaccination, Chapter 4 complements earlier research on anti-vaccination press coverage\textsuperscript{76} by reviewing positive coverage in over four and a half years of Australian newsprint media.

Using illustrative vignettes identified in the media analysis, chapter 5 describes a focus group study of parental responses to media messages about immunisation. Despite much speculation, no published studies report testing parent audiences and analysing how they negotiate competing discourses in terms of their broader experience with vaccination. The study asks what makes positive and negative messages about vaccination compelling.

Their encounter with vaccine providers is fundamental to parents’ decision making and negotiation of conflicting messages about vaccination. Chapter 6 reports on a study of parent-provider discussions on vaccine risk and benefit. Using role plays of four different ‘concerned parent’ scenarios the study describes and evaluates the typical reassurances provided by general practitioners when faced with parent concerns about vaccination.

Finally, Chapter 7 draws together the findings from the anti-vaccination lobby, media, parents and provider components to summarise the different perspectives expressed in vaccine controversies. It proposes a model of the mechanism by which vaccine controversies lead to a sustained decline in vaccination rates. Recommendations centre on how campaign planners, providers and policy makers can improve communication efforts and prevent vaccine controversies “catching fire”.
1.9 Conclusion

This chapter identified empirical research supporting the efficacy and overall safety of vaccines. It emphasised that in an era of low disease incidence, the issue of vaccine risk may take increasing prominence. It showed that as vaccine risk/benefit margins narrow, tension between individuals and populations will increase. However, it established that for disease control or eradication to occur, it is necessary to maintain high vaccination rates. It also identified factors that affect vaccination rates including government policy, service delivery, providers, and parents. The next chapter focuses on how parental attitudes and perceptions affect uptake of vaccination.
Chapter 2 Introduction part II
Parental attitudes to vaccination: a review of theories and studies

2.1 Aim

The previous chapter established the necessity of immunisation programmes. It also briefly described the influence of logistical and provider-related barriers to timely vaccination. Another important influence is parental attitudes and concerns about vaccination. Unlike many other medical interventions that treat an existing condition, vaccination requires that a healthy child undergo an unpleasant procedure for an unseen benefit. This benefit is increasingly intangible as the public receive less exposure to vaccine preventable diseases. For some parents, their attitudes are an important predictor of whether their child is fully immunised. In Australia in 2001, of the 6 per cent of 12 month old children not up to date with immunisation, 71.8 per cent of parents gave their disagreement with, or concern about immunisation as their main reason.37

Understanding the influence of parental knowledge and attitudes about vaccination is also crucial to predicting how parents might be affected by conflicting messages about the safety and efficacy of vaccines.

This chapter reviews the literature on parental attitudes and perceptions about vaccination and briefly outlines the main theories underpinning this research.

2.2 Theoretical approaches to understanding attitudes and behaviour

To understand parental attitudes to immunisation, researchers have adopted a range of theories from the fields of health promotion, mass communications, marketing and cognitive psychology. Most commonly, barriers to full vaccination are understood through comparing demographic, knowledge, and attitudinal variables of parents of fully vaccinated with those of partially and/or non-vaccinated children. The Health Belief Model and the Theory of Planned Behaviour are commonly used to structure the variables used in such studies.48 58 65 77-79 The Health Belief Model suggests that before a
parent can adopt the protective behaviour of vaccination, they must first perceive their child to be susceptible to a disease which in turn is considered serious. They must also see that vaccination is an effective action where perceived benefits outweigh any costs or barriers. The Theory of Planned Behaviour is similar to the Health Belief Model but it suggests that intentions to act are strong predictors of actual behaviour. The theory also recognises the influence of those social norms and expectations relevant to immunisation behaviours. Studies using the theory have investigated intentions to vaccinate a future “hypothetical” child.

Some researchers and campaign planners employ a social marketing approach to understand behaviour and promote immunisation. They use the principles of marketing with an emphasis on the consumer (parental perceptions), product (how the product is described), price, promotion and placement (i.e., accessibility). Others use theories from cognitive psychology, particularly risk perception, judgement and decision making to understand and predict vaccination behaviours.

Another approach used is mass communication theories of message framing and audience reception. These theories provide the potential to understand parental responses to media messages in dedicated campaigns and news coverage. The communication process is understood in terms of audience, message, source, and channel. These theoretical perspectives have long histories in elucidating ways that people are influenced by discourses on a wide variety of issues in the health, political science and consumer marketing areas. They have been used by those seeking to influence matters as diverse as voting intention, purchasing, and a wide variety of preventive health issues. Chapters 4 and 5 explore their applicability to vaccination decision making in further detail.

### 2.3 Reasons for partial vaccination

Studies seeking to understand why parents fail to fully vaccinate their children typically measure pre-identified knowledge and attitudinal variables. Some assess the relative
importance of variables and others analyse relationships between variables using statistical techniques. A final group of studies use qualitative approaches and elicit parental beliefs and experiences using open-ended and semi-structured inductive research traditions. All have made important contributions. Bazeley and Kemp reviewed a range of these studies. They concluded, from an Australian parent’s perspective, that children are not fully vaccinated for four reasons: 42

- claims that doctors or health workers advised against it;
- the baby was sick;
- parental apathy e.g. didn’t get around to it; and /or
- mistrust of vaccines

The first two issues relate to contraindications from providers and to a genuine misunderstanding by parents. These issues and the issue of parental apathy have been addressed through comprehensive campaigns that combine improvements in service delivery with provider and public education. However, parental apathy links with broad complacency about rarely seen diseases.

A framework for understanding this problem is the theory of availability. 90 This theory suggests that exposure to an event creates perceptions that it will happen again. In particular, accessible, easily imagined or widely reported risks are likely to be overemphasised while risks, for example, from polio and pertussis are becoming less available to parents. A study of Sydney parents in 1992 found that only a minority knew anyone with diphtheria (4%), tetanus (10%), polio (29%) or pertussis (38%). As vaccination attains its aim of better disease control, these figures will continue to fall. 58

Compounding the problem of a decrease in disease risk awareness is the likelihood of attention being drawn to vaccine risk. For example, Gellin et al. found an inverse relationship between the perceived likelihood of infection and concerns about vaccine side effects. 74 Other studies have also found that perceptions of disease severity influence parents’ beliefs about the importance of vaccines and their safety. For
example, the widespread belief that measles is trivial and innocuous affects the uptake of the vaccine.\textsuperscript{48, 77, 91, 92} Taylor et al., found that parents who saw varicella as a minor disease were more likely to magnify perceptions of vaccine side effects.\textsuperscript{79}

One pervasive concern relates to the immune system of the child. Bond found that mothers, regardless of their child’s vaccination status, were concerned that vaccines weakened immunity.\textsuperscript{61} Another study found that multiple vaccines given at the one visit exacerbated this concern.\textsuperscript{93} A recent US national survey found one quarter of parents felt that their child’s immunity could be weakened by too many vaccinations.\textsuperscript{74} Providers share this concern. In one study, 21 per cent said they would not administer four vaccines simultaneously despite safety assurances.\textsuperscript{50} Such concerns represent a challenge when schedules are increasingly crowded with new vaccines and combinations.

Concerns about the interaction between a child’s immunity, health status and a vaccine might be a factor in the widespread adoption of false contraindications by parents and providers. The belief that pertussis vaccination was contraindicated in children with a family history of allergy, asthma or epilepsy was the single most important reason for parents not having their child immunised against whooping cough in the UK.\textsuperscript{48} That the child was “unwell at the time” was also a prevalent reason given by parents for delaying vaccination in both Australian and UK studies.\textsuperscript{35, 54, 77} These beliefs persist even though a minority of such factors are true contraindications.\textsuperscript{94}

The persistence of these beliefs in the face of efforts to correct them may indicate deeply embedded beliefs about the immune system as sacrosanct, complex, mysterious and highly responsive to environmental triggers. It would be plausible, therefore, for people to believe that in altering the immune system, vaccination might interfere with the child’s immunity in some complex and unseen fashion. The apparent mystery of this process and its potential outcome introduces a worrying degree of ambiguity for parents. Recent years have seen an increasing range of diseases being linked to a faulty immune system.\textsuperscript{95} Not surprisingly, opponents of vaccination readily mobilise the “vaccination as
cause of all manner of ills” discourse. Chapters 3, 5 and 6 explore the way that opponents of vaccination, parents and providers talk about the effects of vaccines on the immune system.

Other concerns about side effects also affect vaccine uptake. In the ABS Children’s Immunisation survey, 6.6 per cent of parents whose children were not immunised against pertussis gave their main reason as concern about side effects. Sutton and Gill found that unspecified fears of the pertussis vaccine were the second most important reason for children not being immunised.35

Some studies reflect concerns about a specific vaccine peculiar to the country in which the survey occurs. For example, UK studies conducted during the late 1980s and early 1990s reflected lingering concerns about the pertussis vaccine. These had begun a decade before when the vaccine was publicly linked to neurological damage.48

People also voice concern about new vaccines for diseases where there has previously been no scheduled vaccine. Concerns revolve around the untried and unfamiliar nature of the vaccine. This was the case with the Hib and MMR vaccines when they were first introduced in the UK. In Manitoba, uptake of the new hepatitis B vaccine was lowered by media and community publicity about an alleged but unproven link between the vaccine and multiple sclerosis. Although similar publicity occurred in British Columbia, the influence in Manitoba was believed to be stronger because in that province, the vaccine was new and hence less familiar.97

2.4 Vaccine risk perception – heuristics and biases

Psychometric techniques using scales to produce quantitative measures of perceived risk provide insights into the so-called biases operating when people assess vaccine risk. Researchers sometimes draw from the broader study of heuristics, that is, the rules of thumb or mental shortcuts that people make in order to deal with complex information. While heuristics facilitate efficient information processing and rapid decision making,
they can lead to predictable biases. Some studies have tested the influence of heuristics on vaccination decisions. They include studying the effects of omission bias, regret, ambiguity, bandwagoning, altruism and free-riding on intention to vaccinate.

### 2.4.1 Omission bias and anticipatory regret

People are more likely to avoid risks flowing from an action or act of commission than from an omission, even when the latter appears more risky. Ritov and Baron demonstrated this omission bias in a study where student subjects were reluctant to vaccinate a hypothetical child even when the risk of death was greater for the disease than the vaccine. They concluded that action carried a greater sense of responsibility than an inaction or passive acceptance of risk.

The anticipated potential to regret a decision is also influential. In a further study, Ritov and Baron asked subjects to imagine themselves as policy makers faced with the choice to institute a hypothetical vaccination programme. In the scenario, the choice to institute the programme carried risk of death. However, this programme would end in fewer deaths than the anticipated epidemic if they did not institute the programme. In addition, Ritov and Baron told subjects that they would later know which children died from the disease and which from the vaccine. This knowledge further lessened their potential to institute the programme. Thus the bias towards omission was greater when the anticipation of regret was present and anticipatory regret was intensified when respondents expected to know the outcome of their decision. Under this theory, parents might avoid vaccination for two reasons: it involves a commission; and it accentuates anticipation of regret over a negative outcome from a vaccine because parents will be highly involved in the consequences.

However, omission bias and regret theory fail to explain why the majority of parents continue to vaccinate their children. One limitation is that many of the studies testing this theory selected samples of university undergraduates, asking them to think about hypothetical scenarios where the outcomes of vaccination and non-vaccination (usually
death) were the same. Their generalisability might be limited to the extent that parents make a real decision about their own children and usually have to weigh different consequences when comparing the deleterious effects of the vaccine and the vaccine preventable disease. Indeed, recent research with parents has found that omission bias operates mostly with those already opposed to vaccination.  

Under current structures that make vaccination a standardised, default position, it is possible that non-vaccination requires more action on behalf of parents e.g. obtaining exemptions or conscientious objector forms and/or justifying one’s decision to doctors. Although this broad social reinforcement might offset the omission effect, if a vaccine becomes publicly stigmatised and its risk less tolerated, parents might find the action of vaccinating a child less tolerable. In other words, omission bias might become more relevant in the future.

### 2.4.2 Ambiguity aversion

Other risk perception theories are helpful in understanding how vaccines might become less tolerated. For example, ambiguity aversion suggests that people avoid taking risks when the outcome is uncertain. Meszaros et al. found that when ambiguity was introduced to parents regarding the possibility of death from a vaccine, their likelihood of vaccinating fell by 34 per cent.

Ambiguity aversion also intensifies the bias towards omission. Hence, when parents perceive expert dissent about vaccine safety this apparent ambiguity in risk presentation may make them avoid vaccinating their children.

### 2.4.3 Bandwagoning, altruism and free-riding

Hershey et al. tested the extent to which a regard for others influenced vaccination decisions. They concluded that people were more likely to vaccinate if they perceived others doing so (bandwagoning). They could also be motivated by altruism if
vaccination was urged in that way. However, some parents appeared less inclined to vaccinate if they were aware of the opportunity to free-ride on the immune status of others. That is, they knew they could avoid vaccine and disease risk because everyone around them was vaccinated. Chapter 5 discusses the relevance of the above heuristics to understanding parental responses to mass mediated controversies.

2.5 Social modifiers of risk response

The above heuristics and other modifiers of risk perception have been identified in over 30 years of research. Initial studies focused on people’s decision making in gambling choices. By the 1970s the research extended this to examining people’s responses to threats posed by environmental hazards. More recently, researchers have looked at the processes and impacts of the social amplification of risk, the way certain technologies can become stigmatised, and the role of emotion in risk perception. Risk perception research has been useful for developing an understanding of why public reactions to health risks do not always correlate with the probability of harm or death assessed in official estimates. For example, in general, Americans overestimate the risk of death from flood and underestimate the risk of death from diabetes which causes many more deaths. Wishing to summarise how these qualitative elements of risk modify people’s responses, researchers proposed a list of “fright factors”. Although mainly applied to responses to environmental hazards, this list might explain why some vaccine safety issues receive apparently unwarranted media and public attention. In general, people are less tolerant of risks if they are coerced and if the risks are inequitably distributed, inescapable by personal precautions, arise from an unfamiliar source, if they are man made, cause hidden irreversible damage, affect the vulnerable, arouse dread, have identifiable victims, are poorly understood by science, and are subject to contradictory statements.

A number of core values underscore these responses. These relate to the desire for freedom, control, fairness and democracy. Such value-based responses to risk challenge the largely held assumptions that numerical estimates of probability alone
inform people’s decisions, hence it is only necessary to have correct knowledge of these 
estimates for people’s concerns to dissipate. This lack of consistency highlights the 
limitations with employing theories of rational behaviour alone to explain vaccination 
behaviour.

2.6 Limitations with theories of rational behaviour

The Health Belief Model (HBM), which measures perceptions of severity and 
susceptibility to disease, has been found to be predictive of vaccination behaviour and 
useful for structuring questionnaires. Nevertheless, researchers have noted some 
limitations. Firstly, it simplifies a dynamic process where perceptions about 
susceptibility, severity and risks of vaccinating change according to the age of the child, 
disease and vaccine. Others contend that the model fails to adequately account for 
environmental influences on decision making. In addition, the HBM measures 
perceptions of susceptibility and severity to the diseases when perceptions about 
vulnerability to vaccine adverse events might also compete. For example, perceptions 
about severity and susceptibility to measles might compete with perceptions about 
susceptibility to and severity of autism when it is publicly but erroneously linked to the 
MMR vaccine. Finally, the HBM has successfully identified perceptions about vaccines 
and diseases as correlated with vaccination status but it does not provide explanations as 
to why parents hold particular beliefs.

Many surveys of immunisation attitudes require parents (or providers) to satisfy strict 
knowledge criteria. Respondents often fail to show adequate knowledge of vaccination 
procedures or safety. Conclusions typically centre on recommendations to better inform 
parents through education. While it is important to address broad knowledge 
deficits, particularly regarding false contraindications, evidence that campaigns to 
increase parents’ knowledge improve vaccination rates remains inadequate or 
inconclusive. Care must be taken with linear assumptions for three reasons. First, 
contextual factors, which are not easily measured, can modify behaviour. Second,
assumptions of rational decision making might not apply. Third, official recommendations are themselves subject to change.

The theory of reasoned action has attempted rightfully to incorporate social norms and expectations but itself assumes rationality. Psychometric researchers, social scientists and media theorists have long challenged the assumption that knowledge affects attitudes and behaviour in a simple linear fashion. Some have suggested that a different type of rationality operates in decision making.

A final weakness with many of the studies employed to measure knowledge and attitudes is that they are almost always cross sectional. They measure the co-existence of exposure and outcome variables at a single point in time and thereby make it impossible to establish cause and effect. As well, prospective studies of interventions based on the HBM are limited in number and potential generalisability. Two randomised trials applied the constructs of the HBM to an immunisation postal reminder system. Although both found a statistically significant increase in uptake in the intervention groups, one study prompted influenza vaccination in an elderly population thus making generalisability uncertain. The other used a HBM-based reminder card that was also addressed to parents in a more personal way that the non HBM-based card. This makes it difficult to determine whether it was the personal nature of the reminder card or the use of its HBM constructs.

For some parents, the constructs of the HBM could measure cognitive processes that were adopted post hoc. For example, parents fully supportive of vaccination, might rationalise their action because they had adequate access to services, a particular world view, a desire to adhere to popular wisdom, or personal experience with an infectious disease. Theories of cognitive dissonance and self perception recognise such a possibility because they see behaviour informing attitudes rather than vice versa.
2.7 The complexity of vaccination decisions

Many studies conclude that vaccination behaviour is inherently complex. In exploratory qualitative research with parents fully supportive of vaccination, a complex interaction is seen between behaviour, cognition, socio-cultural and emotional elements. In terms of cognition, vaccination completers tend to believe that vaccination is important and that it provides complete or almost complete protection. However, such positive attitudes do not differ greatly from parents of partially vaccinated children. Studies suggest that the strongly social nature of vaccination decisions, where notions of what it means to be a good parent, “bandwagoning” (vaccinating because everyone else does it), and having a high regard for medical recommendations are also important. A repeated finding is that complete immunisers do not experience a conscious decision to vaccinate – it is seen as a normal, almost automatic part of life. In other words, the practice of having one’s child vaccinated appears inherently social. It involves notions of responsible parenting, anticipation of guilt if children catch a disease, and fear of social ostracism. Hence, although vaccinating a child is a rational practice, a parent’s decision to vaccinate is not necessarily based on rational decision making in the traditional sense.

Plough and Krimsky’s concept of cultural rationality has been used to describe the interplay between cognitive, emotional, social, cultural and spiritual factors in vaccine decision making. They delineated cultural from technical rationality to describe the differences between lay and expert risk perceptions. Technical rationality “rests on explicitly defined sets of principles and scientific norms. These include hypothetico-deductive methods, a common language for measurement, and quantification and comparison across risk events.” Cultural rationality is characterised by trust in political culture and democratic process and appeal to folk wisdom, peer groups, and traditions. Boundaries of analysis are broad, risks are personalised, and family and community emphasised. Using technical rationality, vaccination experts base their assessments on technical knowledge and results from epidemiological studies but, as noted, individual parents may find their personal experience with vaccines or advice from family members much more fundamental in decision making.
2.8 **Conscientious objectors to vaccination**

Accounts from parents opposed to vaccination provide further elaboration of the extent to which values and other less measurable factors inform perceptions and behaviour. They articulate a complex rationale which incorporates personal experience with attributed adverse events, advice from family and friends, general scepticism about health professionals, and a preference for alternative methods of preventing disease. Rogers and Pilgrim described their rationale as “philosophical or intuitive resistance to the idea of immunization”.

In interviews with mothers in Britain, Rogers and Pilgrim found two distinct groups: those who decided against vaccination at the outset; and those who initially complied but started to question its value. Rather than being ignorant or apathetic, parents demonstrated a strong interest and selective knowledge of the topic. Many actively sought information from health professionals and alternative literature to support their decision. In retrospect, they saw their initial adoption of vaccination as an unthinking and automatic process.

Although many considered polio and pertussis as serious diseases, the mothers saw vaccination as more risky because they believed that it over-ruled or destroyed immunity, particularly in young, vulnerable or “sickly” children. They considered vaccines as causal in a range of conditions including cancer and auto-immune disorders and voiced concern about long term effects. Having chosen not to vaccinate, parents sought alternative ways to protect their children from disease or to manage illness if it occurred. These included homoeopathy, naturopathy, diet, exercise, breastfeeding, calm and loving environments, and a generally healthy lifestyle. For some, the adoption of alternative health practices coincided with their decision to forgo vaccination rather than preceding it as might be expected.
Unlike polio and pertussis, Rogers and Pilgrim found that parents considered measles, mumps and rubella as mild illnesses. Rather than preventing them, they preferred to allow their children to contract them early and develop immunity which they saw as life-long and ‘natural’. Immunisation lessened this opportunity, a concept noted by the researchers as “turning the herd immunity argument on its head”. Some set up informal networks and held “disease parties” to facilitate transmission at an early age. The Natural Immunity, Childhood Diseases Contact Network, based in Middlesex, UK exists for this purpose.

These parents saw vaccination as medical orthodoxy’s interference with a healthy child that posed unnatural, unknown and potentially serious risks. They viewed its promotion in the health care system as unwanted public intervention in private choice. They met official assurances and advice from health professionals with scepticism unless it supported their beliefs. They saw health professionals as playing down vaccine risks, adhering to official dogma and intolerant of non-vaccination decisions. Some parents experienced ostracism from the health care system and were subject to confrontations with health professionals and other parents who did not share their views. Two women who disclosed their position to health professionals reported being denied future care from those services. In an effort to avoid these situations, some tended not to proselytise their beliefs, claiming their child was contraindicated as this was viewed as a more socially acceptable excuse. Other qualitative studies of parents who oppose vaccination have produced similar findings.\textsuperscript{61,93,116-119}

Despite ongoing concern among public health practitioners, dissenting parents represent a comparatively small proportion of parents. Using data provided in the 1995 ABS survey, an estimated 6.6 per cent of parents opposed the pertussis vaccine.\textsuperscript{35} A more recent national poll found a similar result with 5 per cent of respondents reporting personal opposition to immunisation.\textsuperscript{120} According to Bond’s survey of immunisation uptake in users of formal day care only 0.7 per cent of respondents expressed strong concerns, deciding not to immunise.\textsuperscript{54} In a New Zealand study, 0.5 per cent of parents were not immunising their children.\textsuperscript{56} A UK study showed 3 per cent of parents of
unimmunised children did not believe in immunisation. The researchers asked in their report, “Where are the immunisation dissenters?”.

The number of dissenting parents may be slightly under-estimated since they may be suspicious of government surveys, fall under “false contra-indications”, or prefer to claim practical difficulties. If a small percentage of those claiming false contraindications on surveys are actually opposed to vaccination, attempts to correct misconceptions with more information will fail to address the core concerns from which they arise.

Parents opposing vaccination tend to be well educated, older, more likely to be female, of Anglo Saxon background, and have larger families. Qualitative data suggest they tend to project more “fringe” beliefs and behaviours. As well, they are less likely to have been immunised themselves as a child. A small proportion of those opposed to vaccination are from religious groups such as Christian Scientists or Orthodox Protestants in the Netherlands where vaccination violates doctrine. Some communities oppose vaccination because of a particular philosophy. For example, those subscribing to the theories of anthroposophist, Rudolf Steiner, decline vaccination because febrile illnesses are deemed as important to the child’s physical and spiritual development.

2.8.1 The anti-vaccination movement

Spokespeople for vaccination dissenters are often articulate and in positions where they may be able to have a disproportionate influence on others when they become committed to proselytising their beliefs. Some, although not usually those from religious groups, become active members of interest groups. They form parent support networks and organise opposition to any regulation or promotion of vaccination. A few core members can mobilise significant grassroots campaigns aimed at disseminating their beliefs or reducing public confidence in vaccination. They also lobby the media.
A study of 2440 immunisation related articles from Australia’s news print coverage contained 115 articles with statements from those opposed to immunisation. Just under half of those articles quoted the same six individuals, five of whom represented immunisation lobby groups. From this study, and others, it is apparent that grassroots campaigns are regularly conducted against vaccination by relatively small but vocal groups. To demonstrate the impact and significance of this movement, chapter 3 describes this phenomenon in more detail using data collected for 3 years from the newsletters of Australia’s main anti-immunisation group.

2.9 Wider social influences

The anti-vaccination movement operates within a broader social climate. The twentieth century saw rapid advances in new technologies. Australian social researcher, Hugh Mackay, described Australians as voracious consumers of technology (mobile phones, microwave ovens, VCRs) but he also believes we are concerned about its long term effects. Intense public debate over genetic engineering, for example, reflects concerns about the long-term and unknown consequences of medical technology. Infamous events like the thalidomide tragedy signal that much heralded treatments can also have dire consequences that are not immediately apparent.

The wider social context is also producing relevant changes. Firstly, there is a greater propensity to question medicine. With the rise of consumerism the public demands greater participation in decisions about health care and informed consent about treatment options. These changes are reflected in language shifts from “patient” to “client” and “lay person” to “consumer”. Increasingly the medical profession is being held accountable for treatment decisions. Instances where medicine fails to meet public expectations are publicised by a media interested in stories of “falls from grace”.

In addition, medicine now competes with an array of non-conventional therapies. Alternative approaches to health such as naturopathy and homoeopathy are increasingly popular and practices that were once marginalised as quackery now receive significant
positive and serious exposure in popular culture. In 1997, 42.1 per cent of US citizens used alternative therapies while visits to alternative practitioners were estimated to exceed visits to mainstream primary care practitioners. Those who use alternative therapies are committed to environmentalism and feminism. They are interested in spirituality and popular psychology. They subscribe to a holistic view of health, consumerism and they believe in individual responsibility. People perceive alternative health practices as more natural and treatment of the whole person. This concept attracts many when conventional medicine is found lacking, especially in an age of rapid technological change.

Political forces are also relevant. The near global dominance of capitalism and attendant rise of individualism have led not only to greater consumerism in health care but changed attitudes to state “interference” in private life. Streefland believes vaccination resistance movements should be seen within this context. Mass resistance might be stronger in countries with histories of expression of anti-government values than in those which view the state as benevolent. Indeed, anti-vaccination rhetoric, resplendent with antipathy towards state interference in private life, reflects wider civil libertarian concerns.

However, wider social forces should not be applied indiscriminately to understanding vaccine controversies. For example, the assumption that attitudes to state intervention determine vaccination acceptance is contradicted in the individual-rights focused USA where mandatory vaccination enjoys widespread acceptance. Further, contrary to reasonable assumptions that interest in alternative therapies is a product of dissatisfaction with medicine, studies found that this interest reflects more fundamental changes in ways of seeing healing and wholeness rather than just being a reaction against the orthodox.

Despite the widespread application of consumerist notions in health care, it is apparent that people do not make choices about their health care in the same way they choose products from a supermarket shelf. Their relationship with their doctor, trust, emotions,
and the intensely personal and bodily nature of the medical encounter place it in a different realm.\textsuperscript{129} This presents a challenge to broader utilitarian-based assumptions that given ‘perfect’ information, people will always make a rational choice. Such assumptions fail to account for (1) the existence of imperfect information and uncertainty, and (2) ways of thinking about risk which embody other value systems.

More fundamentally, a model of the informed consumer as a metaphorical island, alone taking responsibility for his or her choices can be at odds with an issue that appropriates communitarian values. Unlike the individual’s choice to eat a diet high in cholesterol, the choice to decline or defer vaccination carries direct consequences for others. Health economists and social scientists have criticised the automatic application of individualistic principles to understanding and addressing health problems.\textsuperscript{130-132}

In all these exceptions it is clear that a dynamic interplay of forces gives rise to public vaccination controversies. However, little empirical research has sought to define and explore the interaction between such forces in a situated and naturalistic way.

2.10 Overseas experience with vaccine controversies

The medical literature contains much speculation but little published research on how media coverage of negative messages about vaccination affect parents’ decisions.\textsuperscript{14,76,133-136} The best available evidence is ecological, where vaccination rates are measured before and after intense negative coverage. Mason and Donnelly compared vaccination rates in the distribution area of the South Wales Evening Post (SWEP) with data from the rest of Wales. The newspaper ran a “protracted campaign against the MMR vaccine”. After this, the SWEP distribution area experienced a 13.6 per cent decline in uptake, significantly greater than the 2.4 per cent decline in the rest of Wales. Despite the limitations with ecological data in drawing causal associations, this decline confirmed anecdotal impressions from health professionals that negative media coverage was affecting vaccination acceptance.
However, the largest decline in vaccination rates was seen in the UK in the mid-1970s during and after the pertussis vaccine episode noted in Chapter 1. Although controversy had been brewing, the ‘tipping point’ was attributed to two national television documentaries. This UK experience is frequently alluded to in the medical literature. However, no apparent studies have systematically investigated the mechanism by which mass confidence declined dramatically. Other studies have not found any substantial decline in vaccination rates after negative media coverage. For example, when a one hour documentary about the pertussis vaccine was shown in the US in 1982, much public and expert comment ensued but the country experienced little effect on vaccination rates. Since 1998 in the UK, MMR vaccination rates have dropped by 6 per cent after the publication and subsequent prolonged and intense media coverage of a study by Wakefield and colleagues hypothesising a link between MMR, inflammatory bowel disease and autism. In their ecological study, Gangarosa and colleagues linked the activities of movements against whole cell pertussis to declining vaccination rates. However, with ecologically based studies it is difficult to isolate other factors not attributable directly to lobbying and consequently determine individual exposure to negative media coverage.

In explaining mass shifts in public confidence, various authors have proposed a combination of elements including the media, the anti-vaccination movement, providers, sole experts, medical journal articles, liability lawyers, and characteristics of the vaccine or disease such as low efficacy and incidence respectively. Journal articles questioning vaccine safety are published, media reports arise, and vaccine opponents lobby but most controversies fail to attract the public spotlight in a sustained fashion.

This thesis contends that it is the nature and a combination of the above elements that lower public confidence in vaccination. As Begg stated:

A lot depends on how the media react and look at the arguments, and hopefully it will be a five day wonder. But any one of these scares has the potential to catch fire, and I do get a sinking feeling about them.
2.11 Core aims of this thesis

This thesis combines empirical data from media analyses, interviews with parents and providers and an examination of anti-vaccination lobbying to describe the perspectives of different social actors in vaccination controversies. In discussing the need for a multi-component study, Kaspervon and Stallen\textsuperscript{152} recommended that:

Included should be equal attention to those who seek to intervene, those with competing interest, those to whom the intervention is directed, and those who occupy less central but nonetheless important positions in the social communication web. The latter category of “actors” will become more relevant as researchers and their sponsors become more sensitive to the communication process itself, and not in the least to its wider, institutional context.

A secondary aim of this thesis is to suggest how vaccine controversies might “catch fire”. A model proposed in chapter 6 illustrates the components that exacerbate vaccine safety concerns in the community. Being able to understand, predict and prepare for controversies is central to mounting an effective and efficient public health response to them.\textsuperscript{150} Recommendations based on these findings aim to assist providers, campaign planners, policy makers and advocates in their work.

2.12 Risk communication

These recommendations are based, in part, on the principles of risk communication. Risk communication is “the exchange of information about health or environmental risks between interested parties.”\textsuperscript{153} Public health interest in risk communication arose largely of environmental health controversies in the 1970s when the need to improve responses to community concerns about issues such as nuclear power became evident.\textsuperscript{113}

Traditional views of risk communication have been concerned with a need to better inform the public and reduce what is seen as irrational thinking. This one-way,
“hypodermic” approach has given way to a more inclusive process where the public, technical experts and other stakeholders exchange their positions and engage in dialogue. The application of risk communication principles to vaccination is a recent phenomenon but gives a potentially useful framework for responding to vaccine controversies.

2.13 Summary

This chapter summarised research used to understand vaccination behaviour. It reveals vaccination decisions as inherently complex and informed by cognitive, social, cultural, spiritual, and emotional factors. Hence it presents the argument that no one approach can fully predict vaccination behaviour. The commonly held belief that the facts alone will address parental concerns ignores the complex nature of vaccination decisions and the social contexts of vaccine controversies. Understanding the range of influences is the first step in providing effective responses to parent-held concerns.

One potential influence on parents’ attitudes to vaccination is the content of messages circulated by the anti-vaccination lobby. The next chapter examines the activities and rhetoric of the anti-vaccination lobby.
Chapter 3 The anti-vaccination lobby

3.1 Aim

This chapter reports on two studies of the anti-vaccination lobby. The first study examines the activities of the anti-vaccination movement in Australia, namely the Australian Vaccination Network. The second study examines the rhetorical nature of the claims made by anti-vaccinationists. In particular, it examines the claim that vaccines cause a range of serious diseases.

3.2 Introduction

While staying with friends in Eastbourne in 1877, renowned children’s author, Lewis Carroll, found himself embroiled in a newspaper debate about vaccination. Carroll had read a letter published in the Eastbourne Chronicle where Mr. W. Hume-Rothery put forth his arguments against smallpox vaccination. Hume-Rothery claimed that the vaccine was causing smallpox in large numbers of people. Using his real name of Charles L. Dodgson, Lewis Carroll felt obliged to correct this misunderstanding and proceeded to refute the claims with his characteristic eloquence. This correspondence escalated into an increasingly defensive exchange between Carroll and Hume-Rothery where Carroll, “a trifle ruffled but keeping to the point, retired after the third round”. His opponent continued vigorously until the editor ended the correspondence.

Carroll had encountered, not one man’s misunderstanding, but an entire belief system shared by thousands. His experience is not unique. Debates between parties over the safety of vaccines have occurred in public forums since variolation was introduced in Europe in the 18th Century. Like Carroll, proponents of vaccination become aghast at their opponent’s obvious misinterpretation of medical evidence. They typically launch into extensive rehearsals of factual and statistical information. These rebuttals are usually reactive, taking the audience progressively through the flaws in the argument.
Opposition to vaccination is therefore not new, nor are the dilemmas faced by those attempting to respond. The phenomenon continues today, at times threatening entire programmes. This chapter examines the contemporary anti-vaccination phenomenon.

The anti-vaccine lobby is an active worldwide movement occurring mainly in industrialised countries such as the US, the UK, Australia, The Netherlands, Canada, Ireland, Italy, Sweden, Japan, France and Russia. In Australia such groups have portentous names like the Immunisation Investigation Group or the Vaccination Awareness Network. Most groups claim to be “pro-choice” and not “anti-vaccination”. They promote themselves as champions of transparency in public information and individual choice. Their claims centre on the beliefs that vaccines are neither safe nor effective. Underscoring these core statements are universal themes of cover-up, manipulation for profit, threat of excessive government control and the back to nature idyll. Such discourses are also common in anti-fluoride activism which shares objections to the notion of governments mass medicating citizens with invisible agents perceived as poisonous.

Mostly, parents form such lobby groups. Some base their allegiance on an existing interest in the alternative therapies and natural health practices. Such systems encompass values that reject vaccines as interfering with the body's natural defence systems. Parents in this group often express an underlying antipathy to medical intervention. Their position on vaccination is often realised upon the impending birth of a child. Other parents have at one stage supported immunisation but their child has suffered a frightening but temporary adverse reaction such as prolonged crying. Such parents speak of dissatisfaction with the response of health professionals to such incidents. They then embark on phases of questioning and decision making. A final group have children who are disabled or suffer from a chronic, permanent and usually idiopathic condition which they believe to be a result of vaccination. Some, but not all autism support groups share this belief. Since vaccination is strongly reinforced in the parenting environment, health care and educational sectors, parents doubting or
declining vaccination speak of feeling marginalised and portrayed as radicals or non-compliant.\textsuperscript{115} In their isolation, many find a welcome source of support in lobby groups. They become committed members who, with evangelistic fervour, seek to warn others about vaccination and thereby perpetuate the movement’s survival.

In recent years, the Internet has provided groups with a rapid international forum for communicating, networking and coordinating lobbying efforts. In this medium, anti-vaccine writings proliferate. On 20th September 2000, the key word, "vaccination", was used for the search engines Google, Yahoo, Netscape, Excite, Infoseek and Lycos. On average, three out of the first ten links were to homepages that warned parents about the unacknowledged “dangers” of vaccines. In Google and Lycos, the homepage of the Australian Vaccination Network (AVN) appeared as the first link. However, the richest, most candid and revealing communication occurs via email discussion lists where people circulate newly published articles that support their views, advance their own theories about vaccines, make calls to action, convey personal stories, and share their anti-vaccination resolve.

Academic and government interest in anti-vaccination movements has continued to varying degrees since the late 1800s when organised movements resisted compulsory smallpox vaccination.\textsuperscript{166} In the last five years, interest has surged with articles in the medical literature attempting to shed light on the contemporary anti-vaccination phenomenon.\textsuperscript{15, 76, 128, 145, 146, 167, 169} This renewed interest possibly reflects a rise in anti-vaccination activity and influence although no strong evidence exists to support this hypothesis. Authors briefly describe the movement’s characteristics, its activity on the world wide web, and its specific claims against vaccination. Others authors have explored the ideology embedded within the claims.\textsuperscript{76} Gangarosa et al. demonstrated their potential impact, linking rising incidence of pertussis in some countries to anti-vaccination activities.\textsuperscript{15}

However, no researcher has set out to describe the mechanism of influence systematically or provide detailed descriptions of the lobby’s activities. In 1997, I
became a member of the Australian Vaccination Network (AVN). During this year I received their quarterly newsletter and observed a public rally and parliamentary debate in Sydney. Members of this and other groups distributed newsletters, disseminated messages in the media and local communities and organised regional lecture tours for prominent speakers. From my observations, it was apparent that the anti-vaccination media coverage was not incidental. During the period 1993 to 1997, all articles from the Australian newsprint media were content analysed. Just under 5 per cent of them (n=115) contained statements from those opposed to immunisation. Of these, under half (n=55) quoted the same six individuals, five of whom were linked to the AVN. These individuals actively sought media exposure to disseminate their messages. Hence, the organised efforts of this cohesive group fostered significant media coverage about vaccination.

Part 1 of this chapter explores the anti-vaccination phenomenon in Australia and demonstrates that at least since the early 1990s, a small group has dedicated itself to dissuading Australian parents from vaccinating children through organised, comprehensive and behind-the-scenes efforts.

Prominent in anti-vaccination discourse is the allegation that vaccines cause all manner of ills from cancer to violent crime. Part 2 of this chapter explores this theme in further detail. It lists the diseases commonly attributed to vaccination in anti-vaccine writings and then identifies the factors common to such attribution when, as will be shown, strength of evidence is not their unifying factor. The analysis reveals that many of the attributions are embedded in cultural responses to risk introduced in chapter 2.

3.3 Part 1: The Australian Vaccination Network

3.3.1 Introduction

The Australian Vaccination Network (AVN) is Australia’s main anti-vaccination lobby group. It officially formed in 1997 through the amalgamation of several smaller state-
based organisations. These included the Vaccination Awareness Network in NSW (which had formed in 1994), the Vaccination Information South Australia and the Australian Council for Immunisation Information. In 2000, the AVN claimed 1500 members. It included over 50 local groups around the country, and 91 professional members from chiropractors to midwives. Its central office in Bangalow on the North Coast of NSW holds a library with books, cassettes and videos. Publications such as *A Shot in the Dark* and *Vaccination the Right Choice?* can be purchased via mail order as can information packs such as the *Measles Pack*, the *SIDS Pack* or the *Conscientious Objector Pack*. Videos are also available. On video, *Vaccination: the hidden truth* provides vivid accounts from five Australian doctors and one vet who cite vaccination’s alleged dangers.

In 2000 the AVN became a Public Benevolent Institution with an elected national committee, state committees and an Annual General Meeting. The organisation is sustained by membership fees, donations and the efforts of volunteers. Members are parents, grandparents, health professionals or interested parties. A 1998 AVN membership survey was sent to 1000 members. Of the 445 responses received, 94 per cent were parents and 89 per cent were women. Respondents generally had above average education and an average income. Forty five per cent had not vaccinated any of their children and a further 22 per cent had vaccinated only their firstborn. Half of those with a vaccinated family member reported an “adverse event” but only 15 per cent said they changed their attitude for that reason. Interestingly, 67 per cent had consulted an alternative health provider in the past year while just 51 per cent had consulted a doctor, compared to NSW population data where in 1998, 87.1 per cent of persons aged over 16 years reported consulting a general practitioner in the past year. The overall data suggest that most AVN members have an existing hesitancy about mainstream medicine, an interest in alternative health, and a subsequent antipathy to the idea of immunisation. Membership of the AVN provides them with support for their non-adherence to vaccination.
The AVN publishes a quarterly newsletter called *Vaccination: The Choice is Yours* which is sent to all members. Each issue contains an editorial, updates and advice on lobbying, calls to action, summaries of new studies, reprints of media articles, letters to the editor, and reports from smaller regional groups. An annual general meeting also brings members from all over Australia together via the Internet. On the AVN’s official Internet discussion list found at yahoogroups.com, visitors find more immediate and candid communication with an average of 24 messages a day posted. The newsletter and discussion list are a window into the activities of the group. They provide insights into the thinking of those opposed to vaccination and their relationships with others involved in vaccination, particularly those seen as “pro-vaccination”.

The AVN’s official website (http://www.avn.org.au/) claims that the group is not anti-vaccination but pro-information and pro-choice:

The AVN was formed in 1994 by a group of concerned parents, health professionals and others. The AVN came about primarily due to a demand for adequate information on vaccination, to address concerns regarding discrimination and to uphold the right of freedom of choice on this issue.

The AVN is for free choice – not anti-vaccination.

However, their quarterly newsletter, website and lobbying efforts clearly reflect intense opposition to the practice. For example, a 1998 AVN newsletter editorial claimed the following with subsequent comment:

A report on the national campaign for primary children to have their measles-mumps-rubella vaccination has found 25 per cent of parents have not consented to vaccination.

The AVN can be very proud of our efforts in this campaign and the resulting low levels of vaccination.171
An editorial in a 1998 Newsletter sharply reflected the true anti-vaccination intent of the group during the National Measles campaign:

Do anything and everything you can to ensure that this vaccination campaign does not take place and that if it does, our children will be protected in schools from being vaccinated without our permission.\textsuperscript{172}

This study reports on a content analysis of three and a half years of quarterly newsletters. The aim of the analysis is to investigate the types of lobbying in which anti-vaccinationists engaged.

Many of the lobbying activities described in the newsletter were given more detail in the network’s email discussion list. Between January 1999 and June 2001, 12,893 email messages were posted to the AVN’s email discussion list open to members and others. For ethical reasons these postings were not included as research data. Although the list is open to members of the public, researching Internet discussion forums lies across boundaries of public and private. While it is not necessary to seek permission to research published information, most Internet discussion forums require membership and/or registration. The question of whether it is ethical to research Internet communities without the permission of those involved is yet to be resolved in the qualitative research community.\textsuperscript{173, 174}

3.3.2 Methods

Between November 1997 and June 2001 all published issues of the AVN’s quarterly newsletter were read and content analysed. These included volumes 3(4) to 7(2). In volume 3(4), outcomes of lobbying were reported. Therefore, the analysis also recorded these activities as having been initiated prior to the time volume 3(4) was published. Volume 6(1) was missing from the collection, therefore it was not included in the analysis.
The analysis aimed to document the initiation of lobbying and, where possible, the reported outcomes of that lobbying. Instances were documented where accounts were given of lobbying activity or calls to action. These were mostly found in the regular “Job of the Quarter” column, in front page editorials and articles in the body of the newsletter about specific issues. Each issue reported on the activities of smaller satellite groups in a section called “Group Round-up”. These also included calls to action or accounts of where members undertook local lobbying. All such occurrences were documented (see Appendix 2). Each lobbying activity was followed-up through an examination of subsequent newsletters. All purported outcomes were documented along with any other noteworthy, characteristic statements, particularly those revealing the core aims of the group.

3.3.3 Results

Thirteen newsletters were analysed. Their length ranged from 27 to 40 pages. Analysis revealed that the AVN lobbied against 9 major areas (lobbying focus) which had at their core three major issues (core issue). Table 3.1 displays these categories with an example of lobbying for each category.
**Table 3.1 AVN lobbying**

<table>
<thead>
<tr>
<th>Core issue</th>
<th>Lobbying focus</th>
<th>Examples of lobbying</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discrimination and coercion</td>
<td>Maternity and child care allowances linked to vaccination status</td>
<td>Contacted office of Senator Jocelyn Newman about a booklet produced by Centrelink which AVN believed had failed to outline room for conscientious objectors.</td>
</tr>
<tr>
<td></td>
<td>Child care restrictions for unvaccinated children</td>
<td>From volume 5(4): “Contact 5 Child Care Centres in your area and ask if they will care for unvaccinated children. Note the centres and their responses and pass this information to your Support Group Representative or the AVN Head Office.”</td>
</tr>
<tr>
<td></td>
<td>Immunisation certificates on school entry</td>
<td>Request for members to write to their federal Member of Parliament asking for a guarantee not to vote to require proof of vaccination for school entry.</td>
</tr>
<tr>
<td></td>
<td>National measles vaccination campaign</td>
<td>Janet Cragg’s son vaccinated without permission. Case in Federal Court naming Hobart City and Health Minister Wooldridge as defendants. 5(3) case moved to Supreme Court in Hobart.</td>
</tr>
</tbody>
</table>
| Vaccine dangers                 | Adverse events reporting systems                                             | • White pages listing of 1800 number for parents to report “adverse reactions”:  
• “In just over 1 month of operation, our 1800 number has been very busy.”  
• August 1999 Community Service Announcement televised in Wollongong and the South West of New South Wales. |
|                                 | National measles vaccination campaign – dangers of measles vaccine            | • Approximately 11,000 copies of a measles pamphlet distributed in North Coast and 12 local schools near Mudgee. Of the latter, one agreed to send booklet home to all parents.  
• Members visited principals of state schools in Brisbane area with “many printing our 1800 number in the school newsletter and promoting our new MMR booklet”. Members stood outside schools handing out leaflets to parents. 150 measles booklets sent to Brisbane Parents and Citizens Associations. |
|                                 | New vaccines                                                                   | After article published in the *Sydney Morning Herald* and other Australian newspapers about the acellular pertussis vaccine, the AVN lodged a complaint with the press council for misleading information that the new vaccine would eliminate side effects. |
|                                 | Illnesses related to vaccination                                              | Press release on alleged MMR connection to autism                                                                                                       |
| Alternatives to vaccination     | Natural health is better than medical intervention                            | AVN was invited to attend Northern Rivers Holistic Nurses Conference.                                                                                   |
Each issue of the newsletter contained reports of regional group activities. These included persistent letter writing to newspapers, advertising in local newspapers, lobbying of editors, and holding stalls at local seminars and fairs. The reports also contained accounts of members initiating letter-writing drives to people with public profiles who had been vigorous in their promotion of vaccination including politicians, newspaper editors and radio announcers. Groups circulated leaflets, posted information sheets to public noticeboards in local shopping centres, and attended vaccination information sessions held by local health officials where they sought to dominate question times. Finally, members held regular coffee mornings where they attempted to reach new parents with their messages and support existing members. During the study period, local support groups commenced and folded. Group leader burnout was also a feature as shown in this comment from AVN president, Meryl Dorey in a March 2001 issue of the newsletter.

I have been suffering from the early stages of burn-out for at least 2 years now and it has reached a point where it takes all of my energy just to sit down at the computer and read my emails – let alone do anything like writing letters to newspapers or making appointments to see politicians.\textsuperscript{175}

Despite this, the study period represented a time of active grass roots lobbying, particularly in the first half of the study period.

The analysis also revealed that lobbying took place via three major avenues. These included the regional, metropolitan and national media, the local community, and the political arena.

\textbf{3.3.3.1 Media lobbying}

Between November 1997 and June 2001, the AVN extensively lobbied the national and local print and broadcast media. When members found articles that shed doubt over the safety of vaccines in overseas newspapers and journals, they reproduced this into a press release and circulated it to major media outlets. Such releases included a story about the
rotavirus vaccine being removed from the US market after links to intussusception, the replacement of the oral polio vaccine with the injected vaccine in the US schedule, and a congressional hearing about the links between anthrax vaccination and Gulf War Syndrome. Occasionally, their releases were successful. For example, a Western Australian girl developed a rare haemorrhagic disease after measles vaccination. The AVN issued a press release to this effect which caught the attention of a popular current affairs television programme in Perth which subsequently broadcast the story.

However, the most significant lobbying of the broadcast media occurred in late 2000 when members of the AVN alerted two national current affairs programmes to Andrew Wakefield’s claim that the measles-mumps-rubella (MMR) vaccine was implicated in autism. The producers of both “60 Minutes” and “A Current Affair” indicated early interest in running the story. Consequently, AVN members made a more concerted effort to have the story aired. Core members asked others to email, call and send a facsimile to the television stations as “concerned parents” with the right to hear the full story about MMR and autism. Core members also linked producers to parents with autistic children who were willing to go on television. Both programmes eventually aired the story in late January 2001. Hectic Internet discussion rooms and reports of numerous calls to Immunisation Coordinators throughout the country indicated that the programmes generated widespread concern among parents about the alleged link.

During the research period, the AVN also used regional television networks to advance their message that vaccines were dangerous. In 1999, the AVN successfully lobbied NSW regional television stations to air a “community service announcement” that warned parents about vaccine reactions. It urged parents to report vaccine reactions to the AVN’s 1800 number. The reactions included swelling, fever, unusual crying, neck stiffness, convulsions, anorexia, vomiting, diarrhoea, change in sleep pattern, respiratory disorder, dizziness and fatigue, skin rash, severe coughing, and headache. The Community Service Announcement ceased when the Commonwealth Department of Health and Aged Care protested.
The AVN also advertised their 1800 number in the 1998 Sydney White Pages under “Immunisation”. The AVN leadership, predominantly in the form of president, Meryl Dorey, also encouraged members to call radio talkback programmes and air their views or write to local newspapers. For example, in response to the announcement of a national adult measles campaign in 2000, the newsletter published a press release and urged members to:

> target the people who this campaign is aimed at – University Students and adults. Please send a copy of this release to any universities, TAFE Colleges or other adult education facilities near you. If any of these places have a newspaper or radio station, please be sure that you send a copy there as well.177

As noted, some AVN press releases were published. They often stirred up a rash of reactive letters from local health professionals in damage control mode. However, few of these efforts achieved their goals as only a small proportion of intended messages reached the public arena. In a 1999 editorial, Meryl Dorey lamented,

> The AVN sent out press releases about every single one of the above events rotavirus, Gulf War and polio. Each time, I thought that there was no way this news could be ignored. Each time it was.178

The editorial writer believed that there was a conspiracy at work:

> The AVN has been informed by sources quite high up in one of the major newspaper conglomerates that instructions have been passed down to reporters to ignore anything that we put out whether it be a press release or a story of vaccine injury. This has certainly been evident by the incredible lack of interest displayed by the media whenever we put out a press release.179
3.3.3.2 Community lobbying

In response to their perceived lack of success with the media, the AVN attempted to infiltrate public opinion through other avenues including the Internet and local communities. Like their counterpart groups in the USA, UK, the Netherlands and New Zealand, AVN members were active on the Internet. Vaccination opponents would coordinate then bombard parent chat rooms and bulletin boards with their views. In addition, lobbyists would urge each other to vote on Internet news polls.

In the community, their most notable activities included a successful campaign for the Nursing Mother's Association to dilute their policy on vaccination, and the organisation and promotion of regular lecture tours by prominent anti-immunisationists which generated local press reports. During the 1998 measles campaign, which included a national school vaccination drive, the AVN claimed to have distributed over 11,000 measles booklets in English and other languages informing parents of the dangers of this vaccine. These allegedly went to parents, schools, Parents and Citizens Associations and Principals. One school in regional NSW agreed to send the booklet home to all parents.

The AVN also alerted the public to what they perceived as vaccine dangers via the widespread dissemination of a book they produced, *Vaccination Roulette*. It included many of the core opposing claims interspersed with personal accounts from parents of children allegedly injured by a vaccine. The book was launched at Parliament House in Canberra by Greens Party Senator, Dee Margetts. On its release, it sold 3000 copies. Members were asked to promote it at local bookstores, health food stores, and to alternative health professionals, Nursing Mothers groups, home birth associations, play groups and local markets. Some local groups donated the book to local libraries and *Practical Parenting*, a national mass circulation magazine, advertised it.

During the research period, much of the AVN’s community and political lobbying was in the form of litigation threats, particularly during the national measles campaign when the AVN claimed to lodge a lawsuit against the Australian Federal Government in the
Administrative Appeals Tribunal. It assisted parents who claimed their children were vaccinated without their permission in taking the Federal Government to the Federal Court. One newsletter included a form letter for members to copy and send to school principals warning them of legal action should they allow children to be vaccinated without parental permission.

3.3.3.3 Political lobbying

Active lobbying of politicians included two visits to Canberra by the national committee in 1997 and 1998. At these, members met with as many Senators, Members of Parliament and senior policy advisers as possible. The perceived systematic discrimination of parents who did not vaccinate their child arose most frequently as an issue of concern and often formed the basis of complaints to government ministers. Under this canopy, the AVN raised issues such as ease of access to childcare payments and better adverse events reporting and follow-up. After these visits to Canberra, members were urged to write to politicians about their concerns. The AVN also established links with members of parliament sympathetic to their concerns. For example, members were urged to vote for Alan Corbett, a New South Wales Independent and founder of “A Better Future for Our Children” party because he was sympathetic to their cause. Corbett also formed links with members when he hosted a parliament house forum on immunisation in 1997 which had given equal time to opponent and proponents of vaccination to advance their arguments.181

AVN members expressed particular bitterness about requirement that parents consult with a doctor before obtaining conscientious objections to vaccination. Members were urged to voice their objections to federal members, the Commonwealth Ombudsman, the Privacy Commission and the Queensland Council of Civil Liberties. Newsletter editorials and letters to the editor contained reports of members having difficulties in finding providers who would sign their forms. Some claimed this prevented their access to allowances. In response they set up a list of “sympathetic doctors” who would sign
the forms with minimum fuss. Parents were also asked to send accounts of discrimination based on vaccination status to the authorities.

### 3.3.4 Discussion

During the study period, the efforts of a relatively small number of parents to advance their agenda in the media, community and political environments were remarkable. The analysis demonstrated that the messages of the AVN entered a range of arenas where message recipients may have been unaware of the organised and coordinated nature of the correspondence. For example, an interview with a producer of a national current affairs programme revealed her belief that messages in support of the MMR-autism story reflected generalised community interest rather than the coordinated actions of one interest group. Chapter 5 examines the perceptions of parents in regard to the existence of an anti-vaccination lobby.

The AVN’s lobbying efforts had in common a deeply embedded opposition to immunisation. Typically, they launched their opposition on appealing platforms such as the upholding of individual choice, freedom from discrimination, informed consent for medical intervention, and the right to full information. The latter was couched in euphemistic terms. The group repeatedly emphasised that they were not anti-vaccination but pro-information and pro-choice and that their job was to inform and educate parents. Their requests for improved adverse events reporting, for parents’ rights to access allowances for their children and for the right to choose whether or not to vaccinate without discrimination would be goals shared by proponents of vaccination. However, such goals arose from very different agendas. In the case of the AVN, these goals fundamentally related to an implicit desire to dissuade parents from vaccinating their children.

Their implicit opposition to vaccination was evident through the AVN’s highly selective filtering of new research findings for publication. In the newsletter, they summarised only studies that, at face value, supported AVN claims. These included studies that dealt
with the affects of vaccines on the immune system, instances where diseases occurred in communities with high vaccination rates, and studies that suggested causal links between vaccines and disease. Between November 1997 and June 2001, the newsletter never published abstracted studies that supported overall safety and general efficacy of vaccines or rejected hypothesised causal associations between vaccines and serious disease. On the discussion list, members subjected such studies to intense scrutiny. This pattern was also characteristic of posted rapid responses to published articles on the Internet. (See, for example, the rapid responses to a study published in the *British Medical Journal* refuting the association between MMR, bowel problems and autism\(^{182}\) [http://bmj.com/cgi/content/full/324/7334/393#responses](http://bmj.com/cgi/content/full/324/7334/393#responses)).

In the area of heuristics and biases this phenomenon of selective filtering of information is known as confirmation bias. The theory postulates that once peoples’ beliefs form, they interpret new information according to whether or not it confirms their beliefs.\(^ {107}\) In the context of forming beliefs about vaccination, confirmation bias means that new information about immunisation is particularly important. It can be difficult to change people’s views once established. As previously noted, opposition to vaccination usually develops over time and it is likely that new parents reach stages of particular vulnerability to misinformation. The first stage might be the antenatal period when expecting parents first consider childhood vaccination. Hence, the advice parents first receive from a health professional about vaccination is crucial. They first stage may also be after a child is vaccinated and suffers from side effects which were unexpected because parents were not forewarned. Another crucial stage may be when a parent presents to a provider after an adverse event and is dissatisfied with how the provider deals with their concerns.

At these crucial stages parents can become receptive to information disseminated by the anti-vaccination lobby which they encounter via the media, Internet or through their local communities. It is therefore particularly important that providers are sensitive to parental concerns during initial immunisation encounters and subsequently if a child suffers distressing side effects. This issue is explored further in chapter 6.
3.4 Part II: “All manner of ills”: The attribution of serious diseases to vaccination

3.4.1 Introduction

The anti-vaccination movement is not only interesting because of its lobbying activity. The movement’s claims about vaccination are often embedded in rich discourses that connect to wider social issues. The most pervasive claim is that vaccines cause a host of modern ills with unknown or uncertain origin including asthma, cancer, AIDS, Legionnaires disease, shaken baby syndrome, attention deficit disorder, autism and even violent crime. This claim forms the core of much anti-vaccination activity, from requests for better reporting of adverse events to the dissemination of new studies casting doubt over the safety of vaccines. It is the claim likely to have the greatest effect on parents since it relates directly to natural parental anxieties about the fearful, mysterious diseases that attract strong news media attention. Indeed, recent controversies that caught fire had at their core the hypothesis that a vaccine was responsible for a serious disease or disability such as encephalitis – the UK 1970s pertussis vaccine; multiple sclerosis - France 1999 hepatitis B vaccine; or autism – the UK 1998, to the present MMR vaccine.

The websites of major anti-vaccination lobby groups in the USA and Australia contain photo galleries with graphic images of children with brain damage and other serious illnesses, allegedly caused by vaccination (see, for example, http://www.avn.org.au/robert_s.htm). The writings of such groups range from the apparently reasonable to the overtly bizarre with one much quoted opponent linking vaccines with sexual deviance and “homosexuality”. They raise concerns about excessive use of technology and science’s interference with the body's natural processes but, paradoxically, mobilise much scientific rhetoric to advance the case against science and technology. Sometimes this process produces contradictions.

For example, in 1999, the Glenaeon Rudolf Steiner school in an affluent Sydney suburb, contacted Mark Donohoe, a Sydney general practitioner and occasional public opponent
of vaccination. They asked him to provide an expert report of the potential health implications of erecting a storage tunnel vent less than one hundred metres from the school. The vent was designed to allow air to escape from a nearby stormwater overflow system during heavy rain. Despite repeated official claims of its safety by the Health Department and Water Board, sections of the local community rigorously opposed the proposed vent. In Donohoe they sought an articulate and qualified expert to lend scientific credibility to their concerns. After a review of the medical literature, Donohoe concluded,

On the basis of the work undertaken in reviewing the scientific and medical literature, and with the proximity of the Glenaeon school in mind, I advise that the risk to health of the local community would be unacceptable if the proposed wastewater storage tunnel vent were to be situated at the proposed location at Scott’s Creek.

I advise this, in part, because the data so far gathered support the existence of a low but definite risk from both pollutant chemicals and from microorganisms, and that this risk is borne primarily by schoolchildren and the pregnant, infants, other children, the sick and the aged.184

A year later, Donohoe was asked to speak at a vaccination debate held at a Natural Therapies Trade Exposition in Sydney. In his address, Donohoe revealed some apparent contradictions in his previously expressed beliefs about risk posed by microorganisms.

Life is risk, it has been always. The reason that we are here and survivors is we took those risks and we survived them. We won our battles with micro-organisms and we still remain in those battles. No amount of medical technology, no amount of design or otherwise will take away from the fact that we live in a pool of micro-organisms which we either find friendly, which we either cooperate with or we don’t.185

Donohoe’s use of micro-organism risk language was inconsistent with the Steiner school philosophy which regards childhood infections as important to spiritual and physical development to the extent that many parents shun vaccination.122
These persuasive but contradictory statements reveal an expedient use of science. Since they belie explanation under standards of technical rationality, it is necessary to examine the cultural threads of the opposition. The connecting themes expose many of the fright factors discussed in chapter 2. Risks posed to pregnant women, children, the ill and the aged (the vulnerable) made even infinitesimal risk less acceptable. The local community lacked control over the vent’s location and felt that mysterious, unseen miasma and chemicals floating in the air would pose disease threats. Similarly, vaccination is seen as an unwanted and unnatural interference, this time infiltrating the body of the child rather than just the surrounding air.

Links made between vaccines and all manner of ills reveal similar contradictions in thinking about risk. The host of ills attributed to vaccination are rarely supported by even rudimentary epidemiological evidence. Vocal opponents undergo complex contortions in logic, excavate obscure journal articles, misquote authors from more reputable journals or claim an elaborate cover-up by the medico-pharmaceutical axis that obscures the ‘truth’ from parents. For example, Obomsawin stated that vaccination was a “medical racket hatched by a pharmaceutical industry beholden to its investors, and religiously dispensed and defended by allopathic medicine men.”

Independent panels have conducted extensive reviews of the medical research literature to investigate the hypothesised connection between the vaccine and most of the conditions and diseases amplified in anti-vaccine writings. As noted in chapter 1, the US Institutes of Medicine provide regular comprehensive updates on possible vaccine adverse events. Their conclusion to date is that vaccines carry a very small, uncertain, or no risk for the conditions listed in this analysis. Studies of possible causal associations are continuing. They will become increasingly important as vaccine risk benefit ratios narrow and public tolerance reduces.

Significantly, some of the officially accepted potential adverse events are virtually ignored in anti-vaccine writings. For example, The Australian Immunisation Handbook
directs notification to Adverse Drug Reactions Advisory Committee for further investigation if orchitis, osteomyelitis, thrombocytopenia, toxic shock syndrome, or anaphylaxis occur after vaccination. However, the Australian Vaccination Network mention little of these conditions when circulating materials on the dangers of vaccines. Such an exclusion seems counter-intuitive when anti-vaccination groups would be expected to embrace the credibility offered by official backing.

The discrepancies noted above suggest that strength of evidence does not underpin the links that anti-vaccinationists make between vaccines and serious diseases. Other more implicit elements appear to be motivating such groups to amplify such associations. The following analysis identifies diseases and conditions currently attributed to vaccination. It examines the characteristics of such attribution. Although it does not attempt an in-depth examination of the scientific validity of each association, it notes where evidence bearing on causality has been determined in Institutes of Medicine reports or when the *Australian Immunisation Handbook* lists them as possible vaccine adverse events. Anti-vaccination claims tend to lie on a continuum ranging from the bizarre and obscure to the apparently reasonable.

### 3.4.2 Aim

The aim of this investigation was to identify common aspects to the diseases listed in anti-vaccination writings. As already noted, such diseases usually have uncertain origin. The analysis asked what other cultural elements about the diseases make it attractive for anti-vaccinationists to attribute them to vaccination.

### 3.4.3 Methods

The criteria for selecting anti-vaccination writings centred upon those that might be encountered by parents seeking Internet information. Hence those that received mass circulation were selected for review. The search included anti-vaccine group home-pages, widely quoted books, and press reports. Previous research listed all explicit
claims made in Australian newspaper letters to the editor and quotes from anti-vaccination spokespersons. These were grouped into a listing of four main arguments against vaccination. The most commonly held argument was that vaccination could lead to a variety of diseases (see Appendix 3).

The four arguments formed a core list which was supplemented with a list of diseases and conditions attributed to vaccination via a search of major anti-vaccination websites and frequently quoted books. The websites were collected over a three year period. They included homepages for major anti-vaccination groups in the UK, USA, and Australia plus those that were located within the first ten hits of the aforementioned keyword search. The search term “vaccination” was used as this is favoured by anti-vaccinationists who tend to reject the word “immunisation” because it refers to the process of becoming immune to a disease after being vaccinated. This rejection arises from their belief that vaccines do not confer immunity and are ineffective in preventing diseases.

A third source was the AVN’s book, *Vaccination Roulette* which was widely distributed in Australia (see Appendix 2). A second book by Viera Scheibner, Australia’s best known opponent of vaccination, was also used. The book, *Vaccination: 100 years of Orthodox Research Shows That Vaccines Represent a Medical Assault on the Immune System*, forms the basis of the claims made during her address. These claims are often repeated in local press coverage during her national and international speaking tours. Several websites reprinted text from other popular anti-vaccination publications thereby broadening the range of publications used.

From the writings listed above, instances were extracted where a disease or condition was causally attributed to vaccination. The attribution was made explicitly and found in at least two separate sources. Sites were examined until nothing new was found, a standard technique of qualitative analysis known as saturation. Table 3.2 provides a listing of all conditions with an illustrative quote. The list of pathologies was examined for characteristics common to each disease or condition. The list was independently
examined for characteristics common to such attribution’s and common themes were identified.
Table 3.2 Diseases or conditions attributed to vaccination in anti-vaccination writings

*listed as adverse event in *The Australian Immunisation Handbook* \(^\text{17}\)
# evidence of a causal relationship with vaccine/s in US Institute of Medicine reports. \(^\text{19} 190\)

<table>
<thead>
<tr>
<th>PATHOLOGY</th>
<th>EXAMPLE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>NEUROLOGICAL/BEHAVIOURAL/DEVELOPMENTAL PROBLEMS</strong></td>
<td></td>
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<tr>
<td>&quot;These (vaccination) programs have spawned the profusion of twisted and distorted individuals who have created the American family and the American society we know today&quot; (^\text{183:253})</td>
<td></td>
</tr>
<tr>
<td>Brain damage</td>
<td>&quot;Vaccinations are very neurotoxic and have been linked with many neurological disorders, like encephalopathies, epilepsy, convulsions, ADD, LD, autism, mental retardation, depression, anxiety, CNS disorders, paralysis, Guillain-Barre Syndrome, nerve deafness, blindness and SIDS. The neurological disorders associated with vaccinations are diverse and numerous. Vaccinations lower IQ as well as contribute to the overt mental disorders and neurological diseases listed here. The relationship of vaccinations to encephalopathies and neurological diseases have been surfacing in medical journals since the advent of mass vaccination programs.&quot; (^19)</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>&quot;In the past 30 years, as vaccine recommendations have increased routine childhood vaccinations to 37 doses of 11 different vaccines, there has been a dramatic rise in the numbers of chronically ill children in the US, including a doubling of those with learning disabilities, asthma, ADHD and diabetes.&quot; (^192)</td>
</tr>
<tr>
<td>Attention deficit disorder</td>
<td>&quot;This book advances the perhaps startling thesis that childhood vaccination programs cause a wide range of neurologic disabilities, and that these disabilities yield the bulk of the autistics, minimally brain-damaged, and sociopaths who have undermined the American educational system and the American society, giving this country during the past two decades the highest crime rate in its history.&quot; (^183:249)</td>
</tr>
<tr>
<td>Autism</td>
<td>&quot;Discussion of why &quot;Johnny can't read&quot; started in the mid-1950s, when this vaccinated generation started going to school, as did the rise in auto-immune diseases. But when this generation came to the age of 18 (1963) and entered the adult statistics, IQs started to decline, the crime rate started to rise.&quot; (^183:8)</td>
</tr>
<tr>
<td>Dyslexia</td>
<td>&quot;the &quot;sociopathic personality&quot; which has emerged on a mass scale in recent decades - and which is responsible for a disproportionate amount of crime and social violence - is causally linked to the childhood vaccination programs.&quot; (^183:5)</td>
</tr>
<tr>
<td>Violence and crime</td>
<td></td>
</tr>
<tr>
<td>PATHOLOGY (cont’d)</td>
<td>EXAMPLE (cont’d)</td>
</tr>
<tr>
<td>---------------------</td>
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</tr>
<tr>
<td>INFECTIOUS DISEASES</td>
<td>&quot;Instead of providing protection against acute infectious diseases, vaccination drives the disease deeper into the body and leads to chronic infestation by the pathogenic agent. Subacute sclerosing panencephalitis is one of many examples of this slow process. Warts, herpes, shingles and AIDS are other examples.&quot; (Scheibner V. 1993.)</td>
</tr>
<tr>
<td>Legionnaires Disease</td>
<td>&quot;Outbreaks of such deadly diseases as the Legionnaires disease synchronous with intensified 'flu vaccine campaigns, are a warning to all of us that something very wrong is happening as a direct consequence of 'flu vaccine injections. To see the connections, one has only to scrutinise sporadic seasonal outbreaks of Legionnaires' disease in the countries that offer - by quite forceful advertising, especially in autumn and winter - a variety of 'flu vaccines.&quot;</td>
</tr>
<tr>
<td>HIV/AIDS</td>
<td>“We have an epidemic of life-threatening illness from failed immunity (including cancer and AIDS). Are we paying an unacceptable price for the medical innovations of our childhood?”</td>
</tr>
<tr>
<td>Guillain-Barré Syndrome *#</td>
<td>&quot;Flu vaccines not only do not prevent influenza outbreaks, they introduced serious and deadly reactions like the Guillain-Barre syndrome and the Legionnaires' disease.&quot;</td>
</tr>
<tr>
<td>“Brain eating” amoebas</td>
<td>“BRAIN-EATING BUGS: THE VACCINES LINK: Vaccines are known to be contaminated by micro-organisms, but several single-celled invaders are now considered responsible for such serious diseases as to warrant a complete rewrite of immunisation policies.”</td>
</tr>
<tr>
<td>AUTO-IMMUNE MECHANISM KNOWN OR SUSPECTED</td>
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<tr>
<td>Irritable bowel diseases</td>
<td>“Keep up with this particular section of the AVN site because there will be some very interesting research released over the next couple of months regarding the connection between MMR vaccination and the development of autism, Crohn's Disease and Irritable Bowel Disease.”</td>
</tr>
<tr>
<td>Allergies (* as 'allergic reaction')</td>
<td>“Allergies or, the poisoning of a planet” By Veronica Griffin, M.Sc. Ph.D. (Chapter in Vaccination the Choice is Yours.)</td>
</tr>
<tr>
<td>Arthritis*</td>
<td>“Additionally, Fisher points out that there are no studies being conducted -- as there have been for cancer and heart disease -- to determine the long-term effects of vaccination. Some research has suggested that various defects in the vaccines routinely administered to newborns and small children may be contributing to the current explosion of chronic, neurological and immune system dysfunction in the American population, including asthma, lupus, rheumatoid arthritis, cancer, and AIDS.”</td>
</tr>
<tr>
<td>Lupus</td>
<td>&quot;they realised that 'slow viruses' found in all live vaccines … can hide in human tissue for years. They may emerge later in the form of encephalitis, multiple sclerosis, and as potential seeds for the development and growth of cancer.&quot;</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>“The culprit behind asthma and allergies: vaccination” (title of article).&quot;</td>
</tr>
<tr>
<td>PATHOLOGY (cont’d)</td>
<td>EXAMPLE (cont’d)</td>
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<tr>
<td>OTHER</td>
<td></td>
</tr>
<tr>
<td>Cancers</td>
<td>“We have created this website to tell our son's story and to share with other parents the information we have found about pediatric brain tumors and about childhood vaccinations.”</td>
</tr>
<tr>
<td>Diabetes</td>
<td>“Vaccines Proven To Be Largest Cause of Insulin Dependent Diabetes in Children, Diabetics Advised to Seek Legal Counsel Now, Before Their Right to Compensation Expires” (Title of press release)</td>
</tr>
<tr>
<td>Gulf War Syndrome</td>
<td>&quot;Yielding to increased pressure, the US and British health departments and apartments of veteran affairs have had to face up to the fact that something is drastically wrong with these war veterans. Was it a human trial of new vaccines?&quot;</td>
</tr>
<tr>
<td>Leukaemia</td>
<td>&quot;All vaccination has the effect of directing the three values of the blood into or toward the zone characteristics of cancer and leukaemia ..... Vaccines DO predispose to cancer and leukaemia&quot; (Quote from Professor L.C. Vincent Founder of Bioelectronics)</td>
</tr>
<tr>
<td>Shaken Baby Syndrome</td>
<td>&quot;Many infants who suffer the so-called 'shaken baby syndrome' may be victims of undiagnosed vaccine damage&quot; (article sub-title)</td>
</tr>
<tr>
<td>SIDS</td>
<td>&quot;I was a professional scientist and you can't study cot death without stumbling over vaccinations” Viera Scheibner in</td>
</tr>
</tbody>
</table>
3.4.4 Results

3.4.4.1 Idiopathic

Some research has suggested that various defects in the vaccines routinely administered to newborns and small children may be contributing to the current explosion of chronic, neurological and immune system dysfunction in the American population, including asthma, lupus, rheumatoid arthritis, cancer, and AIDS.\textsuperscript{196}

As noted in previous research, anti-vaccination writings show a tendency to amplify causal connections between vaccination and diseases with idiopathic origin.\textsuperscript{76} At some stage, autism, asthma, attention deficit disorder, multiple sclerosis, cancers, diabetes and Gulf War Syndrome have all baffled science and medicine. They have also drawn intense media interest when new claims about their origin arise. Their power comes from their seeming novelty and the suggestion that danger lurks in the familiar. Vaccines appear as a modern day Trojan horse, that is, they appear to bring relief but disguise hidden threats. Psychological research has found that this element of surprise increases the persuasiveness of an argument. McGuire suggested that when people are exposed to new information which challenges widely accepted arguments (or cultural truisms), they are more likely to accept it than if they had time to develop counter-argument to such challenges.\textsuperscript{204} With immunisation, this means that parents who unquestioningly accepted the practice may find sudden exposure to anti-vaccination arguments challenges their beliefs. However, parents given the chance to develop pre-rehearsed refutations, may be able to resist such challenges.\textsuperscript{76}

In addition, positioning vaccines as the culprit for autism, asthma, or SIDS quenches the collective thirst for identifying discreet causal agents that place prevention within the reach of individuals. The implied alternative of avoiding vaccination is simple and passive. It appeals to the human tendency to face risks through omission rather than perform acts of commission.\textsuperscript{99} This reflects more broadly, basic human values centred on the need for control over risk. For example, before research into the causes of Sudden Infant Death Syndrome (SIDS) revealed sleeping position and environmental tobacco
smoke as causative factors, the vaccination-as-cause hypothesis drew public attention. However, when more conclusive evidence provided environmental and practical measures to minimise the risk of SIDS, this hypothesis held less currency. Autism may have taken the place of SIDS as a dreaded condition with uncertain aetiology, seemingly on the increase and capturing media and public attention. In the USA and the UK, in particular, some sections of the mass media and anti-vaccination lobby are suggesting vaccination as a cause to a public eager for explanation.

3.4.4.2 Rise in incidence this century

Along with having idiopathic origin, diseases like autism and asthma appear to have risen in incidence this century. Anti-vaccinationists allege that this increase coincides with receiving more vaccinations.

Instead of epidemics of measles and polio, we have epidemics of chronic autoimmune and neurological disease. In the last 20 years rates of asthma and attention-deficit disorder have doubled, diabetes and learning disabilities have tripled, chronic arthritis now affects nearly one in five Americans and autism has increased by 300 percent or more in many states. The larger unanswered question is: To what extent has the administration of multiple doses of multiple vaccines in early childhood — when the body’s brain and immune system is developing at its most rapid rate — been a cofactor in epidemics of chronic disease?

Vaccination may indeed have coincided with the greater appearance of such diseases but its mechanism is not sinister. First, chronic diseases are more prevalent, partly because of reduced child mortality and an increased life span enjoyed in nations that have controlled infectious diseases through vaccination, antibiotics and sanitation. Second, diagnostic criteria for poorly understood conditions regularly change so that apparent increases in incidence are artefactual. This has been a particular problem with autistic spectrum disorders where lack of consistency in diagnostic criteria over recent decades has led to substantial uncertainty over whether a true secular increase exists.
3.4.4.3 Attribution

Many of the diseases listed in Table 3.2 become apparent in early childhood, that is, at the time when children receive their scheduled vaccinations. Parents understandably search for an agent of blame, scouring their memories for events before the illness. Writing in the *British Medical Journal*, David Goldberg, a consultant clinical epidemiologist, shed light on this phenomenon. In conveying his experience of seeking a cause for his son’s autism, he said,

> One reaction which we, and other parents in similar circumstance, had was to search for a possible cause. Had there been an infection during the pregnancy, an encephalitic element to Adam’s chickenpox, anoxia during birth, lead in our water supply (this was checked), any family history of learning difficulties, or a metabolic disturbance? An explanation might help us to decide whether or not to have another child but more importantly, if we found the cause, perhaps, just perhaps, Adam could receive some existing, or yet to be developed treatment which would reverse his cognitive and social deterioration. We wondered if the MMR vaccine had something to do with Adam’s condition, but, following endless reflection, we concluded that Adam’s first year of development, before the vaccines, had not been entirely normal.

When parents apply *post hoc ergo propter hoc* reasoning, vaccination can become an ideal causal candidate. Reassurances that exonerate the vaccine are often met with dismay by those committed to their theory. For parents who (irrationally) feel guilt for their child’s problem, vaccination is an external cause to grasp. The parents of Lyla Rose, whose story appears on the AVN website photo-gallery, say of their daughter’s unexplained death:

> The first instinctive reaction in such a situation is for parents to blame themselves. For many weeks, my wife and I agonized over what we might have missed or could have done differently. Meanwhile, the logical part of my brain kept returning to the obvious medical event that preceded Lyla’s death -- and that internal voice kept asking the question could the Hepatitis B Vaccine that Lyla received that afternoon have killed her? Most doctors I asked scoffed at that notion and said the vaccine was perfectly safe. But I
began to search around on the Internet and Medline and discovered disturbing evidence of adverse reactions to this vaccine.  

For those who feel anger, vaccination, as a medically endorsed and state funded activity, presents the opportunity for their anger to direct towards faceless bureaucrats and “one size fits all health policies”. This anger taps into existing discourses surrounding excessive government control and abuse of medical knowledge and power and can alleviate the acute distress of uncertainty.

3.4.4.4 Face value biological plausibility

The tendency to attribute a range of diseases to vaccines must also be seen within a context of changes to society’s understanding of disease aetiology. Martin (1994) pointed out that during the 1980s and 1990s a growing number of diseases including diabetes, lupus, allergies, and cancer were re-thought of as diseases of autoimmunity. The immune system was increasingly seen as mediating the effect of factors in a person's environment such as sunlight, electromagnetic radiation, chemical toxins and diet. It is perhaps understandable that, at face value, the vaccine link carries biological plausibility. Vaccination could intuitively be seen as thwarting the already mysterious immune system in some complex and unseen fashion.

3.4.4.5 Chronic and seeded ills with dreaded consequences

Linked to the unseen nature of vaccine effects is the notion that vaccines plant a chronic and irreversible seed of long term and hidden damage. For example, mass media discourse on Creutzfeldt-Jakob Disease (CJD) reported a theoretical or at best infinitesimal risk of CJD from oral polio vaccines where bovine products were used in their development. Anti-vaccination groups latched onto this story. One particularly active anti-vaccination lobbyist on the Internet posted the following comment on her website.
This could potentially be the tip of an iceberg. Read the next story (‘Mad Cow’-type disease risk may be higher outside UK). Could bovine blood products in US and European vaccines be introducing Mad Cow disease into the population? If so, then vaccine programs and vaccine manufacturers are in big trouble.  

Here, the dominant discourse is one of hidden microorganisms entering the body and lying dormant. As noted in risk perception literature, hidden and irreversible risks are less tolerated than those where the risk is obvious.  

Like CJD, many of the ills attributed to vaccination have mutilating, lethal, insidious and dreaded consequences. “Brain eating bugs”, SIDS, and autism are a few examples. As noted extensively in the risk perception literature, such qualitative components of dreaded diseases reduce the acceptability of even minute risks. Consciously or not, groups that spread horror stories about vaccines capitalise on this perception and select diseases particularly feared by society. Dreaded diseases also gain news media attention thus increasing the opportunity for the publication of vaccination dangers whenever a causal implication suggests itself. For example, in one letter to the editor, a vaccine opponent said the following:  

Cot death (directly linked to the DTP vaccine) brain damage, Chronic Fatigue Syndrome, MS, cancer, childhood leukaemia, polyarthritis, autism, are among a growing list of diseases whose onset is either attributable to vaccine related impairment of the auto-immune system, or are new diseases with (innocuous!) names which belie the fact that their origins are directly attributable to the policy of ‘vaccination at any cost’ of which our government and the drug companies have placed us in its grip.  

Sontag draws together the appeal of the dreaded and idiopathic.  

Any important disease whose causality is murky, and for which treatment is ineffectual, tends to be awash in significance. First the subjects of deepest dread (corruption, decay, pollution, anomie, weakness) are identified with the disease. The disease itself becomes a metaphor. Then the name of the disease that horror is imposed on other things.
This preference for linking vaccines to dreaded and newsworthy diseases might explain the tendency for lobby groups to omit mention of recognised adverse events such as osteomyelitis, thrombocytopenia and anaphylaxis. These events are perhaps less familiar and have been less subject to news attention.

### 3.4.5 Discussion

Previous research has found that anti-vaccination writings in the popular press invoked vaccines as explanations for mysterious diseases of uncertain aetiology. This section further explored this phenomenon by identifying other characteristics common to such attribution. Opponents of vaccination reveal their perceptions of risk through such linkages. Rather than medical evidence, this analysis reveals that attributions are linked to some of the fright factors alluded to in chapter 2. Their relevance to vaccination is discussed in Table 3.3.
Table 3.3 Fright factor applicability to immunisation

<table>
<thead>
<tr>
<th>Fright factor (Bennett 1999)</th>
<th>Applicability to immunisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>are coerced</td>
<td>Some may find compulsory immunisation a coercive measure.</td>
</tr>
<tr>
<td>are inequitably distributed</td>
<td>For some vaccines such as rubella, all children bear the risks but others bear the benefits of population immunity.</td>
</tr>
<tr>
<td>are inescapable by personal precautions</td>
<td>Not applicable</td>
</tr>
<tr>
<td>arise from an unfamiliar source</td>
<td>When vaccines are considered as having a mysterious mechanism or containing potent sounding chemicals, then their risks can be perceived as arising from an unfamiliar source.</td>
</tr>
<tr>
<td>are man made</td>
<td>When vaccines are considered as unnatural interference in the body’s natural defence systems, then they can be seen as man made.</td>
</tr>
<tr>
<td>cause hidden and irreversible damage</td>
<td>Disease and conditions such as cancer, autoimmune disorders and autism are chronic and insidious.</td>
</tr>
<tr>
<td>affect the vulnerable</td>
<td>Children tend to be seen and portrayed as the most vulnerable group in society.</td>
</tr>
<tr>
<td>arouse dread</td>
<td>Many of the ills attributed to vaccination arouse particular dread.</td>
</tr>
<tr>
<td>have identifiable victims</td>
<td>Victims can be identified via the Internet and mass media when parents give powerful personal accounts of their struggles to care for a disabled child.</td>
</tr>
<tr>
<td>are poorly understood by science</td>
<td>The diseases attributed to vaccination are or are portrayed as being poorly understood by science.</td>
</tr>
<tr>
<td>are subject to contradictory statements</td>
<td>Apparent contradictions can arise when journal articles and prominent doctors are quoted as supporting the association.</td>
</tr>
</tbody>
</table>

Themes at the heart of anti-vaccination claims tap into widely subscribed values about freedom, control, choice, a desire to raise healthy children, and concern about the pace of modern technology. In such attribution’s we see anti-vaccine discourse embedded in wider social mores and changes. These changes include the profound decline in mortality from infectious diseases in western nations that has shifted attention towards finding explanations and cures for chronic illnesses. The mass media constantly report...
new studies which link idiopathic ills with exotic or familiar agents. In May 2000, *Science* reported that, “Complaints about vaccine safety and debate over a mysterious muscle ailment have prompted researchers to take a fresh look at the use of aluminum.” Studies blaming discrete causal agents tend to draw greater interest than those which suggest a complexity of factors because they place the possibility of prevention within the control of the individual and lend themselves to succinct soundbites. For anti-vaccination groups, these discourses provide a vehicle for the entry of their theories into the public arena.

3.5 Summary

Having described the activities and claims of the anti-vaccination movement, chapter 4 contrasts this with newsprint media frames of pro-vaccination messages. Chapter 5 examines how parent audiences deconstruct anti- and pro-vaccination messages.
Chapter 4 The media on immunisation

4.1 Aim

This chapter examines positive media coverage of vaccination. In order to describe the dominant media messages that audiences receive about vaccination, this study examines positive newsprint media coverage in Australian newspapers collected over four and a half years from November 1993 to July 1998. Previous research examined the rhetorical nature of anti-immunisation reportage. Other studies have quantified the extent of news reportage on immunisation, but none have explored its rhetorical nature or the core appeals that characterise positive reportage.

Part of any comprehensive strategy to understand the appeal of pro- and anti-vaccination rhetoric must incorporate a careful analysis of the arguments. Identifying the proponents arguments is the first step in the analysis. Identifying how they frame their claims in terms of wider social discourses to render these claims both newsworthy and compelling is the very important second step of the analysis.

4.2 Introduction

At times, the news media can influence the process of parental decision making about immunisation. Parents have rated the media as the most prominent source “of information and publicity” about immunisation. Numerous studies rate the media second only to health professionals as an information source. A US study showed that most people learned about the varicella vaccine via the media. Pareek and Pattison’s study of mothers, rated the media as the primary source of information about MMR side effects. Both studies suggest that when information (or misinformation) about vaccination is new or novel, the media take a more prominent informing role.

Pareek and Pattison also found that 29.8 per cent of parents believed the MMR vaccine caused autism and 13.1 per cent said it caused Crohn’s disease despite numerous official...
attempts to deflect misinformation disseminated via the media. This finding highlights the concern that once knowledge is set, it can be difficult to change.\textsuperscript{113} This issue of confirmation bias was introduced in the previous chapter.

The media is influential beyond the individual decision-making level. Mass shifts in public confidence have been attributed to immunisation controversies arising in the media, particularly in the UK.\textsuperscript{13, 15, 220} Conversely, studies of mass media campaigns to promote vaccination have also shown an effect.\textsuperscript{221-223} Immunisation reportage in the news media is therefore an important vehicle through which health workers can promote the practice.

The Australian print media comprises one or two daily newspapers selling in each of the eight state and territory capital cities, plus a plethora of daily and weekly regional newspapers serving regional or rural areas. The country has one relatively low selling national newspaper. In a population of 15.13 million aged 15 and over, readership statistics of metropolitan newspapers in 2000 showed a Monday to Friday 48 per cent readership with Saturday 61 per cent and a 60 per cent on Sunday.\textsuperscript{224}

Controversies about the safety of vaccines arise sporadically in the Australian press. Despite rhetoric to the contrary, negative coverage is uncommon proportional to positive or normative news coverage. In a content analysis of 2440 press articles about immunisation, the majority of news coverage was normative or promotional. Only 5 per cent of it was oppositional in nature. However, its qualitative nature rather than its quantity renders it newsworthy and memorable to the wider public and to health professionals concerned about its effect.\textsuperscript{76}

The representation or framing of an issue links it with wider social themes with which it may have no direct relevance. Meaning therefore gets transferred across ostensibly different topics. For example, manifest anti-vaccination claims about vaccines being dangerous and ineffective tend to be located under a canopy of more general newsworthy discourses about cover-up and conspiracy, manipulation by venal private
enterprise interests, governments with totalitarian agendas and the back-to-nature idyll. Themes like these can also be found in reportage of issues such as water fluoridation and gun control. Through these inter-textual connections, readers can locate content within a wider constellation of themes that provide them with a frame for understanding.

Similarly, media representation of spokespersons tends to conform to expected stereotypes (e.g. caring doctors, poker-faced bureaucrats, impassioned whistleblowers, Galileo-like paradigm challenging scientists). Such portrayals allow people to sort information into convenient categories. Fowler described a stereotype as,

a socially-constructed mental pigeon-hole into which events and individuals can be sorted, thereby making such events and individuals comprehensible…they are categories which we project onto the world in order to make sense of it.

Spokespersons tend to be stereotyped. How they seek to be presented and how they are presented may be two different things (see, for example, Brown, Chapman and Lupton). Therefore, this analysis comes with the qualification that spokespersons may not intend or agree with their portrayals, although some are more adept at casting themselves in their preferred roles. Public health workers who wish to promote immunisation require insight into how news is framed and how spokespersons are positioned. Such insight can assist in the maintenance of frames which advance the goals of advocacy and illuminate how to reposition undesirable frames. Hence, this chapter sets out to describe the nature of pro-immunisation press coverage and ways in which health experts are positioned in this coverage. The approach will be via a content and framing analysis of all text and images.

4.3 Methods

All Australian press reports on immunisation (n=3090) were obtained from a media monitoring agency. The collection included articles from all of Australia’s metropolitan newspapers between November 1993 and July 1998. Articles from regional newspapers
were also obtained for the period from September 1993 to January 1996 when CSL Vaccines, the organisation from which they were received, ceased this collection.

Because of the greater number of small circulation regional newspapers, the collection of articles contained a higher proportion of regional to metropolitan publications (70:30). To account for the larger readership and political importance of the latter, the sample was stratified to represent both categories evenly. It was also stratified for time periods to account for the sporadic nature of news coverage. \(^7\) Drawing an equal number of articles from each three monthly time period increased the chance of representing each new story rather than over-representing the one story intensely covered within a short time period such as urges for back to school immunisations.

After the above stratification, 240 articles were randomly selected via random number generation. This number was considered adequate to represent the entire sample but small enough to allow in-depth analysis. From this, articles considered completely neutral (24) or oppositional (8) in nature were excluded, leaving 208 ‘positive’ articles. They were considered ‘positive’ because even those that appear at a superficial reading to be neutral tend to be subtly positive in their use of language or spokespersons and quotes included or excluded. Articles were considered neutral if they were purely informative with little rhetorical substance (e.g. newsbriefs informing readers of immunisation clinic times). Articles were considered oppositional when the main content related to anti-vaccination claims (e.g. a letter to the editor from a vaccination opponent).

A qualitative analysis of all articles was undertaken to distil the major themes arising out of pro-immunisation rhetoric. Techniques for analysis were adapted from the literature on framing and critical discourse analysis. \(^2^9\) \(^2^3\) Discourse analysis of text is a process of identifying the ways in which language conveys meaning and alludes to wider issues.

All articles were read and re-read in order to develop a coding framework which accounted for emerging patterns and themes. As themes emerged, techniques of frame
analysis were adopted. Framing analysis accounts for how media reportage on an issue defines the problem, who is blamed for it and what solutions to the problem are proposed. Each article was coded accordingly. This framework provided insights into common threads and interrelationships within the discourse but as coding proceeded, the structure was expanded to accommodate emerging patterns and acknowledge positioning of spokespersons. Once the coding scheme was finalised, the articles were re-analysed according to the following questions and criteria:

- what is the problem?
- who is said to be responsible?
- what are the implied solutions?
- what devices (such as metaphors, visual images, rhetorical devices and stereotypical portrayals) are used to construct the themes?
- how was the spokesperson cast and their typical rhetoric styles.

### 4.4 Results

#### 4.4.1 Problem 1: Disease threat

#### 4.4.1.1 Panic language

The articles most commonly introduced childhood immunisation in the context of disease threat. This representation occurred in 60 per cent of articles. Many conveyed headlines with dramatic language that had the potential to incite a sense of alarm and panic in the reader. Adjectives such as 'alarming', 'catastrophic', 'grave', and nouns such as 'death', 'violent', 'deformity' and 'epidemic' characterised these passages. The language implied a sense of general drama:

Goondiwindi parents have been warned against a strain of "killer measles" which is sweeping southern Queensland (Article; metropolitan, 31 August, 1994).
4.4.1.2 Diseases personified

References to diseases often appeared in the active voice, as if they were malevolent, purposive, almost anthropomorphic entities akin to murderers. For example, a virus does not *seek and destroy or lurk* but such language constructs an intentionality that animates what might otherwise be described in drier, less engaging language. The active voice was used to paint images of diseases as threatening agents out to 'attack'.

The horror diseases of yesterday are still lurking around (Article; regional, 31 August 1994).

Mum’s Warning: Measles Can Be a Sleeping Killer (Headline; metropolitan, 29 July 1994).

The spectre of disease threat included passages where language conveyed images of the diseases brutalising vulnerable children:

“if nothing was done, Australians could again see babies being born deformed because of rubella, young men becoming sterile because of measles and one in 4000 unimmunised children dying of whooping cough,” he said (Article; metropolitan, 10 April 1996).

4.4.1.3 Quantification rhetoric

Twenty five per cent of articles provided a paragraph or two listing data on disease morbidity and mortality. Sometimes, as in the example below, these tended to focus on absolute incidence rather than rates per population.

Health Department statistics have shown the number of pertussis cases in Victoria rose from 71 in 1991 to 527 in 1993, and there were 481 cases in 1994. About 4000 cases of whooping cough were believed to have been reported in Australia last year (Article; regional, 29 April 1995).
4.4.1.4 Stories and their morals

Despite the power of personal testimony, only 5 per cent of articles contained personal accounts of parents whose children were affected by vaccine preventable diseases. Such stories tended to be framed as lessons or moral tales of what might happen if a child was not immunised. This was either in the form of powerful testimonial accounts from parents whose children had died from vaccine preventable diseases or articles where the story or photograph of a child currently suffering from a disease implied a “this could be your child” lesson for all parents. Two articles in this latter group included photographs of listless babies hospitalised with measles or pertussis. The babies were attached to an array of tubing and monitors. Even the unusual account of a woman who contracted polio from her recently vaccinated child took the opportunity to conclude that all contacts should be vaccinated against the disease:

Dr Michael Whitby said the case reinforced the need for polio vaccination. "If you are vaccinating your baby against polio it's important to vaccinate anybody else in the household who hasn't already been vaccinated (Article; metropolitan, 16 October 1995).

4.4.1.5 Lessons from history

More common that stories outlined above were lessons of history. These lessons, aiming to communicate the seriousness of diseases, occurred in 12 per cent of articles. These 'tales of yesteryear' came mostly from politicians, but editorials often harked back to the times when diseases were much more prevalent and visible in the community and vaccination was rarely questioned. One flamboyant celebrity doctor left the reader with the image of a prominent older Australian offering his wisdom.

“Older people and some older doctors recall the terrible stories of yesteryear as these horrifying diseases killed or maimed our kids.” (Article; metropolitan, 21 April, 1996).
In her role as Australia’s Federal Government health minister, Carmen Lawrence also recalled past experiences. Her statement was reported in a number of publications.

“We have been spoilt in a country like Australia,” Dr Lawrence said. ”Many young parents have never come into contact with the terrible diseases such as polio and diphtheria that plagued children in Australia before effective vaccines were available” (Article; metropolitan, 12 May 1995).

Invoking lessons from history venerates a past when vaccination was more appreciated. It implicitly invites the reader to stereotype such spokespersons as older and wiser and rebuke the complacent younger generation who do not appreciate their safer existence.

4.4.2  Problem 2: Low vaccination rates

4.4.2.1 Quantification of low rates

The release of the Australian Bureau of Statistics 1995 National Childhood Immunisation Survey received widespread coverage. The report estimated full vaccination rates for children aged 3 months to 6 years at 52 per cent. The figure comprised children in all states who were fully vaccinated on time against all diseases on the schedule. When the recently introduced Hib vaccine was included in the figure, the fully vaccinated rate dropped to 33.1 per cent. One editor’s choice of which statistic to quote was revealing in this case. He misinterpreted the latter figure.

The ABS puts {full vaccination} at only 52 per cent although this data is disputed by some medical authorities and may be as low as 30 per cent in some pockets of the nation and approaching 90 per cent in others, including metropolitan Melbourne (Editorial; metropolitan, 21 April 1996).

In other instances the same figures were used to lament low immunisation rates and provide a platform to quote various spokespersons on the cause and solutions for the problem. For example, reporters tended to quote federal health ministers in the context
of rebuking the decisions of other governments for their own lack of political commitment to immunisation. Medical experts and Australian Medical Association (AMA) representatives tended to quote the 1995 statistics to justify their rebuke of the neglect of parents. Some called for compulsory vaccination,

Dr Segal attributed the low levels of immunisation to laziness. He recommended compulsory immunisation as the only way to ensure immunisation levels rose (Article; metropolitan, 22 July 1995).

4.4.3 Who is to blame?

As indicated above, articles tended to flow from the statement of a problem to the allocation of responsibility for that problem. This question of blame for diseases and low vaccination rates was central to many articles. Five distinct categories emerged: the nation as a whole; government; providers; parents; and the anti-immunisation lobby. As coding proceeded, the existence of not only the blamed but the blamer became evident. Medical spokespersons constituted the largest representation of blamers. Their comments about blame occurred 65 times more than similar comments from parents. Table 4.1 summarises these patterns.
Table 4.1: Who is blamed for low vaccination rates?

<table>
<thead>
<tr>
<th>BLAMER *</th>
<th>Nation</th>
<th>Government</th>
<th>Providers</th>
<th>Parents</th>
<th>Anti-vaccination lobby</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Politicians</td>
<td>10</td>
<td>7</td>
<td>0</td>
<td>11</td>
<td>2</td>
<td>30</td>
</tr>
<tr>
<td>Doctors</td>
<td>18</td>
<td>12</td>
<td>3</td>
<td>25</td>
<td>7</td>
<td>65</td>
</tr>
<tr>
<td>Other health workers</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>4</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Parents</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Journalists</td>
<td>2</td>
<td>4</td>
<td>5</td>
<td>7</td>
<td>2</td>
<td>20</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>31</strong></td>
<td><strong>25</strong></td>
<td><strong>8</strong></td>
<td><strong>47</strong></td>
<td><strong>12</strong></td>
<td><strong>123</strong></td>
</tr>
</tbody>
</table>

*News actor represented in articles as apportioning responsibility*
4.4.3.1 The nation - Australia's shame

During a 1997 national campaign to promote pertussis vaccination, some newspaper headlines alluded to television footage of an infant with the disease. For example:

BABY BOY THE FACE OF A NATIONAL SCANDAL “This is a national scandal and a situation which does not need to happen in modern-day Australia,” he said (Headline and quote, metropolitan, 29 July 1997).

Low vaccination rates as a national disgrace arose in one quarter of articles. In this case, ‘nation’ implied not just parents but all citizens and government. The issue was most commonly embedded within the statement that Australia's vaccination rates were lower than those of many impoverished Third World countries. This statement received extensive national coverage:

For a country that once pioneered the development of vaccines and led the fight for the global eradication of smallpox, Australia's immunisation record is now a disgrace. …. these figures place Australia behind not only most industrial nations but Third World countries such as Vietnam, China and Cuba, which have achieved up to 95 per cent (Opinion piece; national, 29 January 1997).

Its popularity was further indicated by its re-appearance in articles over a three year period. Essential national indicators like immunisation are usually expected to exceed rates in developing countries which, in popular discourse, are portrayed as sources of ‘exotic’, ‘rampant’ and hence poorly controlled infectious disease.233 The statement subtextually referenced concepts of racial hierarchy and a notion of alleged threat for Australia because it contradicted these expectations.

The coverage also compared Australia to the US which was usually venerated as the gold standard. For example, despite the USA experiencing controversies about the safety of vaccination which have at times, flared up quite considerably in the media,135 139 one Australian immunisation expert was quoted as saying:
“It's not a debate I've seen going on anywhere else" he said. "It hasn't been going on in the US. People accept that their children should be vaccinated." (Article, metropolitan, 31 January 1997).

In lamenting low vaccination rates as a collective and national problem, articles often referred to children using the collective pronoun, “our”, implying social rather than individual ownership,

"It is a fact that many zoo animals at risk such as the red panda, cats and elephants still have better rates of immunisation than our children." (Emphasis added, article; regional, 27 January 1995.)

4.4.3.2 Government

In 20 per cent of articles low vaccination rates were mentioned as a reflection of a lack of government coordination, funding commitment, inadequate service provision and vaccine cost. When federal politicians referred to government responsibility, they always apportioned blame to a lack of state or previous Australian federal government commitment. In some articles, the entire context for introducing immunisation was a conflict between state and federal governments over who was responsible for the problem.

GOVERNMENTS BLAMED FOR MEASLES-RELATED DEATHS IN QLD…Dr Lawrence (then Federal Health Minister) said the States were at fault, guilty of a 'decade of neglect' in their immunisation policy (Newsbrief; metropolitan, 25 May, 1994).

Medical spokespersons were the next group most commonly quoted as charging the government with a degree of responsibility:

He described the Government's failure to fund the national immunisation strategy in the May budget as "inexplicable" and said vaccines should be made accessible to all
Australians regardless of financial or geographical restrictions (Article; national, 14 September 1994).

4.4.3.3 Providers

In the articles, providers received little criticism for low immunisation rates. Only 4 per cent of articles referring to them as a significant factor. The criticism generally came from non-specific reportage and medical experts. Only two articles had provider factors as the focus of the report.

SYDNEY - Complacency about the rubella virus by the community and some doctors could have contributed to an alarming increase in reported cases. "People, including doctors, think there is not much measles around at the moment, why bother (with vaccinating)," he said (Article; regional, 13 September 1995).

4.4.3.4 Parents

In contrast, parents received the greatest blame for diseases and low immunisation rates. This blame was commonly advanced using castigatory language issued is statements from politicians or medical spokespersons. The comment on low rates was the most common platform from which the accusations of parental complacency and laziness arose:

'CHILD ABUSE' NOT TO IMMUNISE: Failing to get children vaccinated is akin to child abuse, according to one of Australia's experts on immunisation (Headline and lead sentence; metropolitan, 14 June 1994).

The most common medical spokespersons who were positioned as blaming parents were representatives of the Australian Medical Association (AMA), Australia's powerful doctors’ union.
Queensland faced a public health disaster because parents were failing to fully vaccinate their children, the Australian Medical Association warned yesterday (Article, metropolitan, 25 May, 1995).

However, editorials and statements attributed to politicians carried the strongest castigatory language.

The threat of a national epidemic of measles underlines the selfishness of those who do not immunise their children (Editorial; metropolitan, 21 May 1997).

Dr Lawrence said complacency by parents, who wrongly thought vaccine preventable diseases no longer existed, was killing children (Article, metropolitan, 2 October 1994).

An article that focused primarily on an immediate threat of disease such as a local whooping cough outbreak, articles tended to replace castigatory remarks with urges or pleas for parents to immunise their children.

4.4.3.5 Anti-vaccination lobbyists

Relatively few articles contained statements by commentators blaming the anti-vaccination movement for low vaccination rates.

The risk of children catching whooping cough has risen as a result of a recent 'anti immunisation' movement.

(Article; regional, 7 September 1995)

4.4.3.6 Individual shame and collective pride

Although parents were the most popular agents of blame for low immunisation rates, articles which focused on improved rates never attributed this to the individual efforts of parents in the region but to better service provision, new regulatory structures or the
dedication of local health professionals. For example, where a local government official in Victoria said,

"I think Croydon's high immunisation rate can be attributed to the maternal and child health nurses and their diligence in making sure mothers know about having their child immunised" (Article; metropolitan, 14 September 1994).

4.4.4 The proposed solutions

4.4.4.1 Immunisation - the modern medical miracle

From the frames of disease threat and irresponsible parents, most of the reviewed articles concluded by proposing solutions. Alternatively, where the main focus of an article was on measures to improve immunisation rates, articles typically invoked disease threat and irresponsible parenting in their conclusions. Solutions to the problem of vaccine preventable diseases tended to convey immunisation as the stereotyped 'modern medical miracle' in language which built on the sense of drama initiated in the opening rhetoric about diseases.

IMMUNISATION - THE 20TH CENTURY LIFESAVER: More babies and small children have been saved from death and illness through immunisation than through any other medical strategy this century (Headline and lead; regional 28 October, 1994).

Immunisation is the most important weapon in the fight against infectious diseases (Opinion piece; metropolitan, 1 August 1997).

4.4.4.2 Military metaphor

As in the above example, military metaphors were liberally used. Health professionals, for example, were portrayed as gallant soldiers fighting a war against 'killer' diseases.
WORLD EXPERTS HERE FOR MEASLES BATTLE: An international team will lead a vaccination program to head off an expected measles epidemic from New Zealand (Headline and lead; metropolitan, 4 September 1997).

The following passage evoked an image of an army of nurses marching on schools.

Nurses will visit 7000 primary schools in a campaign to stamp out the diseases and head off an epidemic (Article; metropolitan, 10 July 1998).

4.4.4.3 Stern directives

Directives to parents from doctors to immunise their children were very common. They often provided short headline grabs, particularly in rural articles.

DOCTORS SAY IMMUNISE (Headline; regional, 2 March 1994).

4.4.4.4 Threats and pleas

Almost as a last desperate measure, the threat of reduced performance at school was held up as yet another consequence of failure to immunise.

"If there are a lot of cases then they {children} could be absent from school for a long time and that can only do harm to their academic performance." (Article; regional, 14 September 1995).

The word ‘plea’ appeared in six headlines implying that health authorities were almost desperate for the public to take preventive action.

PLEA ON CHILD JABS (Headline; metropolitan, 31 January 1997).
4.4.4.5 Compulsory vaccination

Throughout the sample period, representatives of the AMA continued to urge for compulsory vaccination, stating that this was the most effective way to ensure children were immunised. One letter, written by a non-medical academic used very strong castigatory language to advocate for compulsory vaccination.

Obligatory vaccination is the only way the rest of us will be protected from the non-immunised ignorant, apathetic, complacent and pigheaded, who are a drain on the rest of society when they themselves are unnecessarily sick or a source of infection of the innocent. Infanticide with a blunt instrument is illegal in this country, but not, it seems, by infection with a largely preventable disease such as whooping cough. (Letter to the editor, national broadsheet, 25 January 1997)

4.4.4.6 The provision of information

Extensive listings of factual information about the diseases and vaccines characterised 15 per cent of rural and 6 per cent of metropolitan articles. Some of the former reproduced the entire vaccine schedule in a text box, usually accompanied by a characteristic symbol such as a syringe or teddy bear. In 1994, the announcement of an immunisation information package was framed as a way of addressing the low rates problem.

Parents and doctors will have access to a new information kit aimed at boosting Australia's poor immunisation record (Article; metropolitan, November 3 1994).

4.4.4.7 Examples of desired action

Photographs of babies and children being vaccinated served to reinforce immunisation as a social norm and symbol of a desired parental action. Sometimes the accompanying text reinforced the message. For example, one photograph of a baby being immunised carried the accompanying lead sentence,
When Montrose mother Petra Moore gave birth to her second child Kirk 13 weeks ago immunisation was not an issue. "I always knew I'd have my children immunised. It is not something I would not think of doing." (Article; regional, 7 March 1995).

4.4.4.8 Community benefit

The notion of immunisation benefiting society as well as the individual was introduced in 18 per cent of the articles, mostly by immunisation experts, government health officials and editors. Articles advanced the community benefit of vaccination in three different ways: first, vaccination conferred population protection and limited the opportunity for diseases to thrive; second, vaccination protected those who were most vulnerable to the deleterious effects of the diseases; and third, vaccination benefited future generations.

Australians of this generation owe it to Australians of the next to play their part
(Editorial; metropolitan, 21 April 1996)

However, such text was given little prominence, usually being mentioned at the end of an article.

4.4.5 Spokesperson representation

Table 4.2 summarises the proportional representation of all spokespersons referred to or quoted in articles. Members of the medical profession received 64.5 per cent of total representation. Other health workers, such as nurses, received very little attention. Lay representation was also at a minimum, with only 4.3 per cent of articles referring to parents and often only via photographs. The proportion of male to female spokesperson representation was 7 to 3, a similar finding to that of Lupton.234
Table 4.2 Spokespersons quoted or referred to in articles by professional grouping*

<table>
<thead>
<tr>
<th>Medical Spokespersons</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health official</td>
<td>47</td>
<td>16.7</td>
</tr>
<tr>
<td>Politician</td>
<td>33</td>
<td>11.6</td>
</tr>
<tr>
<td>Expert doctor</td>
<td>31</td>
<td>11.0</td>
</tr>
<tr>
<td>AMA representative</td>
<td>21</td>
<td>7.4</td>
</tr>
<tr>
<td>Paediatrician</td>
<td>20</td>
<td>7.1</td>
</tr>
<tr>
<td>Local doctor</td>
<td>11</td>
<td>3.9</td>
</tr>
<tr>
<td>Public health worker</td>
<td>7</td>
<td>2.5</td>
</tr>
<tr>
<td>Division of General Practice representative</td>
<td>6</td>
<td>2.1</td>
</tr>
<tr>
<td>Celebrity doctor</td>
<td>5</td>
<td>1.8</td>
</tr>
<tr>
<td>Anti-immunisation proponent</td>
<td>1</td>
<td>0.4</td>
</tr>
<tr>
<td><strong>Subtotal</strong></td>
<td><strong>182</strong></td>
<td><strong>64.5</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Non-medical Spokespersons</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Politician</td>
<td>20</td>
<td>7.1</td>
</tr>
<tr>
<td>Public health worker</td>
<td>16</td>
<td>5.7</td>
</tr>
<tr>
<td>Council worker</td>
<td>14</td>
<td>5.0</td>
</tr>
<tr>
<td>Parent</td>
<td>12</td>
<td>4.3</td>
</tr>
<tr>
<td>Other health worker</td>
<td>11</td>
<td>3.9</td>
</tr>
<tr>
<td>Researcher</td>
<td>10</td>
<td>3.5</td>
</tr>
<tr>
<td>Anti-immunisation proponent</td>
<td>8</td>
<td>2.8</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>2.1</td>
</tr>
<tr>
<td>Celebrity</td>
<td>3</td>
<td>1.1</td>
</tr>
<tr>
<td><strong>Subtotal</strong></td>
<td><strong>100</strong></td>
<td><strong>35.5</strong></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>282</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

*Each article was coded for up to 4 spokespersons

4.5 Discussion

4.5.1 The rhetorical nature of reportage

Previous research demonstrated the rhetorical nature of anti-vaccination press coverage. This study revealed that pro-vaccination coverage was also subject to rhetorical patterns and framing. Framing has the potential to influence people’s response to an issue. The way that the pro-vaccination discourses identified in this study affects audiences is of interest to risk communication researchers and vaccine advocates. Published research into audience reception of mass media news coverage about immunisation is minimal but the literature on risk communication, decision theory and
message framing provides some insights. A workshop on vaccine risk communication in the US considered input from consumers and researchers. It concluded that promotion of vaccination should come from credible sources, avoid paternalism, be personally relevant, account for how information is framed, address concerns about vaccine safety, avoid threats of mandatory vaccination and avoid using the issue as a political device.\textsuperscript{113}

The following discussion reflects on this chapter’s findings in relation to these recommendations and a wider body of literature.

The stereotypical threat of disease conveyed through their portrayal as active agents, is not new. Examples pepper historical discourse.\textsuperscript{235} 236 233 Discussing the development of science's understanding of illness, Rosenberg\textsuperscript{237}:5 states "Once articulated and accepted, disease entities became “actors” in a complex social situation.” Infectious diseases are invisible and thus conceptually abstract. Their portrayal as active agents threatening to attack a vulnerable public allows them to be mobilised by the imagination. Infectious diseases described in such terms are almost always accompanied by military metaphors. Sociologists have attempted to draw meaning from the prominent use of these metaphors in medical discourse. Lupton\textsuperscript{238} drew on Martin’s work,\textsuperscript{239} to state that,

> military metaphors serve to draw boundaries between Self and Other by representing the body as a nation state which is vulnerable to attacks by foreign invaders, invoking and resolving anxieties to do with xenophobia, invasion, control and contamination.

In discussing the implications of military metaphors, Sontag argued that their abuse, seen increasingly since World War 1, is inevitable in capitalist societies where ethical principle alone cannot legitimate action. Sontag contended that capitalist society, “increasingly restricts the scope and credibility of appeals to ethical principle”. Hence, only a war on disease, cancer or drugs can legitimise the no-expense-spared actions seen because war “is defined as an emergency in which no sacrifice is excessive”\textsuperscript{214}

Dramatic disease portrayals can be powerful. Very dramatic media reporting of disease outbreaks has caused unnecessary public anxiety, inappropriate political response and
inequitable allocation of resources. Conversely, writers with a social marketing perspective argue that in some circumstances tapping into the public’s fear of potentially uncontrollable and invading organisms can motivate politicians to allocate needed resources to an issue and can motivate the public to take necessary preventive action. Recent successful immunisation campaigns in Australia have used appeals to fear to address complacency about measles and whooping cough. The need to emphasise disease seriousness has been supported in studies which demonstrated that low measles vaccination rates are connected to parental perception that the virus is innocuous. The use of a fear appeal has been subject of considerable debate in the public health literature. Those considering its use should refer to existing guidelines.

In addition to the overt generation of fear, articles commonly used statistics about disease incidence and mortality to convey disease threat. Quantification rhetoric is a feature of medical reporting. It has been defined as “the manner in which numerical and non-numerical quantity formulations are deployed when proposing and undermining argumentative cases.” Quantified information does not exist as an entity devoid of any potential for subjectivity. People wanting to convey a message make implicit choices in the way they present data. For example, in developed countries, it is rare to see child deaths presented as percentages of total population because child mortality from infectious diseases is proportionately small. In the articles selected for this study, mortality was usually presented in absolute terms to convey that our society accepts no deaths from a disease for which immunisation is available. Despite the potential for quantified risks to be subject to the effects of framing, their use is important. More subjective estimates such as “high” or “low” are subject to greater range of interpretation.

Despite the media’s propensity for personal stories, accounts of children suffering from vaccine preventable diseases were surprisingly infrequent. Their under-use contrasts strongly with their liberal use in negative press coverage about vaccination. Story supply is likely determine such differentials. The previous chapter noted that lobby groups are keen to convey their message to the wider public. One method used is to
provide journalists with stories of their own children whom they claim to be vaccine injured. By contrast, very few parents form lobby groups to advocate for vaccination. Health professionals tend to initiate, and are sought as spokespersons for positive articles. They are trained to be objective and impassive in presenting information.

This chapter argues that in conveying the seriousness of disease it is legitimate to use stories and images of children affected by diseases to symbolise the weight of disease risk against vaccine risk. Such stories are more memorable than quantification of case and mortality incidence alone because they put a personal face to the figures. As the public receive less exposure to the once very visible effects of vaccine preventable disease (such as children in leg braces because of polio), the media will play an increasingly important role in jogging the collective memory. Personal stories may come in two forms: the story of a child has been affected by a vaccine preventable disease or the testimony from health professionals who have cared for those affected. The latter might be adopted by health professionals wanting to avoid being depersonalised by anti-vaccination lobbyists who seek to mobilise an “us versus them” frame.⁷⁶

4.5.2 The rhetoric of responsibility

This analysis found that parents were most likely to be blamed for low immunisation rates and cases of vaccine preventable disease. This occurs for two reasons. First it relates to the functions of the media. The ultimate goal for the commercial media is to sell newspapers and hence raise advertising revenue. To sell newspapers, editors must select and present topics as relevant and interesting to readers. Journalists aim to make their stories attractive to editors. Hence, the selection of news is pressured by limitations on space, time, and demands for memorable soundbites. These constraints limit the ability to convey dry information on bureaucratic mechanisms which influence low vaccination rates. Simple messages which imply a clear problem and focus on a single agent of blame lend themselves to reporting, particularly in a society grounded in individualism. Second, the focus on individual blame should be understood in terms of how spokespersons were privileged in articles. Politicians were often quoted in the
articles. They focused on individual responsibility perhaps to deflect attention from inadequate service delivery, whether real or perceived.

Other media researchers have demonstrated this preference for individual attribution of responsibility. They show that news stories tend to frame problems as a result of individual human error rather than wider social structures. For the vaccination issue, the portrayal of parents as the primary cause of the problem conflicts with research identifying a myriad of factors including poor government coordination, inadequate service provision, provider misconceptions and lack of opportunistic vaccination. While these factors find their confluence with the individual parent who is ultimately responsible for a child's vaccination, excessive focus on parental laziness and complacency is unfair when the problem is multifactorial and complex. In recent years efforts to address suboptimal immunisation rates in Australia have demonstrated the need for comprehensive approaches to addressing both individual and environmental determinants.

4.5.3 Lamenting low rates

The lamenting of Australia's low vaccination rates raises the more general question of whether disseminating this information is conducive to public action. In their research of the influence of cognitive processes on vaccination decisions, Meszaros et al., suggested that publishing downward trends might discouraging “free riding”, that is, parents who rely on others being vaccinated. In contrast however, Hershey et al. (1994) identified the “band-wagoning” factor where the decision to vaccinate was affected by news of whether others were vaccinating their children. They cautiously concluded that "public health programs to increase vaccine usage should stress high vaccination rates." With this in mind, further research to investigate parental response to reports of low and high vaccination rates would be instructive.

In terms of promoting immunisation, the articles showed that medical spokespersons received privileged voice. In this context the AMA were well represented on the issue.
These findings support those of Lupton and McLean who studied 5157 Australian press items about the medical profession and found that doctors represented 55 per cent of news sources with lay sources representing just 6 per cent.\(^{246}\) In view of the importance of doctors as a source of immunisation information,\(^{74}\) such privileging is advantageous to the promotion of vaccination. However, it would be advisable to have a wider coalition of voices supporting the practice, including parents and older infant health nurses, particularly for those parents sceptical of advice from doctors.

### 4.6 Summary

This chapter identified the major themes of pro-vaccination reportage, the framing of spokespersons and the implications for immunisation advocacy. Not only has anti-vaccination reportage been found as subject to framing.\(^{76}\) Pro-immunisation reportage was also persuasively framed. The reportage conveyed the threat of vaccine preventable diseases using panic language, disease personification, quantification rhetoric, stories of personal tragedies, and portentous tales from the past. Immunisation was promoted as a modern medical miracle, health professionals were portrayed as soldiers in the fight against killer diseases, and calls to immunise were usually conveyed through stern directives. Hence pro-vaccination reportage has the potential to compete powerfully with anti-vaccination reportage, particularly when appealing to peoples fear of infectious diseases.

Despite the potential for the media to be an important source of immunisation information for parents, few have published studies of parent audience responses to media messages.\(^{61,247}\) No apparent studies examine whether parents share the same subtextual interpretations as researchers. The next chapter describes a study of how parents interpret pro- and anti-vaccination media messages.
Chapter 5 Parents on immunisation

5.1 Aim

The previous chapter described the characteristics of pro-vaccination media reportage. Other research has examined the characteristics of anti-vaccination reportage. The study reported in this chapter examined parental responses to negative and positive media messages about vaccination.

5.2 Introduction

Growing evidence confirms that negative news media coverage about vaccination can influence parents’ decisions to vaccinate (see chapter 2). However, it is also clear that immunisation rates are not always inversely proportional to such coverage. This lack of consistency in public responses to negative reportage poses the question, “What type of reportage has an effect on parent decision making and behaviour?” Previous research suggested a link between anti-vaccination messages and the wider themes that they reference subtextually. Typically, rich subtexts allude to a cover-up by rank closing medical professionals, faceless bureaucrats and the profit motivated pharmaceutical industry. Such discourse frames non-vaccination as an informed choice made by parents who are dissatisfied with official assurances, venerate freedom of choice and are suspicious of government intervention. To date, no published work has examined how parents interpret anti-vaccination claims and negotiate competing pro-vaccination messages. Much of the commentary on how parents respond to such messages is speculative.

Using illustrative vignettes identified in chapter four’s media analysis, this study examines parental responses to media messages about immunisation. This research views parent audiences as active problem solvers and mediators of meaning. Audience centred contextual methods to address questions of how messages are mediated ask not, “What do messages do to people?” but “What do people do to messages?” preferably in
natural settings where such messages are normally consumed.\textsuperscript{249} The study focuses on what makes positive and negative vaccination messages compelling. The analysis reflects how media and risk perception theories can improve health professionals’ understanding of parents’ responses. Despite the proliferation of media analysis in public health,\textsuperscript{76, 234, 246, 250-252} and increased interest in discourse analysis, little research has sought to determine whether audiences share the same subtextual interpretations as researchers.\textsuperscript{253, 254}

5.3 Study funding

This study, and that reported in the next chapter, was funded under a project grant from the Australian National Health and Medical Research Council. A team of four researchers, including three Chief Investigators and the candidate, developed the original research proposal for both studies and held regular meetings for the duration of the studies. The candidate conducted all recruitment, group moderation, post-group interviews, analysis, and writing. In consultation with the research team, the candidate obtained necessary ethics approvals, and made modifications to the recruitment and interview processes as the research proceeded.

5.4 Ethical approval

For this study and that reported in the next chapter, ethical approval was sought from the Sydney University Human Ethics Committee which approved both studies. For the study reported in this chapter, it was also necessary to receive ethics approval from the three Area Health Services in which recruitment occurred. Approval was therefore sought and received from Central, Northern and Western Sydney Area Health Services. During the early recruitment phases, permission was also sought and gained for two minor changes to the study protocol. Each year, annual progress reports were supplied to the relevant committees.
5.5 Methods

Mothers of young children were interviewed in focus groups between October and December in 1999. Focus groups rather than individual interviews are the preferred method for exploring subjects where researchers wish to observe how people explain issues to each other. The group approach encourages participation from those participants who initially feel they may have little to say. Focus groups allow research participants to identify with and spark-off each others’ comments. Their conversations might also reflect social conversations that occur in the normal environment. Focus groups are commonly used in studies of audience reception to media messages and in formative research for campaign planning.

This study aimed to recruit at least six groups of six parents (i.e. 36 parents). This number was considered sufficient to elicit a “saturated” amount of information. Further interviewing tends to produce repetitive material superfluous to qualitative analysis. Participants were recruited for focus groups through child health clinics in four demographically varied areas across metropolitan Sydney. The candidate sat in the waiting rooms during Baby Health Clinic hours and approached each mother who presented for a visit. Mothers were asked standardised questions about their attitudes to vaccination (see Appendix 4). Those eligible were invited to attend a focus group. They received standardised verbal information and an Information Sheet (see Appendix 5). Participants agreeing to attend were asked to sign a consent form (see Appendix 6). Participants were told they would receive $20 to offset travel expenses. Those who agreed to attend received a reminder telephone call a day before the planned meeting.

Exclusion criteria included women unable to speak English since this would preclude their involvement in focus group discussions. Since 90 per cent of children are presented for immunisation by their mothers, this recruitment did not include fathers. Rather than focus on women opposed to vaccination, this study sought to interview mothers for whom negative media messages might raise sufficient ambivalence or concern about vaccination to delay or forgo the procedure. Since this group is defined poorly in the
literature, any mother not opposed to vaccination was recruited. No women voiced opposition to vaccination during recruitment so no one was excluded on this basis.

Two of the focus groups were pre-established mothers’ groups. It was found that group dynamics in these natural groups acted as a censor to the expression of varying opinions, therefore, the study avoided recruiting such groups. The decision to avoid natural groups related to the study’s aims — to hear a range of views about immunisation. Although silence and social censorship was of secondary interest and an important group dynamic that was noted across all groups, it was unhelpful to continue recruiting groups who were not forthcoming in their opinions. This finding is reported in detail elsewhere (see Appendix 7) Recruitment henceforth focused on recruiting groups of mothers who had not met each other (constructed groups). However, all data from the natural groups was retained for analysis.

Five of the group discussions were held in the Early Childhood Centres from which women were recruited and one was held in a nearby community centre. During the groups, child care was supplied using accredited child care providers. In four of the groups, at least one member of the research team acted as an observer. Groups met over a period of between one and two hours. Before groups commenced, participants completed a questionnaire to obtain demographic information, children’s age and immunisation status (see Appendix 8).

A list of question prompts was used to initiate open discussion about immunisation (see Appendix 9). All groups were shown two video prompts to elicit reactions (Boxes 5.1 & 5.2). Video 1 constituted typical examples of negative media coverage about vaccination (Box 5.1). It was chosen because it contained all the subtextual themes identified in previous research of anti-vaccination mass media rhetoric. Video 2 contained typically positive coverage (Box 5.2). It was chosen primarily to elicit participant responses to reassurances about vaccination. Two of the six focus groups viewed a third video (Video 3, Box 5.3) because of early indications that mothers placed great importance on the source of information. Video 3, “Vaccination: the hidden truth”, is circulated by the
AVN and shows, among others, five medical doctors presenting their arguments against vaccination. Participants viewed a 5 minute excerpt of this video.

Each group was asked to discuss their reaction to each video prompt. A day or two after each group met, each woman was telephoned by the candidate for further discussion and debriefing. These interviews were not tape recorded but extensive notes were taken.

The research had the potential to unsettle participants because the video prompts contained assertions that vaccines caused serious diseases. Accordingly, three procedures were put in place to minimise potential harm to participants. First, at the conclusion of each group session, participants were given a booklet that addressed concerns about immunisation. Second, the study Information Sheet included the name and telephone number of a medical expert on immunisation who was available to discuss any clinical concerns that arose from the group discussions (see Appendix 5). Third, all participants were called a day or two after each group for an informal discussion and debriefing.

All focus group discussions were taped recorded and transcribed word for word by a specialist tape transcription service given specific instructions about syntax and format. The candidate then checked each transcription to correct inaccuracies and add elements such as laughter or a pause.
Box 5.1 Video 1

Anti-Vaccination Prompt #1

(shown to all groups)


A 7 minute excerpt from this television documentary was shown part-way through each focus group in order to stimulate discussion. The excerpt was chosen because it represented many of the anti-vaccination themes identified in previous research. The excerpt included,

- children believed to be vaccine damaged
  - a boy in leg braces from polio contracted via the vaccine
  - a teenager with cerebral palsy
  - photographs of disabled children taken before and after the event;
- a medical doctor speaking about risks from vaccination;
- accounts from parents of vaccine damaged children;
- parents discussing their opposition to vaccination; and
- comments from the presenter on how Australia is not receiving the best vaccines.
Box 5.2 Video 2

Pro-vaccination Prompt #1
(shown to all groups)


A 5 minute excerpt from a nightly current affairs programme was aired towards the end of each focus group. The excerpt was chosen because of its provision of graphic images of children suffering from vaccine preventable diseases. It included,

- a doctor speaking about the dangers of non-vaccination;
- footage of children in hospital with measles and whooping cough;
- a crying woman, whose child was in intensive care with whooping cough;
- footage of a teenager with subacute sclerosing panencephalitis (SSPE) from measles; and
- a reporter speaking about Australia's low vaccination rates.
Box 5.3 Video 3

Anti-Vaccination Prompt #2
(shown to groups 5 and 6 only)


A 5 minute excerpt from a video circulated via the Australian Vaccination Network was shown to stimulate further discussion. This excerpt was chosen because it contained statements from three Australian medical doctors about:

- the alleged dangers of vaccination;
- accounts of threats against them by others in the medical profession because of their position on vaccines; and
- statements about an alleged cover-up about vaccine risks by others in the medical profession.

5.5.1 Coding and Analysis

The transcripts were coded according to the broad question, “How do parents respond to anti- and pro-vaccination rhetoric?” Transcripts were coded openly and according to existing categories. Open coding attempted to identify emerging phenomena and patterns. Topics (concrete items such as “measles”) and themes (abstract items such as “trust”) were then organised into a coherent hierarchical scheme. Without having seen the existing codes, three investigators read two transcripts and discussed emerging themes. The existing coding structure was altered to account for all interpretations. Transcripts were re-coded according to the new structure. After initial coding, instances which contradicted emerging tendencies were purposively sought. A priori interests and surprising aspects of the findings were noted in a separate document. Once indicative quotes were identified, the surrounding discussions from which they came
were re-read in an attempt to ensure statements were not taken out of context. The group dynamics in which the statements occurred were also considered.

Data were coded with the assistance of the qualitative analysis software NUD*IST 4 which allowed for the coding of text according to any number of pre-identified themes and text retrieval according to that theme. Because of a theoretical interest in risk perception, the analysis also considered *a priori* interests in anticipatory regret, omission bias, and theories of media reception and persuasion.  

5.6 Results

A total of 37 mothers attended 6 focus groups of between 4 and 8 participants. Their mean age was 32 years with the majority (78%) born in Australia and the remainder from the UK, New Zealand and India. Thirty-nine per cent had two or more children while the remainder had recently given birth to their first child. Most participants (61%) had tertiary education. All claimed their children to be fully vaccinated (see Table 5.1).
**Table 5.1 Demographic characteristics of focus group participants**

<table>
<thead>
<tr>
<th>PARTICIPANTS n=36 *</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>range</td>
<td>25 - 40 years</td>
<td></td>
</tr>
<tr>
<td>mean</td>
<td>32 years</td>
<td></td>
</tr>
<tr>
<td><strong>Country of birth</strong></td>
<td>n=36</td>
<td>%</td>
</tr>
<tr>
<td>Australia</td>
<td>28</td>
<td>78</td>
</tr>
<tr>
<td>UK</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>New Zealand</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>India</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>

**Education**

- Secondary: 14 (39%)
- Tertiary: 22 (61%)

<table>
<thead>
<tr>
<th>CHILDREN</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>range</td>
<td>5 weeks - 18 years</td>
<td></td>
</tr>
<tr>
<td>mean</td>
<td>2.5 years</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of children/ participant</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>22</td>
<td>61</td>
</tr>
<tr>
<td>2</td>
<td>8</td>
<td>22</td>
</tr>
<tr>
<td>3 or more</td>
<td>6</td>
<td>17</td>
</tr>
</tbody>
</table>

*One form was not completed*
The themes identified in the analysis formed a hierarchical structure. They are summarised below and expanded upon in the following section:

- Diseases and vaccination
  threat from other people
  the diseases of history
  the value of vaccination
  “it’s something you just do”
  adverse reactions
  new vaccines
  anti-vaccination conceptualisation

- Responses to anti-vaccination video prompts
  the salve of statistics
  informed choice
  media scepticism
  vaccine risk
  regret and omission versus commission

- Core influences in decision making
  trust and distrust
  government
  doctors
  family and friends
  personal experiences
  societal contribution

- Responses to pro-vaccination video prompt
5.6.1 Background beliefs

5.6.1.1 Threat from other people

In the initial exploratory stages of each group, discussion centred on how participants valued vaccination. Predominantly this was contextualised in terms of the diseases vaccination is designed to prevent. Women frequently alluded to notions of vaccine preventable diseases as threatening and frightening. They expressed their fear particularly in terms of new diseases, a sense that there are “more germs nowadays”. Such a concern was revealed in the following discussion between participants of group 1.

And I mean (recording inaudible) concerned about, you know, about my son even crawling on the floor at this stage you know in my own home you know

That's interesting because (pause) I mean you always clean and you're fussy and stuff and everything. But you know I'm cautious about putting them on a change table in a mother's room. Even my daughters are. They say, "Oh, just change her in the stroller Mum." THEY’RE even finicky because you don't know. And I mean it's not like, you know, when the other ones were little. I mean you wouldn't THINK of anything of just being (recording inaudible) falls on the floor, you pick it up, you dust it, you put it in. But these days I won't even think about it. It's like you just don't know.

What's around…

What's around. So you know, I mean all they could get was a bit of a sore tummy or something. But now I mean you don't know what they're gonna pick up and it's really scary.

That's right.

Participants also voiced concern that diseases are being introduced through immigration, and that other people's children threaten contagion.
Increased immigration was seen to pose a disease threat not faced by previous generations. For many, the multiculturalism of Australian society was associated with a greater risk of contagion and a pervading sense that germs from foreign and exotic lands posed an unknown threat. Diseases such as tuberculosis, influenza, Ebola and AIDS were often mentioned.

You come across so many different ranges of people, all of whom carry different things, like look at the ‘flus this year, they have been devastating for adults, not only for children and that’s I think purely because we are out so much and there are so many people interacting, that (pause) didn’t they have a study that if Ebola was released in one country within 7 hours, it could be through like 90 per cent of the world, purely through air flight and contact and

like the way AIDS is

in less than a day

(later) … you sort of have to think, we are a multicultural society, there’s a lot of people coming to Australia that haven’t been vaccinated (Group 3).

This awareness of threat from ‘other’ was reflected in a repeated reference to the threat represented by children who were not vaccinated. It arose particularly in regard to risks posed in childcare facilities. Parents who did not vaccinate were considered irresponsible, posing a threat to others.

I think it’s very irresponsible and inconsiderate for a mother to risk infecting other children. It’s fine for her to do that to her own child if she wants to, but that is basically what they are doing. I’d be very angry (Group 2).
5.6.1.2 The diseases of history

Some participants referenced the past to justify their support for vaccination. Many expressed an awareness of the good fortune of the current generation of parents who have not had to grapple with certain diseases.

I was brought up on stories that my mother had quite a serious childhood illness and she was taken to the hospital and kept away from her family for about 6 weeks… It was quite a big thing and quite traumatic for a small child and you just don’t hear about that any more. I think that's reassuring, I wouldn’t like that experience for my child (Group 5).

The diseases of yesteryear were also observed in the media rhetoric identified in the previous chapter. Only one participant expressed a belief that there was value in contracting diseases.

I think just personally I would put them in the same room to try and get them to catch it… not mumps, but measles and chickenpox, get them all over and done with (Group 6).

This statement supports existing research that indicates mothers do not see measles as a potentially serious disease. 91

5.6.1.3 The value of vaccination

In the context of diseases that threaten children, vaccines were strongly valued for the protection they afforded. In this context, fear of needles, inconvenience and minor side effects were often spoken about as trivial matters.

It’s certainly worth it to go through a day of anguish, for long term protection (Group 3).
Vaccination was also seen as a way through which women could manifest nurturing. Protection was strongly linked with notions of being a 'good mother'.

every mother has that absolute mother love for a child, that they will do ANYTHING to protect, like a lioness with a cub, they would kill to protect their child (Group 3).

5.6.1.4 "It's something you just do"

Along with its link with notions of good parenting, vaccination was often discussed as a very unremarkable, normal part of life, reinforced in many different social contexts including the health care environment and the family. Its normality was also highlighted during post group interviews with participants who had been quiet during the group discussion, suggesting that immunisation was not an issue to which they gave much thought and hence they had little to say about it. Many women said “it’s just something you do” and spoke of their intent to vaccinate their own children as if maintaining a family tradition. Those who spoke of vaccination as normal and automatic conveyed surprise that some people were opposed to vaccination.

I don’t know whether I am old fashioned but I have always thought vaccination is just something that you do. It is new to me that people look into it and read about it first (Group 3).

Not all participants shared the view of vaccination as a standard procedure not requiring much consideration. For example, one woman had delayed vaccination because she was concerned about the long term effects:

To some people it is very easy, it’s like an automatic thing – “yes, we are going to do it” whereas others really research it (Group 3).

This woman spoke in the group of her dilemma when deciding about vaccination. Not blindly accepting an intervention for one’s child is a strong theme in anti-vaccination rhetoric and references notions of responsible parenting.
5.6.1.5 Adverse events

Participants shared remedies for minor reactions to vaccinations. New mothers wanted to know what to expect with reactions as this would raise their level of confidence in dealing with them.

I’m more worried about fever and things like that and how I would handle the situation, because I have no idea, I don’t know how you tell a baby has a fever or what you do with them when they have it (Group 5).

One group discussed this issue in relation to a story of a child who convulsed and “suffered brain damage” after a vaccination. The group agreed that more information about what to expect might have prevented this reaction from being so severe. Hence, rather than acting as a deterrent, the story was interpreted as a need for information tools to handle minor side effects to ensure appropriate action when an adverse event threatened.

Mothers generally expressed a low awareness of specific adverse events. Some groups spent time in question and answer exchanges with participants informing each other about possible vaccine reactions. Minor side effects were discussed in trivial terms, while major adverse events were discussed in language laden with fearful imagery. Rather than the official nomenclature of “adverse event” parents used terms such as “bad reactions”, “things that go wrong”, “horrendous things”, “serious effects”, “damage” and “death”. Brain damage (“encephalitis” and “mental disabilities”) was most commonly identified.

I suppose it’s the serious reactions that worry me whilst the temperatures and the sore legs and stuff are difficult for a day or two, it’s the encephalitis and those things that worry you but they’re very rare (Group 1).
Some talked about getting polio from the vaccine, while other specific events mentioned included “collapsing into a state of unconsciousness”, “long term physical disabilities”, “blindness” and “death”. The causal relation to the vaccine was not questioned.

5.6.1.6 New vaccines

New vaccines featured prominently in the discussions. Participants were keen to determine whether their child was receiving the latest and safest vaccine, particularly the acellular pertussis vaccine. In this context it was important to mothers that providers kept abreast of new information. Two spoke angrily of doctors who had attempted to vaccinate their child with the whole cell pertussis vaccine. Many voiced the reassurance in having a safer vaccine available. The following woman’s child had reacted severely to the whole cell pertussis vaccine. She said,

Infanrix is a purer vaccine and the statistics showed that you wouldn’t get that same type of reaction that they were getting from the older vaccine, so I tried it and we were fine and so I’ve gotten all the rest of my children immunised, but if that hadn’t come along then I probably really wouldn’t have (Group 5).

5.6.1.7 Effect on immunity

A prominent concern was the effect on a baby’s immunity when they received multiple antigens in the one injection. Participants often alluded to the vulnerability of infants.

You are creating a little war in their blood system when they are so little (Group 6).

Others saw vaccination at an early age as protective. They predominantly saw it from the frame of disease protection rather than from the frame of introducing artificial agents into the young and ‘vulnerable’ child.

I want my baby to be covered for as many diseases as possible as early as possible. It just seems that reduces their overall risk (Group 5).


5.6.1.8 Anti-vaccination conceptualisation

Despite its existence, participants expressed little awareness of an organised anti-vaccination lobby in Australia. Participants talked about those who do not vaccinate their children as “burn your bra types”, “hysterical”, “new agers”, “alternative lifestylers”, “naturals”, or as people who “go against it for rebellion's sake”. Some associated non-vaccinating parents with higher education but others perceived it as characteristic of less educated people. Some attributed non-vaccination to the influence of alternative therapists; others to the cultural or religious beliefs that were concentrated in more “ethnic” groups. Others associated it with areas where alternative lifestyle practices predominated. One group described areas thought to contain many non-vaccinating parents as follows:

It’s what we used to call Granola Suburbs (Group 5).

Participants in group 1 associated the idea of non-vaccination with deviant ‘other’ at different points in their discussion:

Yeah well I got told, “Don't put your child in childcare at (suburb) 'cause none of the children are immunised out that way.”

You just sort of think, "Well obviously we're in a good area here."

It's nice to know that 'round here, supposedly, they're a bit better immunised.

Participants in the group from a more cosmopolitan area of Sydney had encounters with anti-vaccination attitudes that were more frequent and diverse. They knew colleagues, friends, and in one case, a doctor, who had not fully immunised their child:

I have a girlfriend who has a baby and she had some of the immunisations but not all of them and she's a doctor (Group 5).
This generated some interest in the group. During a post-group interview, one woman said that she felt this account to have a profound effect on the group, stripping away their initial bravado about anti-vaccinators.

5.6.2 Responses to anti-vaccination video prompts

Video 1 was screened first (see Box 5.1). It showed allegedly vaccine damaged children and their parents speaking of their experiences. It questioned widespread acceptance of vaccination, alluded to possible cover-up of information about vaccine risk and included doctors opposed to the practice. In summary, mothers were initially disturbed by the visual impact of seeing disabled children.

Many showed a complete acceptance of the programme’s latent meaning. They spoke of being surprised that vaccination carried such risks and anger at not having been warned about them previously. Some, however, expressed resistance to the messages, particularly in groups where immunising was already established as a socially desirable practice. For those who expressed a stronger response, non-verbal responses such as the appearance of shock, downcast facial expressions and crying occurred. A typical pattern was for mothers to attempt to reassure themselves or each other about vaccination. This included accounts of personal experience with vaccine preventable diseases, attempts to balance vaccine against disease risk, the notion of regret at what might happen if their child was unvaccinated. More generally, the mothers expressed media scepticism and the pressure to constantly be informed consumers. These responses are discussed below in further detail.

In some groups, the video changed the way participants conceptualised non-vaccinators. They moved from a position of dismissing non-vaccinators as an out group or “alternative” stereotype into a position of stronger rapport with them as parents:
If I was related to someone or if I’d had a previous child who had died or become sick because of the vaccination, I would probably be very reluctant to do it again, like to get my child vaccinated, purely from the emotional perspective, rather than the logical perspective (Group 2).

Many spoke of the visual impact of the footage and how this was much more potent than reading or hearing information about risks and benefits.

You can read that it can cause brain damage, and things like that, but to actually see a kid with polio and to see a child who had had brain damage from the needles is disturbing (Group 2).

Initial responses invoked words like “scary”, “disturbing”, and “upset”. While discussing her emotional response to seeing disabled children, one participant began to cry and had to leave the room briefly. When she returned, she reflected that her emotional response was quite different to her rational response. During the post-group interview she further elaborated that she cried because she wondered retrospectively whether an illness her infant son had experienced might have been vaccine related. The accounts from video 1 had raised a question of causal connection in her own mind. Another mother also spoke of being upset:

I’m a real sucker for those sort of things. I was starting to cry when I was looking at - that is an unfortunate thing of public health measures that some individuals, God forbid that it’s my individual, will suffer (Group 5).

For both participants, the post-group interviews successfully provided opportunities for further debriefing.

Participants also expressed anger and surprise with the latter noted more among new mothers. Those expressing anger exclaimed that they had heard little or nothing about adverse events.
(interviewer) Are you saying that it makes you angry?

(respondent) Yeah, why do we not know about these things? Like immunisation, immunisation, immunisation, but very little on the side effects and you know, your child may be that one who gets brain damage. My little girl is 3 and no-one's ever said to me, “If you immunise her she might be the one who gets brain damage” (Group 6).

This woman used the metaphors of mushrooms and sheep to describe her sense of being kept in the dark and her unquestioning following of convention.

We are all mushrooms and all sheep and we just go ‘baah’ – follow the person in front of us. My mother had us immunised, and so I had my children immunised and my brother and his wife had their children immunised (Group 6).

Not all groups exhibited a strong response to the first “anti-vaccination” video (Video 1, Box 5.1). For example, both groups of new mothers had less engagement with its content. They appeared disinterested, became silent and expressed a greater conformity to conventional wisdom. As discussed elsewhere, their response possibly reflected a self-censorship dynamic where the expression of divergence was more ‘costly’ for groups set to meet again. Some spoke later of a need to guard others in the group from divergent or disturbing stories about vaccination generated through discussion or via video 1. Although a similar dynamic was evident in the groups where participants did not already know each other, it was made more explicit. For example, one mother of two children spoke openly of her concern that two new mothers in the same group had seen video 1.

I feel in a way disappointed, that especially (name) and (name) saw that, because I think it could sow a seed of doubt (Group 3).

The existence of the self-censorship dynamic reflected a context established earlier in all groups of vaccine refusal being deviant behaviour and vaccination as a social norm.
5.6.2.1 The salve of statistics

Some mothers attempted to make sense of the incongruence between their rational and emotional reactions by expressing a demand for “statistics” or the “real figures”. These were valued because they would allow respondents to weigh up risks against benefits:

My first reaction is to get emotionally involved with those sorts of things, but when they finish, my reaction is to then ask what are the real figures (Group 5).

Groups were asked about what made some statistics more believable than others. They highlighted the importance of trusting the person who conveyed them. The interplay between evidence and personal experience was also acknowledged as important.

From my knowledge about … the stories that I grew up with about people who had serious childhood diseases, that seems to fit with the statistics that I get given when I ask for them, but that to me makes that reasonably trustworthy (Group 5).

Others indicated that claims made in video 1 did not make sense against their own experience.

I’ve known thousands of people who’ve had this (vaccine), and I’ve never ever heard of anyone having brain damage. But I have heard of others having, you know, whooping cough and whatever else (Group 6).

5.6.2.2 Informed choice

Those who expressed a need to be informed of potential adverse events often qualified their demand for information with an intent to still immunise.

It wouldn’t change my mind either, if the risk is that small, because you would be able to put it in perspective, but you’d still be glad “Well I was told”. Just say something did happen and you weren’t told (Group 6).
Participants noted the sheer number of choices faced nowadays about health care decisions. When asked how they felt about having greater choice and responsibility to make their own decisions, participants described a sense of ambivalence.

(it's) good because when you have so much information to make the choice, but bad in another way that we can sit there and agonise over the decision of, 'What about our children, what is going to happen?', whereas our parents just did it and didn’t think about it. It wasn’t something they had to worry about (Group 3).

5.6.2.3 Media scepticism

In responding to, and perhaps rationalising the anti-vaccination video (Video 1, Box 5.1), many alluded to general media scepticism and the media’s propensity to propagate negative stories.

The-Joe Bloggs-normal-everyday you wouldn't necessarily see that as being slanted. If you're not a natural cynic with the media you could see that and think, "My God", and if you don't have a GP that you trust the way I do then you don't have someone that you can go and talk to…

that's right, yeah….

and if you have something like that you can't defend…

you kind of feel on your back foot (Group 1).

5.6.2.4 Vaccine risk ("It's a numbers game")

Participants talked about weighing vaccine risks against benefits. They used such comparisons to justify their support for vaccination in the light of challenge. The benefits of vaccination were said to outweigh the risks. In more abstract terms, they sometimes compared vaccine risks with other events seen as rare:
You have more chance of being hit by a bus than having really serious side effect to a vaccination (Group 4).

In this society we take risks all the time. We drive cars, we get in planes, we know there's a side effect and a risk to so many things and we're prepared to take it. We make an educated guess that it’s a numbers game and it's gotta happen to someone, but, "Please God it doesn’t happen to me", that sort of thing – and whereas that, with, seeing a child with that disease, could you forgive yourself for not - knowing it definitely is preventable, you could possibly forgive yourself for the side effect to something you are trying to do for the good of your child, initially anyway (Group 5).

I mean there's ALWAYS a chance of something like that. Even if it's walking out on the road and getting hit by a car or getting the amniocentesis when I was pregnant, whatever, there's always a chance that … and if it does, it happens. It was fated to be and you live with the consequences (Group 1).

Some quantified the degree of risk they would be prepared to take with a vaccine:

Yeah, and then she said like one in one billion or something, had brain damage but to me that risk is just so minimal it’s not even a consideration (Group 4).

Well if it was 1 in 100,000 or 1 in 500,000 I’d be fine, but 1 in 1000, that’s still fairly high, because there aren’t that many people in Australia (Group 6).

I guess I would be more reassured if I knew that it was 1 in 100,000, or something like that. If I was told it was 1 in 500 chance, then I’d probably be starting to – like doubt (Group 6).

One woman saw that having a discussion with her doctor about vaccine risks would be an important component in the reassurance process.
It's the notion that with most other medical procedures that you have, you discuss with the medical practitioner what are the risks, what are the benefits etc before. And it's that sort of reassuring thing even if you have been waiting 3 weeks for the operation, you still have that discussion just before the operation, to reconfirm you are aware of all the arguments for and against. That doesn’t happen with vaccinations (Group 5).

5.6.2.5 Regret and omission versus commission

The mothers often talked about “never being able to forgive themselves” and their “guilt” if their child was unvaccinated and got the disease:

the GUILT that I would feel, because I had not immunised my old child to prevent her from passing that disease onto my son who ultimately died of that disease. The guilt that I would feel! (Group 5)

A few talked of the reverse situation where, in taking their child to be immunised, their actions meant that the child was damaged. However, this was less common.

you have to let go at some stage, but as you said, if it was your child the one, then you would think well, “I did it”. It wasn’t the fact that he got hit by a bus, or you know, a strike of lightning, "I took him to the doctor and I stood there while he had the injection” (Group 4).

If something had happened to my kids as a result of vaccination, I would’ve never been able to forgive myself (Group 3).

5.6.3 Core influences in decision making

Attempts were made to elucidate the elements at the core of the mothers making the decision that vaccination was worth the risk. Participants alluded to trust in doctors, personal experiences with diseases, and the reinforcement of vaccination through social networks of family and friends.
…if I had just seen that and not read anything, or had no outside influences, I would probably say, ‘No I don’t want her vaccinated’, but I’ve had the other influences and I’d decided the other way (Group 2).

Participants noted the importance of a person's original frame of reference in selecting and interpreting information about vaccination.

Yeah and it depends on which - if you’re slightly against immunisation, you're more likely to go and hunt out information supporting your doubts. Whereas if you're for vaccination, then you'll go and hunt out information (Group 1).

5.6.3.1 Trust and distrust

In the first four groups, women noted that because the anti-vaccination arguments were not seen to come from doctors, they were more easily dismissed. Therefore groups 5 and 6 were shown video 3 (Box 5.3). This video had a more profound effect on the groups than video 1 (Box 5.1). In group 5 it triggered discussion of the potential for the pharmaceutical industry to mask information about risks to the public. One participant drew a comparison with the decades long cover-up by the tobacco industry:

The tobacco companies knew for years and years before they told us, they told the public, about tobacco and they knew for something like 30 years (Group 5).

However, some participants rejected the idea of cover-up when it came to vaccination arguing that disease treatments would generate more income for the pharmaceutical industry than would prevention.

5.6.3.2 Government

Some mothers expressed scepticism about governments over vaccination information.
And you wonder if like the government is only telling you what they WANT you to know (Group 1).

Others found it hard to see why the government would pay large amounts for immunisation programmes without good reason.

Wouldn’t they be jumping at the chance to save all that money? It seems that they can cut corners everywhere else, I would've thought this would be a perfect one if there was really.. I guess we're trusting that they really have looked - the public health system has looked at the evidence and made a decision, an informed decision and we're trusting them (Group 5).

Indeed, most discussion evinced a strong degree of trust in vaccination policies and the health authorities who make them. One participant, a new mother who was disturbed by video 1, put this question to the group:

Well they're there to protect us and you know like they set a policy don't they, that immunisation is the way to go? Like they're providing all the free immunisation and I mean they're for the good of us aren't they? (Group 1)

I'm naturally trusting and assume that if the government told me this is the way to do it then it's the best way for it to be (Group 1).

5.6.3.3 Doctors

The issue of trust arose repeatedly, particularly in relation to doctors. The family doctor appeared to be an integral point of reference in vaccination decisions and the negotiation of risk messages.

All the medical people are the ones saying you should get your kids vaccinated. They are the ones who have the experience and the education to know what they are talking about. You would think that they had done the research and say, ‘Well it’s better to have
the child vaccinated than not vaccinated’. And I guess there is a lot of trust that they know what they are talking about (Group 2, emphasis added).

I’ve got a fair amount of faith in my doctor and I tend to trust what she says and trust her opinion, so I think that I would believe what she would say before I’d believe anything I saw on TV (Group 4).

Participants valued doctors who took the time to explain procedures and discuss risks. Some conveyed their own very positive experiences with their doctors, and others talked about dissatisfaction when a doctor seemed unwilling to discuss vaccination, feeling that a doctor who did so might dislike the challenge to his or her authority and knowledge:

If there is a lack of discussion, perhaps there's also a lack of knowledge and whatever on their part (Group 4).

Those who were more sceptical of medical knowledge alluded to difficulties with trust.

I think it's actually REALLY hard to know how to balance it…You get that much information, in the end you have to decide where your confidence lies. Who can I really trust? That's hard.

(Later) That’s the thing, you could end up not trusting any of them, you have to trust your instincts in the end (Group 1).

The generally strong trust of doctors and acceptance of medical knowledge meant that hearing anti-vaccination arguments in video 3 (Box 5.3) from doctors, was more disturbing for participants, as illustrated in this discussion:

And it’s the way you introduced the second video {Video 3, Box 5.3} too, that notion that everyone except the first speaker is a doctor. So there's that notion of um..
Not crazy crackpots.

So maybe I should listen to these arguments.

Yeah, that’s right.

Yes, you trust them to be informed.

(Interviewer) Indeed, this is the first time we have introduced this video into a group discussion and the reason I did it was because parents were saying to us in other group discussions, “Well it’s the source of the message that is important”. So, given that, I was just wondering how that would affect people, the source would affect people.

Yes, well if it is a group that are anti-immunisation, well, they would say that wouldn’t they, they would present those particular types of information. But if you feel there's some professional independence, you are more likely to listen to it (Group 5).

5.6.3.4 Family and friends

As part of the mothers’ post hoc attempts to reassure themselves about vaccination, they frequently mentioned the influence of parents, partner, friends and other social networks whose views were important to them. Some spoke of hearing their own mothers reinforce the importance of vaccination. Siblings too, who were health professionals emphasised its importance.

During the post-group interviews, some women reported they had gone home and spoken with their partner, sister, and/or mother about the issue. It appeared that these conversations reinforced the importance of immunisation and reassured participants disturbed by the new information about vaccines encountered via the videos. During these interviews, the mothers who had appeared unsettled during the focus groups appeared much more resolved about the issue. Finally, some spoke of a husband who was uncertain about vaccination but who had not followed through on his concerns through lack of time, defaulting to vaccinating.
5.6.3.5 Personal experience

Many participants alluded to their personal experience with vaccine preventable diseases as important in their ultimate resolve. The few who were also health professionals spoke about caring for children with whooping cough. Personal stories tended to arise in the latter parts of the group discussion when participants were asked to speak of core elements in their support of vaccination. They spoke candidly and often with a degree of reverence. When they commenced, the group became quiet. During their narrative, facial expressions and exclamations of other members reflected the sacredness with which the others held the stories. One woman spoke of her newborn son being exposed to whooping cough in the maternity ward. Another spoke of receiving a false positive result for hepatitis B and had wished she had been vaccinated during the time she thought she had the disease. Another woman spoke of knowing people who had polio and required leg calipers. Another spoke of travelling in Africa. She reflected on the importance of experience and visual reinforcements.

It’s all very well reading about the awful repercussions of, you know, if you don’t immunise your child they might get X, Y and Z. Until you actually go to another country and SEE the consequences, and see the dreadful, dreadful, dreadful, diseases that…

.. you can’t really appreciate it (Group 3).

For those who did not have personal experience with vaccine preventable diseases, the media played a more prominent role in providing images to reinforce what can happen to an unimmunised child. In every group women recalled an advertisement shown during a national pertussis vaccination campaign:

I still remember a couple of years ago they had a campaign and the (pause) basically the ad was this guy holding this little baby in the hospital with whooping cough and the baby was struggling for breath and that actually moved me.
Hmm, wasn’t that devastating?

Oh that was shocking yeah.

Yeah and I can’t imagine anyone... wanting to put their child through that (Group 5).

5.6.3.6 Societal contribution

Every group raised the benefit that vaccination confers to the wider community. Participants frequently described the idea that immunisation was a social responsibility. This was either conveyed as one's own contribution to reducing risk in the broader community or as an expectation that other parents would do the same.

I don’t like the idea of my child having to have the injections and everything, but I agree it is very irresponsible, I have made sure that my child isn’t going to pass those diseases on to someone else’s and I think it is a common courtesy not to do that (Group 2).

In addition, one mother repeatedly spoke of the tension that vaccination raises between individual and public good.

I think there are two different paradigms too, the whole notion of immunisation as a medical treatment is very much for the public good, not necessarily for the individual good I mean (Group 5).

Some participants expressed concern about the effect of negative publicity on other members’ decisions to vaccinate. They openly expressed their concerns during the groups, afterwards during the individual interviews. Some members who had remained silent during group discussion later admitted to feeling concerned about the effect of conveying their own doubts on others.
5.6.4 Responses to pro-vaccination video prompt

At the end of each group session, participants watched an excerpt from a popular current affairs television programme which was primarily supportive of vaccination (Video 2, Box 5.2). The content was accepted with relief by most participants despite many having earlier expressed their scepticism about “tabloid” television. Some expressed relief at having it reinforce their predispositions. It seemed that when their formerly unquestioned beliefs about the overall value of vaccination were challenged, participants were relieved to grasp at something which reassured them. After viewing video 2, participants spoke of being reassured by a doctor who conveyed the importance of vaccination, particularly after exposure to doctors speaking against vaccination in videos 1 and 3. Many seemed eager to hear a voice that legitimised their own initial support of vaccination. Women spoke of their positive reaction to the doctor. They noted his genuine, confident and credible delivery more than recalling the content of his message.

(Interviewer) What’s reassuring about it?

He seemed to be really confident, like he knew. Like he was really confident in what he believed. I guess his confidence in his argument sort of convinced me.

I agree … the male doctor who did quite a lot of the talking, he seemed very confident in his beliefs and the fact that this is a good thing for children to have and that the risks way, way, way, way out factor the..

..because when someone believes in something, you believe in it too..

That's right.

It's easier to convince someone I’m positive about this, I’m confident about it, whereas she was very "um ah", like, "um ah" (Group 6).
To some, the pro-vaccination doctor appeared more measured and less fanatical than anti-vaccination speakers. His experience at the ‘coal face’ with children was also seen as important.

5.7 Limitations

This study elicited responses from women who were likely to be interested in vaccination and possibly more confident with group situations that those who did not accept the invitation to participate in the discussions. Those who declined to participate may have done so for a variety of reasons. Mothers facing considerable concern over vaccination may have been reluctant to expose their views in a group environment. Conversely, those with little interest in the issue may have been more likely to decline participation, thus leaving a concentration of participants whose reactions were stronger and more extreme.

In addition, the study does not represent the responses of fathers. Plans to recruit a separate focus group of fathers were abandoned due to time constraints. In addition, one focus group would have inadequately represented the range of issues pertinent to fathers, to achieve saturation. Attempts were made in each group to elicit discussion about the role of partners. The discussion revealed that while fathers have a role in decision making about vaccination, it appears to be small unless they have a professional interest in it.

Another of the study’s limitations was the use of focus groups. This method of interviewing cannot provide a systematic account of the knowledge and perceptions of each individual since dominant members can drown out quieter ones. However, focus groups unlike individual interviews, allow researchers to observe the interactive and social nature of the topic of interest. As in the non-research environment, parents discuss aspects of child rearing with each other. These discussions contribute to the formation of their own beliefs and perceptions of what is normal and acceptable. Also, focus groups are beneficial when researching topics subject to social consensus.
Participants may feel more able to voice their doubts or concerns when they see others doing so. In an individual interview, the participant might feel pressure to conform to what they believe the researcher wants to hear, particularly when exploring doubts about practices strongly reinforced in the health care environments.

Another potential limitation of the sample was the exclusion of mothers unable to communicate in English. The predominantly Anglo-Celtic sample of this study does not reflect the multicultural composition of Australian society. However, research in Australia suggests that attitudinal barriers to immunisation are less likely among parents of differing ethnicity where low immunisation rates are usually related to access to health care services.

The majority of participants were tertiary educated which limited the extent to which the results can be applied to less educated mothers. However, women who object to vaccination tend to be highly educated, thus it may have been appropriate that this group dominated the sample.

The study found that participants referred to GP providers much more than public providers of vaccination. This is possibly related to the fact that doctors comprise 80 per cent of all providers New South Wales. A similar study in other Australian states such as Victoria where council clinics form just under 50 per cent of that state’s providers might have found that nurses took on greater prominence, particularly in reassuring parents about vaccination.

In terms of generalisability, the study’s findings may be less applicable in countries like the UK, Japan, France and the USA which, as noted previously, faced considerable outbreaks of negative publicity. In such countries, mothers might be more sensitised to controversies therefore discussions may evolve differently. For example, UK parents could exhibit a much greater scepticism of government bodies because of distrust arising from government’s handling of the variant Creutzfeldt-Jakob Disease issue. However, other aspects of this study’s findings have been reproduced in recently published UK
research examining how parents respond to media messages about the measles-mumps-rubella vaccination and its unproved link to autism and bowel disease.\textsuperscript{247}

The qualitative nature of the present study means that its results must be interpreted cautiously. The results describe the range of responses, identify patterns in them, and contextualise their nature rather than quantify variables or suggest general tendencies. Recommendations based on these findings are by no means conclusive and each situation brings unique considerations. However, the study identified some patterns of response that occur when a mother’s confidence in immunisation is tested. It also identified some of the prevailing values and beliefs surrounding vaccination also found in other research. These are discussed below.

5.8 Discussion

This study revealed the processes mothers employed when their existing beliefs about vaccine safety are challenged. The general notion of immunisation protecting children from threatening diseases is the most salient element in maintaining support for the practice. The continual reinforcement and normalising of vaccination through family, friends and health care providers was fundamental in maintaining support for the practice. The group nature of the interviews revealed a strong social reinforcement of the practice between mothers. Vaccination represents a mechanism by which mothers can enact their socialised role as protector. Here, newer vaccines with less propensity to cause side effects or adverse reactions than their “old” counterparts were seen as particularly important. Immunisation as a social practice has also been demonstrated in research showing a strong tendency to vaccinate when it is perceived that the majority of others are doing so (the “bandwagoning” effect).\textsuperscript{31}

The decision process employed by the participants when their support of vaccination was challenged highlighted a complexity of factors similar to those identified in vaccination defaulters.\textsuperscript{115} Their decision to vacinate was not grounded simply in an objective assessment of risks and benefits. For many parents vaccination was not a
decision to be made but was a largely unquestioned practice. Overall, parents who do or
do not vaccinate their children justify their actions in terms that may not appear rational
to experts.

The study revealed that parents valued vaccination because it represented a point at
which they could exercise control over communicable diseases. These diseases were
feared and parents expressed this by recalling the diseases of yesteryear, speaking about
the threat they consider migration poses and, most importantly, recalling stories or
images of children affected by vaccine preventable diseases sometimes via narratives of
their own experience of the diseases.

The groups framed their discussions about vaccination in terms of wider social issues
demonstrating that like any topic, vaccination often represents a vehicle to express
norms and values. In this study parents expressed attitudes to multiculturalism, their
beliefs about what constitutes good parenting, and the deviant behaviour of rejecting
vaccination. Interviewing in the social context of the group revealed how groups
maintain their own boundaries and delineate what characterises ‘other’.

The group discussions also revealed an appreciation of vaccination in the context of
newer exotic diseases like AIDS and Ebola virus. This suggested that for those who are
unfamiliar with the specific diseases covered, vaccination signified a broad-based
protection against germs “out there”, rather than the specific protection that vaccines
offer. Two broader aspects of modern affluent society possibly feed this apprehension.
First, disease fear is perpetuated by commercial interests. During the time of the focus
groups, television advertising for household cleaning products constantly warned parents
of the dangerous and malevolent germs that lurk in every corner ready to infect
vulnerable children. Second, the newsmedia discourses identified in chapter 4 also
generate fear. For example, they portray infectious diseases as malevolent entities.

Hence, although vaccinating a child is a technically rational practice, the decision to
vaccinate involves thinking that is far from rational in this scientific sense. It
appropriates wider social discourses giving it Plough and Krimsky’s cultural component. Consequently, attempts by experts to convince parents of the safety of vaccination using facts alone fail to account for the wider values and discourses that inform the practice.

5.8.1 The relevance of risk perception theory

Chapter 2 outlined research suggesting that the anticipation of regret over a negative health outcome is stronger when risks are posed via action rather than inaction. However, in this study, women spoke more about their potential to regret their child not being vaccinated and contracting a disease. This apparent contradiction might be understood through the following statement from a post-group interview:

But if something happened to my child because they weren't immunised you would feel a different type of guilt than if they were immunised and something bad happened - in the latter case you had done the right thing - what everyone is encouraging you to do.

Her comments confirmed the suggestions made in chapter 2 that social contexts influence the propensity towards omission bias. Here, it appears that the wide social reinforcement of the practice might mediate the potential for omission bias. Further quantitative investigation might confirm this possibility.

This study also showed that the acceptable levels of risk cited by women (1 in 100,000 or less) were similar to those identified in quantitative studies of maternal tolerance of vaccine risks. Expressed risks of 1 in 1,000,000, followed by 1 in 100,000 have been found to be most acceptable. In a US study tolerable risk of death for a hypothetical vaccine was 2.4 per 10,000. This finding challenges a common fear that risk information might “put people off” since some vaccines have adverse event risks that are similar but most are lower in magnitude.
In this study, mothers employed creative analogies to put vaccine risks in perspective. For example, in a post group interview one woman compared vaccine risk to that of using a baby car seat,

Immunisation is like putting your baby in a car seat - you might not be able to get them quickly out in a vehicle fire but the protection is worth that small risk.

Those considering risk communication strategies might consider adopting similar comparisons although they should be used with caution. First, they should provide perspective rather than trivialise people’s concerns. Second, they should compare like with like. As the above example showed, such comparisons are natural: the bearer of risk (baby) and the action (prevention) were the same.

Another study finding relevant to risk communication was the colloquial use of terms to describe adverse events. Importantly, participants never used the term “adverse events”. This has implications for public communication where there has been intense interest among health professionals, some of whom believe that an accurate non-implicating term is the key to minimising media misinformation.

In 2001, an international immunisation expert’s email discussion list debated the merits of various terms to replace the current US term, “Adverse Events Following Immunisation”. Many had problems with the widespread propensity to apply post hoc ergo propter hoc reasoning to the term. To avoid the implication of causality, list members proposed complicated phrases such as, “Adverse Event Possibly Related to Immunization” and “Adverse Event Temporally Associated with Vaccine Administration”.

However, any consideration of a term aimed at reducing public misunderstanding must be grounded in language with which parents are familiar. This study demonstrated that parents never used the term, “adverse event” but spoke more colloquially of “serious effects” “bad reaction”. They conveyed their rejection of *post hoc ergo propter hoc*
reasoning with statements such as, “It could have been some sort of problem there already” (Group 6). Their comments suggest that it may be unrealistic, with one phrase, to try to encompass the notion that temporal association does not imply causality. Further, overly cumbersome technical terms that frequently change may further mystify vaccination or appear euphemistic. Similar problems have been encountered in the ever-evolving disabilities language.

5.8.2 Shedding light on the MMR vaccine controversy

The prominence held by new vaccines might shed light on the positive response of UK parents to Andrew Wakefield’s suggestion that separate antigens for measles, mumps and rubella should replace the trivalent MMR vaccine. In early 2000, two years after Wakefield’s hypothesis of a link between MMR vaccine and autism first circulated in the UK press, Wakefield and Montgomery published further speculations about the alleged causal mechanism. Hypothesising that the combination of three live vaccines led to inflammatory bowel disease and autism, they proposed that trivalent MMR be abandoned for spaced monovalent measles, mumps and rubella vaccines.176 Their suggestion spread rapidly in the UK press. Although the Department of Health cited the dangers of offering spaced and unlicensed vaccines, parents continued to demand separate vaccines, fuelled by the virulent UK press and the charismatic Wakefield’s willingness to publicly repeat his argument. Such was the demand that some private medical centres began offering separate antigens and media articles told of parents travelling to France for them. In the face of plausible and mass-circulated messages of a vaccine causing a dreadful condition, surprisingly few parents abandoned it altogether.269 Rather, they leapt upon the concept of a safer vaccine.

In the present study, parents did not immediately recoil from the idea of vaccination after hearing news of the many ills vaccines were alleged to cause. Instead, their response was a greater demand for the best, ‘latest model’ vaccines. The acellular pertussis vaccine was the focus of this study. Participants’ tendency to embrace vaccines believed to be the best showed that they wanted to protect their child with the safest
possible action, rather than passively via inaction. Similarly, UK parents were offered something portrayed as safer. Despite its lack of scientific merit, the mere thought of changing the vaccine provided enough reassurance for them. In other words, the feeling of doing something about the perceived risk was better than doing nothing. If this was so, the extensive facts and reassurances about the limitations of monovalent vaccines, advanced at considerable expense by the UK Department of Health failed to address the psychology behind the demand for separate antigens.

5.8.3 The relevance of media theories

Theories about media effects are useful for interpreting parents’ responses in this study as well as the wider public arena where the negative controversy and subsequent changes in immunisation rates do not appear to follow a "dose-response" pattern. The hypodermic model of media effects assumes that tabula rasa audiences uncritically absorb messages. In the early 1980s, media scholars largely discredited this model. They pointed to the social and critical contexts in which audiences interpreted media messages. Hall described three possible readings of a media message: the dominant or preferred reading where the reader (consumer of message) readily accepts the intended message in the spirit in which it was communicated; the negotiated reading, where the reader qualifies the message via competing values or considerations; and the oppositional reading, where the reader completely rejects the intended message.

Parents in this study took a predominantly negotiated but sometimes oppositional reading to the anti-vaccination messages presented to them. Their responses should be considered within the wider Australian context of general support for vaccination which might also explain the uncritical way in which they tended to interpret the pro-vaccination prompts. Many women might have wanted their responses to seem consistent with initially-voiced scepticism over the media as a source of information. That the readings of the anti-vaccination videos became more readily accepted or “dominant” when the messages came from doctors perhaps reflected a wider public regard for medicine, and the underlying importance of source.
5.8.4 Stigmatisation of non-vaccinators

This study suggested that when attitudes to vaccination are strongly supportive, non-immunising parents are strongly marginalised. This might explain the siege mentality demonstrated by anti-vaccination groups where parents who feel alienated by their opposition to vaccination, find a ready source of support in groups and become united and more fervent in their cause.

Many women participating in the study were concerned that negative media publicity might lead others to reject vaccination. This revealed that not only health professionals share concern about the potential effect of the media on parents. In advocacy terms, a willing pool of parents could be mobilised to engage in pro-immunisation advocacy, although locating and mobilising such parents would prove challenging.

As noted in other studies, this study showed that a parent’s decision not to vaccinate a child was considered a decision which had implications for others. Insights into how community benefit is understood and might be framed are increasingly important for issues that draw out tension between the individual and the community. The ways the participants conceptualised community benefit suggest that framing vaccination as an opportunity to contribute to the health of one's community might have some salience for groups where this is valued. For other groups, a strong awareness of how the actions of others affect one's own child was evident in the dynamic of social pressure to vaccinate and an intolerance of free-riding (mentioned in chapter 2).

5.9 Summary

This study examined mothers’ reception of media messages about vaccination. It highlighted some aspects of anti-vaccination material that may be of particular concern to parents. In view of the limitations already mentioned, its findings should be applied with caution, having the study’s sample and context in mind.
The next chapter examines the ways that providers address concerns about vaccine safety that might arise from such messages.
Chapter 6 Providers on immunisation

6.1 Aim

In view of the importance of the clinical encounter for parents, this chapter reports on a study that examined how providers discussed vaccine risk and benefit when presented with parental concerns. The study focuses on general practitioners (GPs) who make up 80 per cent of Australia’s immunisation providers. Using role plays of four different ‘concerned parent’ scenarios the study aimed to describe then evaluate the typical reassurances given by general practitioners when faced with parent concerns about vaccination. Other studies have examined patient-doctor risk communication in cancer, HIV, tobacco, and pap smears but no apparent research has investigated the specific risk-benefit messages that parents receive from vaccination providers.

6.2 Introduction

Their encounter with vaccine providers is a fundamental aspect of parents’ decision making and negotiation of conflicting messages about vaccination. Parents repeatedly rate health professionals as the most important source of vaccine information. Their influence is seen in the relationship between incomplete immunisation status and provider-led false contraindications. Providers also influence parental support for vaccination. Taylor et al. found that parents advised by their physician to have the varicella vaccination were more likely to display positive beliefs about it. Further, Sutton and Gill found that three quarters of parents were encouraged by vaccination advice from a health professional.

Research on parents who become committed in their opposition to vaccination shows they experience a process of uncertainty, questioning and information-seeking where they seek out health professionals for advice and assistance. These studies found
that some parents were unsatisfied. They felt that health professionals did not tolerate questioning and gave one-sided information.

That some parents initially support vaccination then turn against it demonstrates the potential for highly influential interactions with health professionals. However, no apparent research has explored directly the ways in which providers reassure parents with concerns about immunisation. Accordingly, this study sought to determine how providers typically respond to parental concerns or doubts about vaccination.

6.3 Study funding and ethical approval

For details on funding for this study, see Chapter 5. Ethical approval to conduct this study was sought and gained from the University of Sydney Human Ethics Committee. This committee also received an update of the protocol once the interview schedule, information sheet and consent form were finalised.

6.4 Methods

The research method chosen was a role play of four “concerned parent” scenarios. The candidate acted the role of the concerned parent and asked the GPs to respond as they would in the normal situation. Role play was chosen for three reasons:

1. The scenarios would act as a proxy for conversations that might occur in the actual clinical situation.
2. The scenarios would avoid hypothetical questioning such as, “What would you say if…?” It was felt that such hypothetical questioning might see some GPs responding in ways they felt they ought to respond, whereas this study’s interest lay in simulating a situation to observe an actual response.
3. Scenarios would help GPs to mentally place themselves in these situations to recall their own experiences.
6.4.1 Standardised patients

The role-plays involved a “standardised” or “simulated” patient (the candidate) who acted as the patient, presenting the same scripted scenario to each GP. Standardised patients were first proposed by Brown and Abramson. They have been used widely in medical education as an assessment tool but much less in research. Many studies have tested the degree to which standardised patients are a valid and reliable measure of clinical performance. Validity refers to the extent to which a measure reflects what it is purported to measure. Reliability is more specific and refers to the extent to which a measure can reproduce the same findings both within (intra-rater reliability) and between raters (inter-rater reliability). Validity has been demonstrated in studies that have interspersed standardised patients with real patients where respondents tend not to recognise them as actors. High reliability has been demonstrated, particularly when more than one consultation occurs. Standardised patients are also held to be more valid than written methods for assessing clinical performance.

The goals of using standardised patients in medical education and research are similar: to reproduce a scenario that replicates the patient-provider encounter. The purpose for their use differs. Educators wish to evaluate and test how well a student performs a task while researchers wish to describe or characterise clinical encounters.

Much of the educational assessment using standardised patients has looked at pre-defined outcomes of clinical competence using a standard set of criteria. In comparison, research of a qualitative nature has obtained information in an exploratory way with no assigned a priori categories. With medicine’s growing interest in communication skills, the method is being used increasingly in assessment and teaching of interpersonal abilities and in research of doctor-patient communication. For example, in their qualitative study Emery et al. used standardised patients to explore GP attitudes to computer aided genetic risk assessment and Bryans et al. used standardised patients with community nurses to examine the knowledge involved in patient assessment.
Kinnersley and Pill studied GP risk communication where standardised patients presented a range of scenarios of a preventive medicine nature. Finally, standardised patients have been used in studies of how doctors deliver bad news to patients.

For researchers, standardised patients allow the presentation of a consistent scenario across a range of study participants. In addition, researchers can recreate encounters that might be difficult to capture in the clinical setting because they are unusual or require many hours of observation for one encounter.

One disadvantage of using standardised patients is that participants might see the scenario as artificial. To avoid artificiality, scenarios need to be well researched and as realistic as possible. For example, Yelland chose nine minute encounters to replicate the typical short exchanges that occur in the clinical setting. The standardised patients should also appear realistic. Under generous research budgets, professional actors have been employed to act as standardised patients. Skilled in inhabiting a character, actors can make the character more believable. They are also less likely to have any specialised medical knowledge which might interfere with how they interact. The limitations of using professional actors include cost, time required for training, and the logistical difficulty of coordinating attendance of actor, researcher and clinician at the one visit. The budgetary constraints of this study prohibited the use of a professional actor.

Selection of study participants is also important to validity. Clinicians who are likely to have the encounter in real life should be selected. For example, researchers wishing to study how doctors communicate the need for an adult with cancer to receive palliative care would select a sample of oncologists.

Since many doctors are only familiar with the role play they encountered in medical training when used to test performance, researchers must endeavour to put participants at ease and emphasise that the role play is not a test of knowledge or ability. In Australia, role play is being used increasingly for developing the communication skills of medical
students and in fellowship training. Therefore, younger participants in this study were more likely to be familiar with the technique.

### 6.4.2 Scenario development

A number of measures were taken in the study to ensure the standardised patients were realistic and representative. The scenarios were based on typical demographic profiles of women, corresponding concerns, and the ways that these might be put to the GP (Box 6.1). Scripts were drawn from women’s comments in the focus groups, arguments raised in the anti-vaccination literature, a GP survey conducted prior to this study (see Appendix 10) and a review of the literature. The scenarios ranged in terms of the character’s location (rural v. metro), existing stance on immunisation (supportive to completely opposed), employment status (paid employment v. at home), and number of children (from expecting first child to having 3 children). However, all characters had similarly high education levels and all had completed tertiary education. This reflected the demographics of those most predisposed to concerns about vaccination noted in chapter 2.

Proposed scenarios were discussed with a team of three researchers involved in the initial study design. In addition, an experienced researcher in the field of patient-doctor communication attended one meeting. The role plays were then piloted with two GPs. From the above discussions, it was agreed that role plays should be done quickly in succession and face to face. They also agreed that the follow up discussion should involve not only questions but feedback and de-briefing. After each role play, participants would be asked about the realism of the scenarios.

Based on the feedback obtained from GPs in each interview, scenario 4 was altered after interview 5 (see Box 6.1). Rather than requesting wound suturing, a mother asked the doctor to sign a conscientious objector form. The Australian Federal Government introduced these forms in 1998 as a requirement for parents or care-givers with objections to vaccination who wish to claim social security benefits. They must be
signed by a vaccination provider who has discussed the risks of non-immunisation. Discussions with participants suggested that this scenario was more typical than the tetanus scenario.
Box 6.1 Role play scenarios

Scenario 1
Heather Williams is a 34 year old registered midwife with 3 children aged 8, 6, and 4 1/2. She works in labour ward at a nearby teaching hospital. She has come to see you because her 4 1/2 year old, Daniel has a chest infection. You ask if he has had his school entry booster.

"I was a bit concerned about whether he should have it now since he’s a bit sick."

Scenario 2
Susan Kelso is 27 years of age, lives in the inner city area, and has one baby, a 7 week old girl. She is currently on maternity leave from her job in publishing.

“I’m wondering whether we might be better to delay the first shot until she is a bit older.

It's always been at the back of my mind what these vaccines do to their immunity when they are so young and fragile.”

Scenario 3
Phillip and his partner, Cherie, live in a small country town on the north coast. Phillip is currently studying acupuncture and Cherie is a teacher. They are expecting their first child in 4 weeks and come to see you for an antenatal appointment.

"We're really not sure what to make of the whole immunisation thing. We've been reading this stuff on the internet. One was a really sad story about a couple whose little boy is mentally retarded ever since getting his whooping cough vaccination - they had the before and after photos and everything.”

*continued on next page*
Scenario 4*

Janice Cook has 2 children, Nathan, who is 4, and Ashlyn, 6 1/2 years. She is at home full-time. Her son, Nathan, has a deep gash in his leg which needs suturing. You ask if he has had his tetanus vaccination.

"I'm afraid I don't believe in immunisation. Ashlyn had a terrible time after her 12 month DTP vaccine and developed allergies. Since then, I've done a lot of reading about this issue and there seems to be lots of evidence, even in the medical journals, that immunisation is not as safe as we're led to believe.

Anyhow, we've decided it's better for them to develop natural immunity. We try to give them lots of fresh fruit and vegetables, we purify all our water. He hardly ever has colds compared with the other children at day care and certainly doesn't have the allergies that Ashlyn suffers.

We would prefer to vaccinate him homoeopathically.”

*Scenario 4 after interview 5

Janice Cook has 2 children, Nathan who is 4 and Ashlyn, 6 1/2 years. She is at home full-time and would like you to sign a Conscientious Objector form.

“I'm afraid I don't believe in immunisation. Ashlyn had a terrible time after her 12 month DTP vaccine and developed allergies. Since then, I've done a lot of reading about this issue and there seems to be lots of evidence, even in the medical journals, that immunisation is not as safe as we're led to believe.

Anyhow, we've decided it's better for them to develop natural immunity. We try to give them lots of fresh fruit and vegetables, we purify all our water. He hardly ever has colds compared with the other children at day care and certainly doesn't have the allergies that Ashlyn suffers.
6.4.3 Recruitment

Participants were selected randomly from a database of respondents to a previous postal survey. This survey was conducted in May 1999 to examine provider encounters with parental concerns (see Appendix 10). It had randomly drawn 1000 GPs from a commercial mail listing of all practices in New South Wales and Queensland. Survey participants were asked whether they would agree to a follow up interview. Of the 516 survey respondents 253 had agreed to be contacted in the future. Since it was preferable to conduct face-to-face interviews and budgetary constraints limited travel, initial recruitment focused on GPs from the Sydney metropolitan area. From a list of 124 GPs, 15 were randomly selected. Each doctor was sent a letter explaining the research and inviting them to participate in a half hour interview (see Appendix 11). The researcher then called each doctor’s surgery to secure participation and arrange a suitable time for an interview. Once the initial list of potential participants was exhausted, a new list was randomly generated from the list of 124 GPs.

The initial goal was to interview 15 GPs. However, obtaining willing participants proved challenging. Much of the difficulty surrounded establishing telephone contact with the GP and getting past “gate-keepers” such as practice managers and receptionists. Telephone messages were left but only a small number of GPs called back. After a second attempt, no further calls were made. Due to these recruitment problems, the methods for recruitment were changed. Rather than attempting to recruit participants “cold” from the general community, GPs known to have a particular interest in vaccine communication were recruited. Consequently, the first seven interviews were recruited using the initial technique while the last five participants came from the latter category. It was felt that the change in strategy would not compromise the quality of the research since the research sought to both describe the range of strategies used by a range of GPs and to pool the best communicative efforts. Similar mixed recruitment strategies have been used elsewhere.256
6.4.4 The interviews

Interviews were conducted between November 2000 and February 2001. Participants who agreed to an interview were visited in their own practice. Two interstate GPs were interviewed over the telephone. Each participant received an information sheet (see Appendix 12). Permission was sought to tape record the interview and participants signed a consent form as per University ethics committee requirements (see Appendix 13). It was emphasised that the study aimed to describe the different ways health professionals communicate with parents about childhood immunisation. A second aim, given verbally, was to “pool the existing wisdom” to inform future recommendations. It was emphasised that the interview was not a test of knowledge and that confidentiality would be maintained.

Four ‘concerned parent’ scenarios were presented to each participant (see Boxes 1, 2 and 3). These included a brief patient profile then a scripted statement to initiate the role play. The researcher acted the role of the concerned mother and the participant was asked to respond as he or she would in the normal clinical environment. A 10-15 minute discussion followed the scenarios.

All interviews were tape recorded and transcribed. A number of strategies were used to ensure transcripts accurately represented what was said. Tapes were transcribed by a specialist transcription service, non-verbal responses such as laughter, a pause or the person’s vocal tone or volume were indicated in brackets, and each transcription was independently checked for inaccuracies and corrected. To maintain confidentiality, the respondent’s name was not mentioned in the interview and kept separately to the transcription.

6.4.5 Analysis

Doctors have their own styles and these interact with each patient’s personal preferences. The challenge in any analysis of patient-doctor interaction lies in
establishing the specific standards by which communication should be judged. While general guidelines exist and theories abound, the complexities of the doctor-patient interaction make this no simple procedure. This analysis focused on describing and evaluating what doctors said in terms of communicative quality. It did not seek to comment on their accuracy with technical aspects of vaccination unless this was remarkable. The study relied on a number of sources as standards for evaluating the effectiveness of the GP’s communicative efforts: what parents in the focus groups said they wanted; the general recommendations on risk communication; the reflections of two mothers who read transcripts of two interviews; and the researcher’s own in-character responses and post hoc interpretations.

Unlike the quantitative tradition where researchers seek to distance themselves and maintain objectivity, qualitative analysis is interpretive by nature. When the researcher is the instrument, she must be aware of how her own sensitivities and experiences shape the analysis. The qualitative literature labels this as reflexivity. Prior to and during the analysis, I noted in a journal my own experiences and preferences as a patient as well as sensitivities as a researcher. This enabled the analysis to proceed with an awareness of how these might interact with the interpretation.

Along with open coding for themes and patterns a priori interests were also considered. These interests arose from the studies reported in the previous three chapters and the risk communication literature. They included how doctors dealt with expressed non-compliance and the reproduction of pro-vaccination media discourses such as language used to convey disease seriousness and the presence of militaristic metaphors. The analysis also considered whether risk estimates were given qualitatively or quantitatively and how the comparisons between vaccine and disease risk were framed.

Coding proceeded according to the dual perspective of describing typical rhetorical styles and evaluating interactions. Open coding was used where transcripts were read and emerging patterns and themes noted freely. Themes were then grouped into a coherent structure using a hierarchical coding system. Passages preceding the coded
text were read to ensure that they were not taken out of context. A passage could be coded for more than one category. Since the same four scenarios were presented to each GP, transcripts were also grouped by scenario in order to map typical discursive patterns. A sample of transcripts considered to represent a cross-section of themes was read by two women who had young children. One was a teacher and the other a GP. Their interpretation was discussed and incorporated into the analysis. Of particular interest was aspects of communication not noticed by the researcher.

6.5 Results

6.5.1 Demographic profiles of respondents

In all, twenty-eight GPs were approached via a letter and a follow up telephone call. Of the twenty-one who returned calls, eight declined with most citing lack of time and one because she was opposed to vaccination. Twelve GPs agreed to participate. One did not present for an telephone interview at the agreed time and did not respond to further contact attempts. Eleven interviews were completed. One of the GPs preferred responding via email. Her responses were included in the analysis because she represented very strong beliefs about dealing with parents opposed to immunisation. In purposive sampling, it is advantageous to include ‘outliers’ - interesting and divergent cases who broaden the scope of the enquiry and provide richer insights than if the study were limited to only standard cases.

Participants came from a range of socio-demographic and geographical areas. Two came from semi-rural areas with large alternative communities, three from predominantly working class areas, one from a central business district, one from an inner-city practice, and two from suburban middle class areas. Six respondents were women.

Immediately after the role play GPs were asked about the realism of the scenarios. Representativeness often depended on the demographics of the practice. For example, the “anti-vaccinationist” scenario (scenario 4, Box 6.1) had never been encountered by
those in typically working class areas but a GP in a semi-rural/alternative community had experienced an almost identical encounter. One GP who worked with ethnic communities found the scenarios “pretty anglo”. The tendency to question vaccination was already identified as primarily a phenomenon of educated white Anglo-Saxons in Australia. In general, most GPs had encounters similar to the first three scenarios. The fourth scenario, a mother completely opposed to immunisation, was rarely encountered.

### 6.5.2 Themes

The analysis revealed three major themes: strategy, content and context. The first major theme, “strategy”, involved an analysis of responses typical of each scenario. The second theme, “content” examined what GPs actually said and included themes that arose across scenarios. The third theme, “context”, covered themes arising in the post role play discussions. The three major themes are summarised below and then examined in further detail. The following sections incorporate the results and an immediate discussion of the implications of each finding. Although a separate discussion section can be given in qualitative reports, it was felt that this might divorce the implications of each finding from its immediate context.

#### 6.5.2.1 Style and strategy

Emerging from the role plays were characteristic communicative styles and persuasive strategies. They included attempts to engage (acknowledgement, probing, response to cues, notions of choice, the offering of compromise, tailoring to personal circumstances, and personalisation) and strategies to refute anti-vaccination statements (discrediting source, presenting hypothetical scenarios, using a social obligation appeal, giving “you’re wrong” statements, engaging in games of scientific ping pong, invoking scientific discourse and addressing spurious causal associations). The themes noted above are highlighted in bold in the discussion below. They generally arose in the context of a specific scenario. Therefore, they are presented below in the context of each scenario.
6.5.2.2 Content

“Content” referred to the specific information that GPs gave to patients. This category was largely descriptive and informed by *a priori* interests including information on the vaccines (their contents and workings, side effects, new vaccines, paracetamol, adverse events, ingredients, and immunity); the diseases (diseases of yesteryear and descriptive language); and a comparison of vaccine and disease risks (risk framing, quantitative and qualitative risk estimates, the use of written materials, and contextualising vaccine risks). These themes, forming part of the general risk discussion, were usually not scenario specific.

6.5.2.3 Context

Respondents were also given the opportunity to discuss aspects of the encounter that were not reflected in the one-off role play. The social context in which discussion about vaccination was embedded included the GP’s ongoing relationship with the patient, the local demographics that influenced the sorts of people they saw, and the broader social context that parents brought to the interaction such as information gained from the mass media and the Internet. Some GPs specified theories and models that helped to guide their interactions with patients.

6.5.3 Style and strategy  (with sub-themes in bold)

6.5.3.1 Scenario 1

In scenario 1, Heather Williams, a registered midwife, expressed concern that she should delay vaccination for her 4½ year old who had a chest infection. Most GPs said they would probably delay. Some GPs primarily based their decision on clinical reasoning, specifically, the perceived interaction between the vaccine and fever. One felt that if something went wrong, he would never be able to eliminate the vaccine as a possible cause. For others, the choice to delay appeared linked to an intuitive resistance to the
idea of vaccinating in such circumstances, in spite of their familiarity with current recommendations that it is acceptable to vaccinate a child with a minor illness and fever below 38.5 °C.17

I prefer not to vaccinate sick children, mainly because there’s no proven evidence that there’s a greater risk of an adverse event if you actually do vaccinate a sick child, but I think as a general principle it’s better not to do it (GP 7).

Like many, this GP interwove his clinical reasoning with practical issues. He justified a delay because the child’s cover from vaccines given during infancy was still in effect. He felt that it was easier to persuade children to accept a needle just before they started school, “when they’re all boned up about going to school — the big school guy sort of thing”.

Many felt that the clinical uncertainty combined with the woman’s concerns was sufficient reason to delay, particularly if the woman was a regular patient and likely to return. Here they tailored their decision to the patient’s circumstances. Although many did not follow official recommendations, their rationale took into account a range of social, emotional and practical factors that influence the decision process of parents and are a reality of everyday life for health professionals.

6.5.3.2 Scenario 2

In scenario 2, Susan was an “anxious” professional woman who presented with her first baby, now 7 weeks. She asked about delaying vaccination because of concerns that the vaccine might affect her baby’s young and vulnerable immune system. In responding, many GPs probed for specific concerns. Probing revealed Susan as an Internet user who was concerned about certain chemicals and preservatives she thought were in the vaccine. Most GPs used a variety of subtle and unsubtle techniques to establish that Susan was wrong. They then either directly addressed the preservatives issue, attacked her source of information, or turned the vulnerability issue on its head by drawing on
discourses of infant vulnerability to disease rather than vaccine. Many compared disease risk with vaccine adverse event risk. Some went on to discuss the possible vaccine side effects to expect and how the reaction might be minimised.

In terms of the baby being young and having problems with the preservatives, there are not really any preservatives that cause any problems for the babies. The main sorts of side effects are just sort of a local reaction, or a little bit of a lump in the leg. Sometimes they sleep more. Sometimes they are a bit more irritable (GP 1).

Telling mothers what to expect has the potential to reduce the sense of mystery feeding concerns that vaccines interact with the immunity. Most also offered paracetamol. Rather than being made to accept advice passively, Susan was given something to do should a reaction occur. This might increase her sense of empowerment, an issue she faced as a career woman whose sense of control over her environment was already altered by a new baby.

Responses to Susan’s concerns could be broadly described as a “yes, but” strategy. The “yes” was where the doctor acknowledged Susan’s concerns. One GP went so far as to concede his own concerns about vaccination:

Of course you feel anxious about that and as a doctor I also feel anxious doing it. But it’s quite important for the safety of your baby…

It seems awful, and I’m a parent myself and I’ve had three young children, I know how awful it is to give these tiny little ones a vaccine, but it is safer for them to have it, so that they have some protection at that young age from these quite serious diseases (GP 2).

As shown above, the conjunction “but” (with emphasis added) introduced the argument that she should not act upon her concern. This came in a range of forms including the implication that she was wrong:
but what we are actually doing is stimulating it by giving the shots, we’re not harming it (GP 5).

it doesn’t actually damage the baby’s immune system, it actually enhances it and makes it better and stronger (GP 6).

One doctor explained the usefulness of probing as a communication strategy. For her, the strategy was not just good communication but also persuasive.

You need to create a rapport with a person before you can create any change and if all you know about them is that they don’t like vaccination and they are particularly scared about that thing, then you have to validate that, even though you think that is a crock of shit, because that is the only link you’ve got with them so far, and you have to say "Yeah, that must have been really scary when you read that. Isn’t it good that it’s not true". .....It’s only once you have agreed with them, that even for a split second you become their ally before you can start changing them (GP 11).

As noted in chapter 5, discourses surrounding infant immune vulnerability can compete with those of disease vulnerability. GPs used the competition in attempts to reassure Susan.

When they’re young and vulnerable, that’s really the time they need the vaccinations, because some of the illnesses that you’re trying to prevent, have their most damaging effect when they’re very young, specifically things like whooping cough (GP 6).

Doctors did not deny that vaccines alter the immune system, they merely reframed the argument to centre on disease vulnerability rather than vaccine vulnerability. As a strategy, reframing can either appear to ignore the person’s initial question or provide them with an unconsidered perspective. Politicians who use reframing in deflecting criticism constantly deal with this fine balance.
6.5.3.3 Scenario 3

Scenario 3 involved a couple called Cherie and Phillip on a shared care antenatal visit at 36 weeks gestation. Phillip was studying acupuncture and Cherie was a teacher. They were reading about immunisation on the Internet and disturbed by a story of a child with alleged brain damage from a vaccine, accompanied by before and after photos. They wanted to research the issue before making a decision. Mapping of this discussion revealed that doctors addressed three aspects of their concern: the information itself; the source of the information (Internet); and the recipient (mother). The information they challenged was the causal association between the vaccine and neurological damage.

Kids are getting illnesses all the time and it's often very hard to pinpoint that it was the vaccine that it was due to (GP 3).

As shown, the GPs mostly addressed causality in concrete terms. One, however, was creative in her approach, using analogies to address the problem of *post hoc ergo propter hoc* causal thinking.

Most people have their car accidents on the way to work and that is usually within 2 hours of having had breakfast. Does that mean you shouldn’t have breakfast (GP 11)?

However, the GPs mostly attacked the source of information by discrediting the Internet as not “all that accurate”:

anybody can post things on the Internet. So if it’s there it doesn’t necessarily mean that it’s been checked by any sort of level of authority (GP 6).

The frequently uttered message that one should not trust the Internet implied that the woman should trust the doctor. Indeed, many doctors referred to an existing level of trust with their patients. However, where trust is not yet built either because of a patient’s transience or scepticism towards medicine, this strategy may not be helpful.
Pointing women to other more reliable websites might mean that GPs provide an alternative viewpoint while not rejecting their preferred source of information.

Another approach the GPs used was to address the information recipient, the mother. Some GPs did this up front, saying it was good to question and make a considered decision. This included acknowledgement of the emotions raised by such reports and support for the parents as intelligent people, capable of making considered decisions. This established a sense of mutual respect and trust and avoided the adversarial positioning that could polarise Cherie and Philip into taking a stance not necessarily intended. In the context of this situation, the doctor would likely be competing with equally attractive arguments encountered by Phillip in his acupuncture course.

Choice was also a recurring theme in this scenario, with many GPs emphasising it.

But everyone has to make their own decision and I think you’re doing well to be thinking about the issue and trying to find out all the information (GP 9).

One of these statements went on to address Cherie as a teacher, thus tailoring advice to her.

So I’d just say to you as a teacher, just question all the stuff you are reading very hard to make sure it is accurate, if they are quoting any studies that they are quoting a good study, that they aren’t just using hearsay or urban myth to support their arguments (GP 1).

By giving the decision over to her and providing her with some of the tools for decision making Cherie might have felt more empowered than if she was simply told not to believe the information.
6.5.3.4 Scenario 4

Scenario 4 was the most confrontational. This involved Janice, whose four and a half year old son, Nathan, required sutures for a wound. Janice believed her first child, Ashlyn, had developed allergies from vaccination. This experience had set her on a path of investigation leading to a deep opposition to the practice. Therefore, her son had not received any scheduled vaccines but was “homoeopathically vaccinated”. Nathan needed sutures for a wound but had no tetanus coverage. After the fifth GP interview, this scenario was introduced differently so that Janice came to have her Conscientious Objector form signed.

Almost all respondents tried to convince Janice to agree to vaccinate. Of the five doctors presented with the form-signing scenario, only one did not engage in persuasion. Two said they would refuse to sign it. This scenario took the longest to act out, was confronting and uncomfortable to role play, and was often terminated by the interviewer before resolution because of time constraints. Debriefing was hence important after its conclusion. Underlying the difficulties were diametrically opposed belief systems about health and disease prevention. Most doctors began by attempting to convince Janice that her causal thinking had been wrong:

> The fact that it occurred at that time in your child and the child subsequently developed various allergies I think is just a coincidence. It’s just a timing effect, not a cause, and causing that sort of reaction, but it was just something that occurred more or less at the same time (GP 6).

However, Janice could have perceived attributing the allergies to coincidence as dismissive. Ashlyn’s allergies had been a profound catalyst for her swing from conventional medicine. During her “conversion” she had built a new awareness and become a strong activist within the alternative health movement. Janice’s position on vaccination was extremely strong and unswerving. She had developed a deep mistrust of doctors and avoided medical encounters where possible. Homoeopathic vaccination was
secondary to her decision and part of an overall approach to disease management. Janice could well be exquisitely sensitive to suggestions that she did not care for her children.

Most doctors did their utmost to point out the error of her ways. Some offered written information and proposed to extend the consultation over a period of time. In the tetanus scenario, some offered immunoglobulin and even penicillin as a compromise. For Janice, her main motivation was to obtain what she wanted and escape. She even lied to do so, stating in some role plays that she “would think about it”. Some conversations with Janice descended into games of scientific ping pong where she would present her opinion, the doctor would reply, and the conversation would get lost in technical detail. Notably, inconsistency arose between the rhetoric of choice in scenarios 3 and 4. In scenario 3, the GPs acknowledged that it was Phillip and Cherie’s choice whether to vaccinate their child but Janice’s choice was often presented as one where she was denying her child vaccination.

Finally, doctors appealed to Janice’s sense of social obligation to other children who were at risk from her unvaccinated child. A repeated technique was the use of hypothetical scenarios to persuade Janice of her folly.

How you would feel if your child got something? Say your child got measles and another child caught it from your child and that child died (GP 9)?

Hypothetical questions force the respondent into a rhetorical corner where they either inhabit the doctor’s definition of how events would transpire or risk loss of face by appearing negligent. Rather than making a statement about risk, hypothetical questions oblige the person to answer an emotive question about a possibility that may never arise. They are unlikely to be productive in risk discussions because they either alienate the person or manipulate them into action. A better way to phrase this decision might be in terms of a woman’s own choice which also acknowledges vaccine risks and appears more value neutral. The following example from one doctor does not oblige the person to answer an emotive question.
You have to consider the illnesses you are preventing and how comfortable you feel about facing those without immunisation, versus the actual immunisation and the slight risks that are associated with that. That is the balancing act you need to decide in your child (GP 10).

GPs’ attempts to convince Janice to vaccinate reflected their clear discomfort with her position. Although many would later acknowledge little chance in changing her mind, a number gave explanations for their persistence. Many were worried about the child’s safety, particularly in the tetanus scenario.

I’d agree with as in the last mother you probably are not going to get her back, that child is at risk. But you can’t actually sort of you know get a court order easily to make him have a tetanus vaccination. I mean what do you do (GP 4)?

One counted on the chance that Janice would change her mind if there was “an epidemic or a child that they know might suddenly get brain damaged from measles”. Another used a counselling framework to explain his persistence:

If, in a counselling situation, someone makes an invalid statement, and then goes on with something and you don’t challenge it, they read that response as you agree with their position, or concur with it. So I think from the clinical perspective I’ve still gotta say, “Look I don’t agree with it”, just so they understand. But they’ve got the right and you shouldn’t push it (GP 5).

The research environment of feeling a pressure to perform might have artificially generated the persistence many GPs demonstrated in scenario 4. However, non-vaccinating parents often complain of confrontations with doctors who attempt to convince them to vaccinate. In response, the Australian Vaccination Network has establish a list of “sympathetic” doctors in Australia as noted in chapter 3. In terms of performance, some might see unvaccinated Nathan’s exit from the surgery as a personal failure. Underpinning this is the strong professional reinforcement of vaccination and
financial incentives received for each encounter. This notion of failure was revealed in a comment from one GP who did not persist with Janice.

But this isn’t about being successful, this is a mother’s choice. I don’t consider it a failure, if the person doesn’t choose to immunise their child (GP 10).

For him, individual choice prevailed over persuasion. This doctor also reflected on the conflict that can result when a patient and doctor have diametrically opposing views.

I actually think most doctors have a lot of trouble with these sort of patients. They feel quite combatant towards them and quite stupidly evangelical in the same way that these people can be evangelical (GP 10).

Despite their persistence in scenario 4, the discussion revealed that some GPs did not want non-vaccination to compromise their relationship with the patient. One GP felt that keeping the “door open” was in the interests of the child’s health should future medical care be needed.

The first case I had was when I did a paediatric term as an intern, which was my first term, was a young girl of about 11 who had paraplegia from a spinal tumour which had been treated for months by a chiropractor. They had only brought her to the doctor when it was clear she couldn’t walk and it wasn’t getting any better and they sat on this tumour. I’m not blaming the chiropractor or anyone, I’m just saying how strong your belief system must be that you don’t get worried about a child with paralysis. But you want to make it so that when they come to you with this child you’re not standing around saying, "You idiots, how dare you do this to your child!" because then, they don’t trust you anyway. That’s why they didn’t come to you in the first place, so if you make them feel guilty you’re just going to compound what’s a very hard time for them (GP 9).
6.5.3.5 Personalisation

Across all scenarios many doctors responded to each woman’s concerns with reference to their own experiences and beliefs. They did this mostly to identify with concerns or to indicate the acceptability of vaccination. “I mean, at the end of the day I immunise my own kids you know,” one said. Here, the doctors may have been trying to break through a perceived artificial veneer via personalised revelations and to induce a communicative environment modelled on everyday interactions where personalisation is the norm.

Doctors’ attitudes to personalisation varied with some cautious about its use and others believing it to be the most effective way to convince parents. One doctor saw an account of her friend’s son’s whooping cough as further “ammunition” and another took personalisation to the extreme with Janice.

I would tell her that I have counselled parents whose child had died in the past (from a non-preventable cause) and found it particularly distressful. If the patient returned and still wanted me to sign the Conscientious Objector form I would advise her to find another GP as I did not want to expose myself to the stress of potentially having to provide grief counselling to her (GP 8).

For some women the knowledge that a doctor had vaccinated his/her own children might help to allay their concerns by lending authenticity to the action. However, one noted that personalisation may backfire if there is an adverse event.

6.5.3.6 Scientific and technical language

Doctors frequently used scientific and technical words to support their arguments. A child was referred to as “a case”, infections were “opportunistic”, and a risk was “theoretical”. The most pervasive terms were “the studies” and “the evidence”, used to lend the full weight of scientific reason to an argument.
There is no evidence that the immune system gets damaged by having the vaccinations. All it does is basically produce the memory cells (GP 1).

I would tell them that many reports of adverse effects after a vaccine were anecdotal, and not borne out by proper studies (GP 8).

Scientific and technical language may hold sway with only some parents and some doctors were aware of this problem. For example, Janice gave cues that she was conversant with the medical literature so speaking her language was appropriate. However, some parents may not be familiar with words like “opportunistic” or they may find “case” a cold and technical way of referring to a sick child. The concept of there “not being evidence” which was frequently used to deny spurious causal connections, did not mirror the terms used by women in the focus groups (most went as far as wanting “the studies”). Those wanting to take issue with the argument of “no evidence” may ask whether the absence of evidence means no one has sought it yet. This may create more, rather than less, uncertainty surrounding vaccine causal associations. Perhaps it would be better for scientifically literate parents to receive written information on studies conducted which negate the claims forming the basis of their concerns. Booklets such as *Immunisation Myths and Realities* are useful for this purpose.261

The disadvantages of using scientific language mainly relate to the recipient’s preferences and literacy level. Although words conveying scientific rigour (“studies”, “populations” and “evidence”) might speak the language of experts, parents with limited scientific literacy may find themselves launched into unfamiliar territory where the language merely alienates them. Ultimately doctors risk exacerbating the divide between the abstract scientific world and the down to earth “organic” experience of child rearing. Mishler referred to this as a struggle between the discourse of the lifeworld and of medicine where we find “different and incompatible ways of organizing and thinking about experience.”288 Indeed some doctors spoke of the challenge of communicating across different paradigms at a time when post structuralism, holism, alternative health and its associated concepts are increasingly popular.
The real problem is that people don’t really have understanding of the scientific method. I can’t take them through 6 years of science at high school. But there is a strong concept out there, that if I believe something is true then that’s true. The perception is the reality. And a lot of them actually receive that through their education, the more sociology school, I suppose, of education: “If I believe it’s true, then it’s true.” And that’s the biggest problem, just generally, that they don’t even understand the concept of scientific methods. You can’t start talking about details. It’s not in there: there’s no paradigm; there’s no models; there’s nothing. And that’s the really sad thing. The other reason people use the natural therapies is because they push wellness, they don’t push illness, and wellness is not the absence of illness, it’s an entirely different subset of values and things. When I as a doctor talk about holistic care, I talk about you know, not forgetting the patient’s got a heart as well as chest or as well as an abdomen. So when they talk about it they talk about spiritual beliefs and self actualisation and a whole range of other things that are really important to how well people feel (GP 5).

6.5.4 Content – what was said

6.5.4.1 The content and workings of vaccines

Anti-vaccination literature pay substantial attention to the make-up of vaccines. Chemical agents such as formaldehyde and mercury and culture media such as monkey kidneys and cell lines from aborted foetuses are mentioned in order to portray vaccines as toxic concoctions – witches’ brews – which maim or kill children. GPs responded in several ways to the notion of vaccines harbouring toxic ingredients. Some questioned their presence. Others stated that the acellular vaccine used less chemicals than others. Others addressed the issue epidemiologically. Some justified the use of additives. For example,

If you’re going to take a medicine that’s based on a real germ, you have to kill the germ somehow so it’s not going to be actually dangerous and then you have to somehow get the killed germ from the lab where you've made it through to the doctor’s place in a
format where it’s still going to be good and effective and not breaking down or decomposing or anything like that (GP 11).

This description did not deny the presence of chemicals but explained their necessity in lay terms. Similarly, another GP compared vaccine additives to the preservatives used in everyday foods thus linking vaccines with a familiar and everyday product.

But they’re usually no worse than any of the other things that are in foodstuffs, there are preservatives in that as well (GP 7).

6.5.4.2 Vaccination side effects

In the focus groups, women, particularly new mothers, wanted to be equipped with knowledge about side effects. Although the scenarios elicited little direct information about side effects, GPs offered it frequently, volunteering information about what to expect. In discussion, doctors emphasised not only the practical but psychological value of warning parents about side effects and giving them actions to take to mitigate their effect.

If you tell them what reactions they can expect to see, very often they’re reassured, because they know they can do something about that. If they’re relatively mild reactions - they have a fever, or something like that, you can say, “Well, OK, you can sponge them down, give them a tepid bath, give them Panadol,” or whatever. They know that they can do something about that and they’re in control (GP 6).

Some GPs felt that warning about side effects was strategically important in terms of preventing antipathy to vaccination.

That is true for everything really, whether it’s vaccination or any other therapeutic regimen, the more people know about it the better they adhere to the therapeutic – in fact – agree to have it done and if they know about the side effects they’re more likely to be happy with it. And if something comes along they’re not surprised by it. And I think that
a lot of the reactions – if someone’s not knowledgeable about possible reactions then as in that last scenario, people can form incorrect conclusions and then react in a very negative way, because they just don’t know what is happening and they’re angry that they weren't warned. And then very often because they’re angry they won’t be tolerant of any arguments, they just won't accept any more, they form a negative opinion of that and that’s it, they just shut it out, they just don’t want to know about it (GP 6).

According to this GP, information about side effects acted as insurance against parents being taken by surprise. Left to make their own conclusions about vaccines possibly begins a journey into mistrust. His impression is supported in the risk perception literature where such a phenomenon is understood as confirmation bias introduced in chapter 3. Once new knowledge is set, it is difficult to alter and new information is filtered according to whether it confirms ones existing understanding. This is an instance where adhering to principles of informed decision making and valid consent might also increase people’s salience towards vaccination.

6.5.4.3 Panaceas

When the role plays raised questions about vaccination, paracetamol and new vaccines were mentioned so frequently and in such varied contexts that they seemed to take on a role of panaceas for all concerns. They were regarded as remedies to address the physical (child’s potential reaction) and the psychological (the mother’s anxieties) as revealed in one GP’s statement to Heather Williams.

And the other thing we can do is you can always use some Panadol or paracetamol as soon as you get him home if you’re worried he’s going to get a fever. That’s not standard practice anymore but if you’re worried you can do that, it’s a safe procedure (GP 9).

One doctor was explicit about not only the antipyretic but psychologically therapeutic effect of Panadol and other measures.
People rightly or wrongly see Panadol as something pretty harmless and safe, and sometimes you can use just a little bit of a lever like that to say, “Look if we prepare for this properly and we do it carefully, this is what happens”. And I also always write down all the batch numbers and everything and report it in their books and go to a bit of trouble, so that it’s all been… I say, “Just in case we have any problems, we know what they’ve had”, and they appreciate that because they know it’s all been recorded. It’s being taken seriously, it’s not just a quick jab (GP 4).

Similarly, the acellular pertussis vaccine took on a panacea role. This vaccine was incorporated into the childhood schedule in 1999, replacing the more reactogenic whole cell vaccine. In the focus groups discussed in the previous chapter, this vaccine formed a focal point for parents who felt that a new vaccine would answer many of their concerns about side effects. This study revealed that the immunisation encounter feeds that impression. In all scenarios, doctors used the “new vaccine” to address concerns about side effects, vaccine ingredients, neurological damage, and, in scenario 4, to attempt to convince Janice to vaccinate. In the following instance, the acellular vaccine became a panacea for all vaccine adverse events.

Well, let me say there certainly are complications occasionally from vaccination. I won’t dispute that. But they are very rare, and in fact the older pertussis vaccine is the one that was causing the problems. That’s the whooping cough vaccine. We now have an acellular pertussis vaccine which is must safer (GP 2).

A doctor’s frequent recourse to a medicinal remedy for psychological concerns should be understood in its broader context of medical training and patient expectation. Doctors are conditioned to help and to medicate, historically offering Valium to the anxious housewife and some still offering antibiotics to the virally infected. Although training now places greater emphasis on treating the whole person, change is gradual. Patients are not passive recipients in this process. Many are reassured when medicated and, among parents, paracetamol is a popular remedy for an unwell or unsettled child. Despite paracetamol no longer being recommended after vaccination, its value must also
be seen in the ability to empower mothers with something to do for their distressed child.

6.5.4.4 Diseases

The frequent mention of vaccine preventable diseases in the role plays was unsurprising. Of greater interest was how their risk was conveyed. This analysis examined how GPs used specific words, adjectives and metaphors to convey disease seriousness. A substantial literature on the effects of risk framing initiated an \textit{a priori} interest in whether disease and vaccine risks were quantified (e.g. “one in a million”) or described in qualitative terms (e.g. “rarely”). How the GPs compared disease and vaccine risks was also noted.

6.5.4.5 Diseases of yesteryear

Many doctors reproduced the kind of promotional discourse appearing in the popular press (noted in chapter 4), such as taking recourse to lessons from history.

Many people have never known how much distress these common childhood diseases caused. However, one only need visit a 19th or early 20th century graveyard and the picture would be much different (GP 8).

Such statements had subtexts of the “spoiled now” generation who “don’t know how good they have it”. The difficulty with the “diseases of history” or “tales from the war” response is the reliance on historical risks to prompt a present action. The logic here is awkward: if the diseases are no longer with us, why vaccinate? Despite this, parents also appropriate such discourse and use it to reinforce the importance of vaccination. Clearly a notion of not wanting to be labelled the spoiled, self-absorbed me-generation and to repeat the epidemics of the past has some resonance. In addition, doctors called upon the current risk from pertussis.
6.5.4.6 Descriptive language

A second rhetorical device identified in the role plays was the use of dramatic language to convey the seriousness of diseases. Words such as “die” and “killing” were common. A doctor trying to convince Janice to vaccinate said,

The problem is that tetanus is a very real disease and it is capable of killing and certainly in the old days people died - without intensive care - people died from tetanus. And even with intensive care, people of any age are susceptible to it if they’re not vaccinated, and it’s a killer disease (GP 2).

GPs also mentioned smallpox and diphtheria in terms of the diseases of yesteryear that “killed or maimed children”. They listed whooping cough and measles as diseases that can kill children today but the latter was only mentioned twice. Compared with pertussis, measles poses a smaller risk of death to the individual who catches it. However, there are more deaths from measles worldwide than from pertussis because of its sheer prevalence. The minimal attention GPs gave to measles mortality highlights the challenge of communicating a risk of death that arises from a disease’s prevalence rather than its seriousness.

Other dramatic terms used in the role plays included “dire consequences”, “damage”, “horrifying”, “nasty” and “devastating impact”. Undoubtedly, such language has the potential to alarm people. However, it is true that children can die from vaccine preventable diseases. Two questions arise: as disease prevalence reduces can doctors promote vaccination by referring to the severity of the diseases only and not mentioning their absolute rate of incidence? Second, when vaccine risk outweighs disease risk such as with polio, should a doctor continue to give the impression that a child faces a risk from that disease or should they promote vaccination only as a societal good? These challenging questions are addressed at the conclusion of this chapter.
6.5.4.7 Disease risk versus vaccine risk

In the role plays, GPs spoke specifically about the risk from vaccine preventable disease. They also specified vaccine side effects. However, most GPs were vague about vaccine adverse events. They only used terms such as “serious reactions”, “adverse effects”, “adverse outcomes”, “bad reactions”, and “severe damage”. A typical verbal risk equation would specify morbidity arising from disease but not from vaccine adverse events.

If a small infant gets whooping cough, they have got quite a good chance of having some sort of respiratory damage, either getting scarring of the lung, or even to the extent that during the acute illness, they can actually die and that’s a much higher incidence than any reactions to any vaccinations (GP 6).

This comparison between vaccine risk and disease risk compared poorly defined risks with well defined risks. This situation may render vaccines even more mysterious and uncertain, thus reducing their tolerability. Bogardus recommended that when physicians discuss risks with patients, they should identify all the pertinent unwanted outcomes (such as death, disability or pain). The lack of specific information about vaccine adverse event risk might reflect a reluctance to talk about risks for fear of alarming people. It may also reflect continuing uncertainty among health care providers surrounding the link between the whole cell pertussis vaccine and neurological damage. Their reluctance to specify vaccine risk might also indicate that GPs, who are expected to keep afloat of knowledge in multiple areas, may simply not know the risks. Indeed, researchers recently found that 80 per cent of UK immunisation providers were not aware of the documented association between the MMR vaccine and idiopathic thrombocytopenia purpura. In view of this, written materials for parents play an important role in supplementing brief discussions.
6.5.4.8 The framing of risks

A substantial literature has explored the effects of message framing on people’s responses to risk.\textsuperscript{292-293} Many studies found that risks framed in positive terms were more acceptable than those framed negatively. For example, if it is said that “90 per cent of children do not develop side effects”, people are more likely to adopt vaccination than if it is said that “10 per cent of children will develop side effects”. The finding varies according to whether the respondents are highly involved and the nature of the behaviour itself (disease prevention versus disease detection).\textsuperscript{88}

In this study, doctors always gave vaccines/disease risk equations in loss terms. For example,

So if he got measles and got say brain damage from that, that is still much more likely than getting the reaction from the vaccine (GP 1).

Framed in positive terms, vaccination might be spoken of in terms of gaining disease prevention with immunisation rather than in terms of the dangers associated with being unprotected.

A second major decision influence is associated with whether risk reductions are framed in relative or absolute terms. If applied to a preventive action, a relative risk reduction can overemphasise the benefit of an action to reduce a risk.\textsuperscript{294} For example, a person might be said to have their risk of brain cancer halved by using drug A. In other words, the relative risk reduction from taking drug A is 50 per cent. However, when the benefit of drug A is considered in terms of the underlying incidence of brain cancer, the change is much less impressive. For example, if the underlying risk of brain cancer is 0.0002 per cent and the risk is reduced by a half to 0.0001 per cent, then the absolute risk reduction from taking drug A is 0.0001 per cent.
In this study, GPs rarely made vaccine/disease risk comparisons in absolute terms to acknowledge that almost all children are vaccinated and hence face (albeit small) vaccine risks, yet most do not contract the infectious disease. Informed decision making guidelines advise that absolute risk reductions be given to patients as these are a more accurate representation of risk. Applied to vaccination, absolute risk reduction, say from pertussis vaccination, would account first for the underlying incidence of pertussis in the community and then the subsequent risk of pneumonia or encephalitis from pertussis disease. Over time or between outbreaks as pertussis disease circulates less in the community, the benefit from vaccination would appear less impressive.

In the specific case of vaccination there are severe limitations with calculating and presenting absolute risk reductions. For a given individual, their risk of contracting an infectious disease changes with outbreaks and the influence of herd immunity. Absolute risks also fail to reflect the influence of time. That is, if people ceased vaccination because of a small absolute risk reduction today, the diseases would return in the future. Hence each person’s rational response to a low absolute risk reduction would collectively increase the underlying risk. In terms of the heuristics mentioned in chapter 2, absolute risk reductions fail to reflect the consequences of “free riding” (relying on the immune status of others to avoid vaccination). Broadly, these individualistic assumptions that form the seldom acknowledged foundation of the informed decision literature imply that people act in isolation as autonomous agents. Applied to vaccination, their limitation is their failure to account for the societal nature of vaccine benefit. One way of overcoming this limitation is to discuss the effect of one’s decision not to vaccinate on the whole community. The previous chapter found that parents understand and appreciate this message.

6.5.4.9 Risk Quantification

The doctors occasionally quantified risk estimates but their estimates varied. For example, one doctor gave the risk of neurological damage from the whole cell pertussis vaccine as theoretically 1 in 310,000 while another gave it as 1 in 10,000,000. One GP
felt that quantifying risks was culturally appropriate for Australians as a nation of gamblers.

People these days are generally aware of odds. We’re supposed to be a nation very highly prone to gambling and so they’re aware, if you say there is this chance and that chance (GP 4).

6.5.4.10 Qualitative risk estimates

The literature cautions against sole use of qualitative risk estimates because they lack precision and can mean different things to different people. In the role plays, the qualitative words GPs used to describe incidence of serious reactions to vaccines included “occasionally”, “rare”, “tiny”, and adverbs such as “fairly”, “very”, “extremely” and “extraordinarily”. To describe the seriousness of infectious disease, they used words like “significant”, “good chance”, and “quite common”. These qualitative risk estimates were popular and almost always given with the explicit purpose of allaying concerns. Some GPs proceeded to quantify the risks and almost all GPs offered written material which would presumably optimise the chance that parents received detailed estimates on the nature and the magnitude of the risks.

6.5.4.11 Written materials

Providing written information is appropriate for active information seekers and can supplement a brief discussion in a face-to-face consultation. Together, written materials and patient-provider discussion facilitates informed decision making without using valuable consultation time that might otherwise be monopolised by a prohibitive explanation of the risks from each disease and its corresponding vaccine. Materials offered by GPs included the parent information booklet, Understanding Childhood Immunisation. Some also photocopied the back cover of The Australian Immunisation Handbook which lists common adverse events and what to do about them. A publication aimed at providers which addresses “Immunisation Myths and Realities” was sometimes offered as GPs had found it helpful. Such publications might make
GPs feel more competent to answer detailed questions, therefore, they are an important commodity for the GP, as well as the parent.

6.5.4.12 Contextualising vaccine risks

In terms of talking about risk, one potentially helpful approach would be to put vaccine risk into a context of other risks taken in everyday life. For example,

I guess there are a lot of things in life where you do need to balance up the risks. When you get in your car, for example, you have a 238 chance (sic) of being involved in a car accident every time you start down your driveway. And yet the convenience of the car is just so great that we do it all the time and don’t even think about it (GP 11).

Similar ideas about risk in everyday life and chance were introduced by the women in the focus groups. The following comment of a participant in group 1 of the focus group study provided the basis for the Heather Williams character in scenario 1:

In this society we take risks all the time, we drive cars, we get in planes, we know there's a side effect and a risk to so many things and we're prepared to take it, we make an educated guess that it’s a numbers game and it's gotta happen to someone, but "please God it doesn’t happen to me” (Group 1).

6.5.5 Context

Post role play discussions highlighted the importance of the social context of patient - GP encounters. Factors influencing these included the local demographics, the GP’s relationship with patients where risk discussions extended over a period of time, the influence of the mass media, and theories that helped guide communicative efforts.
6.5.5.1 Trust and the relationship with the patient

The most important contextual element in discussions about risk was the doctor’s relationship with his or her patient. The previous chapter emphasised that parents saw trust as a fundamental element in a discussion about vaccine risk. Doctors expressed similar sentiments:

People (don’t) come in cold for vaccination. It’s nearly always bubs whom, I’ve confirmed the pregnancy and you have quite a strong relationship by the time you see the baby and they tend to trust you (GP 5).

A North Coast GP recounted the story of a child unvaccinated until 18 months because of the parents’ misconception that he would experience a negative reaction because of his racial background. Through sensitively addressing their concerns this GP built such trust that when the family moved away the couple continued to attend her surgery by virtue of flights from Sydney until their son was fully vaccinated.

For some GPs, maintaining the relationship received priority over convincing a parent to vaccinate. However, one doctor put vaccination before the relationship to the extent that she refused to see a mother again unless her child was vaccinated. Her strong personal feelings were possibly related to a family member who had pertussis.

6.5.5.2 Temporality of the risk discussion

The risk discussion with patients was not confined to one encounter but often occurred over several consultations.

In a mum like this, who is literate, I would probably photocopy the back of the NH&MRC handbook, because it nicely lays out the illnesses we are trying to prevent...
and the side effects. And say, “Look I’d like you to have a bit more of a read about it and maybe talk to me again when you have the evidence” (GP 10).

When asked about the most effective way to reassure parents about immunisation some GPs felt that spending time with patients developed a relationship where trust could be established. This theme arose in a discussion of strategies with GP 5:

But you’ve gotta wing it sometimes. I think you haven’t gotta sell ‘em on the first consult. All you’ve gotta do is open up the bidding.

It’s much better to back off and give them a little bit of time so you get a result, than to push the issue and lose them totally.

Perhaps it is when GPs feel pressured to resolve an issue immediately that discussion can become adversarial. Extending the risk discussion over time also provides parents with the opportunity to reflect on the information given. It gives them time to clarify further questions so they do not feel pressured to make a decision.

6.5.5.3 In the war zone

As noted in chapter 4, news media-generated military metaphors cast health professionals as gallant soldiers in battles waged against infectious diseases. Martin suggested that such metaphors also cast immunity as an internal system ready to wage war against external invaders. During the role plays, GPs used military metaphor in different and more subtle ways. They stated that vaccination provided babies with a defence to help fight infectious disease. However, rather than speaking of battles against infectious diseases, GPs saw themselves battling to convince people to immunise. Here doctors frequently spoke of information “out there” (emphasis added).

There are other people out there who sell information based on other belief systems and values (GP 5).
There is a lot of information **out there** about boosting immune systems with all sorts of things now, like all sorts of so-called naturopathic and other ways (GP 6).

They also warned parents about anti-vaccination propaganda “out there”.

There is what we call a thug organisation **out there**, well and truly spreading that sort of stuff around (GP 7).

There are a lot of people **out there**, some people who have a very strong anti-vaccination agenda. So you do get a bit of distorted information, particularly on the net or particularly from some sources. You can’t always trust the information (GP 5).

Information from the media, the Internet and the anti-vaccination lobby compromised the external battlefield. For GPs, their patients embodied this outside environment bringing in various opinions, arguments, and fashions in thinking. By implication, the doctor’s surgery represented the centre of calm and rationality, the “war room” where those who entered equipped themselves to counter-attack the outside influences. Implicitly embedded in the GP discourse was the message, “Don’t trust what is out there, trust what is in here”.

### 6.5.5.4 Practice characteristics

Some doctors summarised their local demographics in stereotypical terms. They identified the suburban middle class area of the “compliant/educated”, the anglo working class areas of the “apathetic/media gullible”, the ethnically diverse outer urban area of the “traditional and folk medicine beliefs”, and the inner urban areas of the “educated/media-savvy/alternative types.”

### 6.5.5.5 The media

Practice demographics sometimes changed the degree to which media messages influenced the encounter between the GP and patient. Doctors practicing in areas
considered less media savvy reported having to deal with fallout from media reports. A negative media story about a vaccine would prompt parents to attend the surgery with their concerns. One GP would regularly scour the local newspaper medical columns to keep up with “what is out there”. Doctors also supplemented their assertions of the seriousness of the diseases with potent campaign led images, such as an infant with whooping cough shown repeatedly during the 1998 pertussis campaign.

One GP respondent was a local media spokesperson for immunisation. She received support from her local Division of General Practice which itself was highly involved in immunisation. The role play and our interview occurred after two national programmes covered the MMR-autism issue. In this context she made comments about the need for doctors to be forewarned and forearmed about media stories.

But if these people are coming to me, they must be going to every other GP. Every other GP doesn’t know the background of the studies that are done. How are they going to access this information? They graduated 10 to 20 years ago; they aren’t going to find it in any textbook. It’s research that has only come out in the last six months. We probably ought to be setting up some funding body that could make a free central website that pings the message to every GP or every division at least, so you get that information out in a structured format. Half the time you don’t know what you need (GP 11).

Recommendations based on this comment are included in the next chapter.

6.5.5.6 Communicative models

Some doctors, in particular GP 5, specified models and theories to guide their communicative approach. One doctor saw the need for a strong delineation between orthodoxy and alternative medicine from the perspective of scientific validity.
As a DOCTOR you’ve gotta be really clear about where the line is ‘cause people get - if you go and see a doctor who pushes some sort of homoeopathic stuff you can get VERY confused about what has scientific validity (GP 5).

Two GPs used the Stages of Change (Transtheoretical) Model\textsuperscript{295} described below:

With the patient…. you are going to say, “Where are they? Are we going to get somewhere or aren’t we.” Secondly, to make sure that my message coincides with where they are, so I’m not going to give a different message depending on where the patient is coming from. The third one is “Can I take their position and bring them to mine” (GP 5)?

This framework helped the GPs to understand their patients and respond accordingly. When deciding how to respond to Janice in scenario 4, one GP made a mental ‘diagnosis’ of her stage of readiness for change which assisted his choice of ‘treatment’.

In terms of readiness for change alright -- if you want to get behavioural change out of people, you want to try three positions, like, “Don’t talk to me. I don’t want to know about it”, “Give me the information, I’m shopping”, or “Don’t bother me with details just do it”. They’re the three basic levels or readiness for change. So she is number one (GP 5).

Another GP had developed a generic question, “Have you had any doubts about your decision” (GP 10). He found this question useful across a variety of situations where he needed to decide whether patients were firmly entrenched in their resolve. If they were, he considered it a waste of his time to attempt to change them. In the Janice scenario, he was the only GP who seemed to respond to her cues. He attempted to understand but not persuade her.

This GP also found the principles of cognitive behavioural therapy helpful. He explained the therapy as structured problem solving. It included questions about the pros and cons of a decision.
What are the pros, what are the cons of the way that I’m doing things, thinking about other ideas, and that is what you do. You basically expose people to the other side, because they are usually going down this path, and you and I would start to think of the opposite things to challenge ourselves automatically. That is how tertiary educated people work, but those people don’t. So you actually have got to expose them to the other side and then help them create a balance, and you give them time, because they then have to go back to their partner, and talk about that, or their family and stuff like that, and so they might need to delay the needle. Or they might be comfortable by the end of that and say ‘Oh yes! Great! The guy is talking to you. Do it’.

### 6.6 Limitations

This study examined the discourses of eleven GPs who were likely to be good communicators and interested in immunisation. The recruitment strategy and sample size limited the study’s generalisability. However, it provided an indication of the range and complexity of GP responses to immunisation concerns. It can therefore provide scope for future quantitative investigations and a foundation for tentative recommendations.

A second limitation of this study was that it did not examine risk communication from other immunisation providers such as nurses and Aboriginal health workers. These groups would be interesting because, first, specific contexts in which these professionals work (council clinics or remote areas) influence how risks are communicated. Second, their training is also influential. Other studies indicate that nurses see their roles and communicate risks differently than physicians. Since this study was resource and time-limited and such comparisons would have required sufficient numbers in each group, sampling was limited to GPs. Further research with public immunisation providers is recommended, particularly when generalising study results in states such as Victoria where public providers make up half of all providers.
A third potential limitation of this study relates to the use of role play. Some GPs might have felt a degree of artificiality or might have spoken to the actor as a researcher rather than a character. However, participants were given the opportunity to comment on realism and factors not reflected in the once-off role-plays. Instances where the research process may have unduly influenced outcomes have been noted.

6.7 Discussion

This study identified many positive aspects of GP communication about immunisation. Almost all doctors acknowledged the mother’s concerns and sought to understand them further. Many tailored their discussion to the individual circumstance of the mother and validated her existing practices. Many GPs spoke of the mother’s choice in relation to vaccination. Information provided about immunisation compared vaccine and disease risks and included written information. All doctors spoke of the importance of their relationships with their patients and some offered them time to consider their decision further.

Less advisable aspects of the encounters were doctors becoming adversarial; discrediting a woman’s source of information; asking hypothetical, “How would you feel if” questions; over-using scientific language; entering into games of scientific ping pong; or giving bland “You’re wrong” statements. The anti-vaccination scenario (scenario 4) revealed the difficulty doctors face when their paradigms diametrically oppose those of their patient. It also revealed the subtle ways that apparently neutral communication can become persuasive. Janice’s choice was framed as denying her child protection from diseases. Probing sought to find holes in an argument rather than provide understanding.

This study highlighted the way some doctors communicate vaccine risk. Underpinning the issue of patient-doctor communication are changes over the last two decades with regard to consent for treatment. The landmark decision of Rogers v Whitaker instigated new recommendations for the way doctors should inform patients about an intervention or diagnosis. In this case, Mrs Whitaker underwent surgery to improve the appearance
of her right eye, damaged by a penetrating injury 40 years earlier. The operation carried a 1 in 14,000 chance of sympathetic ophthalmia which she suffered and which consequently rendered her almost totally blind in her remaining good eye. She successfully sued Dr Rogers for failing to inform her of this risk and won $808,564.38 in compensation. The judgement stated that doctors would be negligent if they failed to impart material risks, defined as follows:

A risk is material if, in the circumstances of the particular case, a reasonable person in the patient’s position, if warned of the risk would be likely to attach significance to it or if the medical practitioner is or should reasonably be aware that the particular patient, if warned of the risk, would be likely to attach significance to it.298

This judgement meant that it was no longer acceptable for the medical profession to define standards in regard to the risks they should outline to patients. What a reasonable person would want to know now defined the standards.299 300 For valid consent to occur, patients must now be informed about all the risks associated with a treatment. In particular,

Known risks should be disclosed when an adverse outcome is common even though the detriment is slight, or when an adverse outcome is severe even though its occurrence is rare.301

In addition, informing patients of risk should take into account whether the intervention is straightforward and whether the person is well when they receive it.301 Applied to immunisation, this suggests that for valid consent to occur, parents must first receive an exhaustive account of each vaccine, the disease and attendant risks. However, studies have found that practice rarely reflects recommendations.53 Molnar commented that,

It would be an unrealistic expectation for medical practitioners to expound endlessly with the patient on each and every possible risk or complication which might arise. But in fact, Chief Justice King in F v R listed exactly these matters as relevant factors for the
medical practitioner to consider, and this was almost ten years prior to the decision in Rogers v Whitaker.\textsuperscript{299}

Providers have been criticised for their failure to include a vaccination risk/benefit discussion in a consultation.\textsuperscript{53 302} Although such studies acknowledge the perennial limitation of time, few provide recommendations to communicate risk efficiently and appropriately when many parents do not indicate a need for in-depth discussion. For example, how much time should a doctor devote to discussing each vaccine, disease and attendant risks in a 15 minute consultation that must also address problems with breast feeding, questions of infant development, and postnatal contraception? There is a clear divide between recommendations and the capacity for providers to explain them within the constraints of busy clinical settings.

The USA has somewhat addressed this problem with the provision of a Vaccine Information Sheet (VIS) which is mandatory for each medical encounter. However, relying on such standardised methods to communicate vaccine risk has some limitations. First, the VIS has arisen in the litigious US context. To date, the Australian environment is less so. Second, the VIS cannot replace the patient-provider relationship which forms the basis of the vaccine risk discussion. Indeed Davis found that parents desire not only written materials but a verbal discussion about risk.\textsuperscript{53} Finally, the VIS relies on a standard level of literacy which precludes some patients from comprehending the information contained in it. For others, the VIS lacks detail and comprehensiveness.\textsuperscript{113}

A risk communication perspective might address the dilemma of providing parents with information that does not use up valuable consultation time. In the clinical encounter, risk communication is more than a top-down supply of information. It is an exchange between both parties. As noted by the doctors in this study, trust is fundamental to a relationship in which discussion about risks and benefits can occur. Kerridge and Mitchell concurred that consent,
is not so much an action (of “consenting a patient”) but an iterative process of shared and informed decision-making, that is, an ongoing and integral part of the therapeutic relationship.  

This perspective acknowledges that providers and parents have responsibilities. While providers need to give information and elicit concerns and questions, parents need to communicate their information needs. In this way, providers can identify parents with high information needs and pay appropriate attention to a comprehensive risk discussion.

In Australia, a range of health care services share the burden of information provision about vaccination. Parents have access to vaccination pamphlets in maternity units, Early Childhood Centres and doctor's surgeries. In some maternity units, midwives are required to discuss vaccination with women before discharge. With the introduction of a hepatitis B vaccination at birth, it may be necessary to bring a greater level of standardisation to the information provided then.

6.7.1 Information giving or persuasion? An ethical dilemma

This study showed doctors reproducing promotional messages conveyed in the media. It also revealed attempts to persuade parents to vaccinate. As already noted, a key question in evaluating doctor–parent interactions is, “Against what standards should the interaction be compared?” The risk communication framework values a process of informed decision making while an advocacy perspective values the behavioural outcome of high immunisation rates in communities. If, in the medical encounter, immunisation promotion receives priority, does the inherent persuasion sacrifice autonomous informed decision making to maintaining high immunisation rates?

Problems arise from dichotomising the situation in this way. The first problem is the notion that information is either neutral and ‘true’ or persuasive and ‘biased’. As previously noted, ‘truth’, in the form of medical evidence changes. As well,
communicative exchanges are subject to the effects of framing and interpretation. All communication is motivated and thus persuasive to some degree. This study showed doctors playing a self- and government-appointed role to promote immunisation. However, much of the informed decision making literature shuns persuasive communication. For example,

The exchange between physician and patient in the process of informed consent must be free from manipulative influences. Such irrational influences on the part of the physician can lead to orchestrated decisions that are not substantially informed and in most cases are non-autonomous.

Informed decision making guidelines are usually based on decisions about treatments where uncertainty exists, individual preferences are primary, and decisions against the grain of current evidence are unlikely to affect others (such as with cancer treatment or screening). Although Gwyn and Elwyn asked, “How then do we achieve shared decisions in healthcare which neither defy clinical logic, waste resources, or disregard our patients’ ideas, concerns and expectations?” most writing in the area of patient decision making are yet to fully confront this difficult balance.

Health professionals often encounter such ethical dilemmas. For example, parents insist on antibiotics for a child with a viral infection but inappropriate prescription is costly and contributes to overall antibiotic resistance, a situation with significant repercussions for the wider community. In situations like this, informed decision making (where the health professional avoids influencing decisions) appears misplaced. Situations where parents make decisions on behalf of children are also unique because the decision makers do not bear the direct consequences of their choice.

The medical literature reflects the failure of informed decision advocates to confront and resolve situations where autonomous decision making has negative effects on the wider community. A Medline, 1960 to 2001 search using the keywords “compliance” (2222 hits) and “informed consent” (21716 hits) found only one article when these categories were combined. The total volume of hits suggests that rather than indexers not seeing
such terms as cardinal, perhaps proponents of informed decision making avoid tricky situations where adherence might be optimal in societal terms. The mismatch also reveals a more fundamental difference between the individualistic principle of autonomy in informed decision making and the problem of population effects (noted in chapter 1 as the “tragedy of the commons”\textsuperscript{30}).

State regulations have been employed to persuade individuals to adopt preventive behaviour. However, proponents of informed decision making and post modernist writers often refer to them as “paternalistic”.\textsuperscript{306, 307} In situations where non-adherence puts self and others at risk, society needs guidelines for upholding the ethical and legal imperative of valid consent while acknowledging the wider societal effects of an individual’s decision.

The shared decision making framework somewhat addresses this problem by making room for physicians to state their position.\textsuperscript{308} In some countries, the state has alleviated the burden of persuasion through compulsory vaccination while Australia offers various incentives to encourage parents to complete the vaccination schedule. Guidelines for ethically persuasive health communication campaigns recommend that the nature and direction of persuasive communication should rest with community panels.\textsuperscript{242} Indeed, women in the focus groups emphasised that their valuing of vaccination did not preclude their desire to make an informed decision.

6.8 Summary

This chapter described and evaluated the typical reassurances that 11 GPs provided to parents who voiced concerns about vaccination. It also suggested ways that GPs might improve their vaccine risk communication with patients. The study showed that respectful communication often satisfied the criteria for shared decision making while still promoting vaccination. However, clashes between these goals reflect deeper conflicts between individuals and the wider community that are not resolved easily. The next chapter makes recommendations for ways providers might optimise their risk-
benefit communication with parents. It also brings together the findings from the other studies reported in this thesis to provide recommendations.
Chapter 7 Discussion and recommendations

7.1 Aim

This chapter summarises the findings from the studies reported in this thesis. It then discusses some of the changing social contexts that potentially influence public acceptance of vaccination in industrialised countries. A mechanism is proposed for the way vaccine controversies might “catch fire”.

The final section of this chapter makes recommendations for how policy makers, campaign planners, and health professionals might respond to vaccine controversies in the public arena and in the medical encounter. Suggestions for public responses are underpinned by the principles of risk communication and advocacy. They include suggestions for how proponents of vaccination might respond to anti-vaccination lobbying and ensuing parental concerns. Suggestions are also made for how providers might improve their communication with parents who are concerned about vaccination.

7.2 Summary of differing perspectives in vaccination controversies

This thesis describes the interplay between four active participants in vaccination controversies: the anti-vaccination lobby; mass media; parents; and providers. Australia currently enjoys high vaccination rates and wide public support for the practice. However, this support, within wider social contexts, provides the potential for vaccine safety controversies to take effect. Past events demonstrated the potential for dramatic shifts in parent and provider confidence in vaccination. These included the UK pertussis vaccine controversy in the late 1970s and Japan’s cessation of the whole cell pertussis vaccination programme after two children allegedly became brain damaged from the vaccine. More recently, Andrew Wakefield’s hypothesis that the MMR vaccine could lead to inflammatory bowel disease and autism appears to be causing a decline in UK vaccination rates.
7.2.1 Anti-vaccination groups

Chapter 3 explored the way an active and vociferous group opposed to childhood immunisation lobbied the media, local communities and politicians (see Table 3.1 and Appendix 3). While the lobby’s core concerns were that vaccines are dangerous and ineffective, their platforms for lobbying included perceived discrimination and an individual’s sacrosanct rights to information and choice. At least from 1997, the Australian Vaccination Network has made concerted efforts to publicise the alleged dangers of vaccination but between 1997 and 2001 only a small proportion of their messages reached the public arena via the mass media. Of concern, however, was the Network’s potential to readily mobilise grass roots media campaigning when news interest occurred. There also existed vast amounts of information on the Internet questioning the value of all scheduled childhood vaccines.

The Internet is growing in popularity as a source of health information. Parents who wish to use this medium to research vaccination before making a decision are likely to encounter large amounts of information about vaccine safety which is of varying quality. The face-value credibility of some information found in this medium means that parents and health professionals without sufficient training in evaluating the quality of epidemiological evidence could rely on other factors to make decisions.

7.2.2 The Media

Attitudes to immunisation are formed partly through discourses in the news media. Here, opposing parties in vaccination debates adopt different but equally powerful discourses to advance their arguments. These are summarised in table 7.1. Chapter 4 outlined characteristics of pro-immunisation rhetoric. The threat of vaccine preventable diseases was conveyed using panic language, disease personification, quantification rhetoric, stories of personal tragedies, and portentous tales from the past. Immunisation was promoted as a modern medical miracle. Health professionals were portrayed as soldiers
in the fight against killer diseases. Calls to immunise were usually conveyed through stern directives.

These discourses competed with the anti-vaccination appeal to alternative pathways of disease prevention embedded in the back-to-nature idyll. Compelling testimony of allegedly vaccine-injured children gave human interest to news stories. Here, parents were pitted against authorities with stereotypes of the caring nurturer embodied in the mother contrasted with the cold hard face of science embodied in the (usually male) clinician. Immunisation reportage tended to simplify a continuum of positions polarising them into the choice between science and nurturing; intervention and nature. In a loss of complexity, the possibility for compromise or a coexistence of approaches was not presented.
Table 7.1  Framing both sides of the vaccination debate

Adapted from Carey (1994)\textsuperscript{252}

<table>
<thead>
<tr>
<th>Area of argument</th>
<th>Pro-immunisation frame</th>
<th>Anti-immunisation frame (From Leask (1998)\textsuperscript{76})</th>
</tr>
</thead>
<tbody>
<tr>
<td>Who are we?</td>
<td>➢ experts concerned about diseases ➢ grave authorities issuing stiff rebukes</td>
<td>➢ intrepid truth seekers ➢ friends to parents ➢ advocates of informed choice ➢ parents with first hand experience</td>
</tr>
<tr>
<td>Who are they?</td>
<td>➢ mischief makers ➢ well intentioned but misguided ➢ fanatics</td>
<td>➢ doctors unable to admit folly ➢ governments with a totalitarian agenda ➢ faceless, grasping pharmaceutical industry</td>
</tr>
<tr>
<td>Views about diseases</td>
<td>➢ threat to health</td>
<td>➢ prevented by measures such as good diet, fresh air, exercise ➢ not as serious as we are led to believe</td>
</tr>
<tr>
<td>Views about vaccines</td>
<td>➢ modern medical miracles ➢ safe and effective ➢ necessary for all</td>
<td>➢ erode the immune system ➢ cause all manner of idiopathic ills ➢ toxic chemical cocktails</td>
</tr>
<tr>
<td>Explanation for low rates</td>
<td>➢ parental complacency and apathy ➢ lack of service coordination ➢ lack of government commitment</td>
<td>➢ parents are becoming more informed about their children’s health and not just accepting the status quo</td>
</tr>
<tr>
<td>Solution to low rates</td>
<td>➢ parents just need the facts ➢ castigate, plead ➢ compulsory vaccination</td>
<td>Not applicable</td>
</tr>
</tbody>
</table>

When anti-vaccination claims are given mass media coverage, health professionals voice considerable concern over the effects of such claims on public confidence in immunisation.\textsuperscript{14 133 143 146 309}
7.2.3 Parental responses to the media

Parental responses to anti- and pro-vaccination discourses occur within wider social contexts. The focus groups study found that mothers had differing degrees of interest and involvement in vaccination. Some demonstrated little interest in the issue. They considered it a normal part of childhood where other concerns dominated. Others were affected by controversies to varying degrees but their responses were never as passive recipients of information. Most mothers actively wrestled with negative information about vaccines and few accepted it at face value. When challenged, participants' belief in vaccination was reinforced by recourse to normative beliefs because it was consistent with mothers wishing to protect their children from diseases. In addition, certain aspects of the reportage modified its effect. Anti-vaccination rhetoric was most potent when it came from medical sources and/or included stories and images of allegedly vaccine-damaged children. Participants demonstrated complex risk and benefit assessments in making decisions and drew on analogies to explain their position. Rather than citing data on disease incidence or risk benefit equations to reassure themselves, parents recalled images and stories of children affected by vaccine preventable diseases. They also spoke of their relationships with health professionals, the advice of family and friends, and scepticism about the media as a source of information. All of these were important influences on their negotiation of conflicting messages.

In summary, the results suggested that, although some anti-vaccination themes resonate with parents, it could be difficult for public exposure to one negative media story to result in a sustained drop in vaccine coverage. Nevertheless, the nature of the controversy, media representation, the availability and charisma of sources, and the story’s effect on providers are important. The study’s limitations must also be kept in mind. To make definitive conclusions, it would be necessary to test the hypothesis of little effect on a sample representative of the immunising population using a prospective study.
7.2.4 Providers

This study found some typical response patterns when providers responded to parental concerns about vaccine safety (see Chapter 6). Doctors acknowledged the mother’s concerns, tailored their discussion to the individual circumstances of the woman and conveyed the possibility of choice. They attempted to compare the risks of diseases with the risks of vaccines using mainly qualitative estimates of absolute disease and adverse event incidence. Possibly less helpful aspects of the encounters included instances when doctors became adversarial, discredited the mother’s source of information, asked hypothetical, “How would you feel if…” questions, used scientific language excessively, entered into games of scientific ping pong, or gave “you’re wrong” statements. As these responses suggest, doctors found it difficult to communicate with patients whose paradigms were diametrically opposed to their own. Wider influences on the nature of these encounters, included the doctor’s underlying relationship with the patient, messages from the mass media, and theoretical models that helped to guide their communicative efforts. Doctors made their position on vaccination clear through both subtle and direct techniques. They gave opinion, conveyed emotion, and provided accounts of their own experiences.

7.3 Predicting vaccine controversies “catching fire”

Through an understanding of the above perspectives, this thesis proposes a model for ways vaccine controversies might “catch fire” and cause sustained declines in vaccination rates. Influencing the development of this model has been the slow escalation of the UK’s MMR-autism controversy. Throughout the duration of the research for this thesis, there was the opportunity to witness the escalation of this controversy via media articles obtained contemporaneously, an email discussion list of UK vaccination experts, anti-vaccination activity reported via the AVN, and regular commentary in medical journals.
There is often the opportunity for journalists to take the findings of medical studies out of context and amplify them. For those with limited skills in critical appraisal of research methods, some articles appear to raise serious concerns about vaccine safety. However, such studies usually attract minimal media attention. Hence, it became pertinent to ask, “Why did the MMR issue arouse sustained media interest?” The issue appeared to contain certain elements that allowed Wakefield’s theory to circulate until it became embedded in public consciousness and accepted by some UK health professionals. Its escalation informed the development of a model that illustrates the conclusions made in this chapter (see Figure 7.1). However, at the core of the model are the findings from the more general research reported in this thesis on the discourses of the anti-vaccination lobby, mass media, providers and, most importantly, parents. Prior to outlining this model, it is necessary to discuss the wider social shifts that could influence the propensity for vaccine controversies to “catch fire”.

7.3.1 Wider social shifts

7.3.1.1 Vaccination and its worldwide value

To understand the amplification of vaccine controversies it is first important to identify why they do not occur more often. As noted in chapter 2, journal articles appearing to question vaccine safety are published regularly, media reports arise, and vaccine opponents lobby the news media, Internet, and their local communities. However, most controversies fail to attract the public spotlight in a sustained fashion.

Influencing this resistance is the widespread support that society expresses for vaccination: a practice which consistently appears to be valued strongly regardless of country and culture. Warring sides in Afghanistan, Angola, El Salvador, Lebanon and the Philippines have held "days of tranquillity" to allow polio vaccination and other humanitarian efforts to proceed unhindered. Similarly, this thesis demonstrated that positive discourses about vaccination prevail in the media, among parents, and among
health professionals. This finding is supported in population data indicating that more than 97 per cent of parents support vaccination.37

However, some wider social changes bring potential threats to the way public concerns about vaccination might take hold in the future. The wider society accepts vaccination as a normal, routine and unquestioned part of parenting. This normalisation means that parents faced with new information about vaccines may not have developed sufficient defences or “antibodies” when this “cultural truism” is challenged.204 As noted in chapter 5, mothers were ambivalent about knowing their acceptance of vaccination was unthinking and automatic. The desire to appear to make considered and informed choices interacts with the modern tendency to question things that society once accepted as truth as seen in myth debunking. Similarly, recent decades have seen an increased predilection for debunking heroes where people previously seen as great are reconsidered or ‘revealed’ as flawed.

Vaccination appears to be undergoing the same scrutiny. In May 2001 a metropolitan Sunday newspaper magazine listed the 11 myths of Motherhood. One was the “myth” that “Immunisation is necessary”.311 It included AVN president, Meryl Dorey’s account of why she decided against immunising her children. Repeated exposure to such notions may result in an increasing sense that it is sophisticated to question vaccination. Unthinking acceptance may be aligned with images of the ignorant masses, while researching immunisation signifies a more enlightened parent. Similar shifts in childrearing practices were seen in the 1950s when formula feeding was introduced. At that time its steep rise in popularity was attributed to the notion of it being a modern and sophisticated practice. However, formula feeding as a replacement for breast feeding had adverse public health consequences in developing countries where people sought to emulate the west but where formula powder mixed with unsterilised water caused diarrhoeal disease. This similarly had a serious public health impact.

Anti-vaccination rhetoric has eagerly adopted the language surrounding freedom of choice and informed decision making. These concepts appealed to the mothers
interviewed in the focus groups. Although the framing of vaccination as a choice in the private medical encounter is important, its popular conception as such is more worrying. Parents wanting to research vaccination will encounter a wealth of anti-vaccination material on the Internet, via public lectures, tracts and books.\(^{312}\) Hence, a parent’s choice is not just subject to evidence but the concerted efforts of lobby groups and to the whim of fashions in thinking about health.

### 7.3.1.2 Changed concepts of the immune system

The potential appeal of anti-vaccination discourses should also be seen in terms of changed concepts of the immune system. An increasing range of diseases are being attributed to immune malfunction.\(^{95}\) This changed understanding of disease aetiology may, in part, be responsible for the prevailing concern among parents that vaccines have a negative effect on the immunity.\(^{61 \ 74 \ 93}\) Popular discourses surrounding the vulnerability of the child, the immune system, and the external environment interact with each other. They also appear to interact with concerns about vaccination. Anti-vaccinationists portray this interaction in an almost caricatured way with vaccines described as toxic chemical cocktails capable of inflicting serious harm on infants. One letter writer to a newspaper declared, “I refuse to endanger my children’s health and well being by pumping their young bodies full of highly toxic, immune destroying material.”\(^{313}\) The immune system is thus portrayed as the soil in which vaccines sew ‘dangerous’ seeds.

Discourses on a child’s immune-vulnerability find their roots in popular portrayals of a baby as pure, a *tabula rasa* upon which the world leaves its indelible psychological and chemical mark. The creation of this portrait begins in pregnancy where the developing foetus is seen as vulnerable. Women are told to avoid anything from drinking coffee to using oven cleaner because the placenta is an imperfect barrier against chemical agents which may harm the developing foetus. Once the child is born, the immune system becomes the a buffer between the external worlds and the internal body. When interactions between a person’s immunity and the outside environment go wrong,
pathologies can arise. A plethora of diseases are now attributed to immune malfunction. In her anthropology of the immune system, Emily Martin remarked on the, extremely pervasive use of the immune system as a kind of “field” against which many phenomena have been given new interpretations and understandings. Over the course of the 1980s and 1990s, numerous long-identified conditions were redescribed as immune system dysfunctions. Martin listed sunlight, the seasons, smoking, silicone breast implants, electromagnetism, radiation and, a great many factors in a person’s environment that had long been thought to influence health were explicitly reinterpreted, their effects, for good or ill, now understood to be mediated through the immune system.

In this context, it appears biologically plausible to link vaccines to immune-mediated disease because they interact with the immunity in an unseen and mysterious way.

Martin also examined lay perceptions of the immune system. People perceive the system as complex, mysterious and yet somehow competent to deal with its external environment. Similarly, she found that militaristic metaphors in the popular press ask audiences to believe that the immune system was competent to fight external invaders like the (American) nation state was equipped to win wars.

Proponents of vaccination implicitly ask parents to believe that (1) birth miraculously transforms the vulnerable foetus into a robust infant able to handle artificial immune-altering agents; (2) that the immune system is not competent on its own but needs artificial help to fight disease; and (3) although many interactions are thought to be involved in immune malfunction, vaccines are the exception. In other words, parents are asked to momentarily put aside the beliefs they have formed through lay and medical discourse. Such a request might be unacceptable but for the equally powerful messages that support the practice of vaccination. These include discourses of threat from
infectious disease and values associated with the need to actively protect children perpetuated by the mass media, among lay people and health professionals.

Martin uncovered other lay concepts of the immune system beyond the militaristic metaphor. Some people saw the immune system as an ecological system in fine balance with the environment.\textsuperscript{95} This places vaccination as an unnatural and ultimately destructive intervention that thwarts an internal ecosystem. As over fishing in rivers and estuaries disturbs relationships between all living organisms, vaccines mount “artificial” reactions that interfere with the body’s evolved function. Hence, vaccines might be seen as somehow disturbing a natural internal balance. Opponents of vaccination see diseases like whooping cough mounting natural reactions whereas vaccination is believed to be artificial. Attempts to stop this natural mechanism with a vaccine are alleged to produce unintended, unseen, and potentially catastrophic changes. Chaos theory links to this concept with its illustrative proposition that the flutter of wings from a butterfly in Africa influences the occurrence of a tornado in Indonesia.\textsuperscript{314}

Anti-vaccination rhetoric contains direct references to vaccination as unnatural interference in human evolution. For example, in the vaccination debate introduced in Chapter 3, Donohoe, contended that natural selection, in the form of allowing wild diseases to run unabated, was preferable to active, human intervention.

We again are the survivors of at least five thousand years of evolution. Now that may not sound long. But when you’ve had bacteria that can kill, as herd immunity can be seen, that’s a long enough (sic) to select out those people who have been reasonably good at managing their microorganisms; good enough to survive and good enough to procreate.\textsuperscript{185}

Donohoe believed immune naive communities were created when diseases like smallpox were suppressed by vaccination. He saw HIV or other serious infections as the catastrophic results of artificial interference in natural processes:
we have vaccinated and feel that we have eliminated large numbers of disease. We then step back proudly saying that we have won. And then find something like the HIV or even a worse infection move straight in on that immune naivete and take advantage of us in the worst possible way. I would put it to you that if I were given the choice to trust biology or technology, I’d go for biology.\textsuperscript{185}

After this concluding remark in Donohoe’s address, the audience applauded and cheered loudly, such was its appeal.

\section*{7.3.2 Catching fire in the media}

Discourses like that of Donohoe’s are occasionally adopted by journalists eager to frame news so that it links with wider social values and concerns. However, often, it is not what is said, but who says it, that signals whether the message should be amplified. For journalists, as with parents, the perceived quality of an information source is of great importance.\textsuperscript{315} A theory advanced in a prestigious publication or institution is likely to be given much more weight than an obscure biomedical journal unknown among journalists and the wider public.

In the MMR-autism controversy, Wakefield’s initial hypothesis was published in \textit{The Lancet}, a prestigious and established international journal. Regardless of the weakness of the paper in supporting causality, it had enough credibility to attract considerable attention. The response of those seeking to diffuse its effect possibly fanned the flames ignited by the hypothesis. However, such a possibility is difficult to verify.\textsuperscript{102} In addition, in media terms, Andrew Wakefield was “good talent”. He proclaimed himself as a doctor who listened to parents and took their opinions seriously: “Everything I know about autism, I know from listening to parents”.\textsuperscript{316} Wakefield was also a surgeon from a credible institution with an attractive appearance, calm demeanour and superior ability to frame his argument. For example, a month after his original paper appeared in \textit{The Lancet}, that journal published a number of letters concerned about the study’s validity and its effects on public confidence. Wakefield responded,
Sir-Our publication in *The Lancet* and the ensuing reaction throws into sharp relief the rift that can exist between clinical medicine and public health. Clinicians duties are to their patients, and the clinical researcher’s obligation is to test hypotheses of disease pathogenesis on the basis of the story as it is presented to him by the patient or the patient’s parent. Clearly, this is not the remit of public-health medicine.\(^{317}\)

Here, Wakefield tapped into existing tensions between clinical medicine, concerned with individual patients, and the population perspective where risk assessments are based on aggregate data. Those seeking to compete with this appeal and refute his theory would find reframing the argument challenging. Compounding this was the existing public anger and mistrust in government assurances over the new variant Creutzfeldt-Jakob Disease (vCJD) affair.\(^{318}\) *The Lancet*’s editors, as well as news journalists, made reference to this context. The publication had received strong criticism within medicine for publishing the 1998 Wakefield paper.\(^{319-323}\) In their defence, the editors warned that, “Recent history, the talk of new variant Creutzfeldt-Jacob disease, for example, tells us that full disclosure of new data is preferable to well-meaning censorship.”\(^{324}\)

In conclusion, science generally takes a back seat when competing against the more powerful elements of apparent source credibility and a context of mistrust. When they dominate, factual and scientifically rigorous information will not douse the flames of controversy on their own. A comprehensive approach is needed that accounts for existing perceptions of risk and a realistic expectation of the role of the media. The principles of risk communication may also be helpful. These issues will be addressed at the end of this chapter.

### 7.3.3 The undercurrent of anti-vaccination lobbying

In concert with charismatic opinion leaders is the willingness of parent lobby groups to mobilise support for a theory that a vaccine is dangerous. In particular, heartwrenching personal accounts of allegedly vaccine-injured children provide time-pressured journalists with ready made televised hooks for news stories about vaccination. In their work on technological stigma, Gregory et al. stated that when such stories are sustained,
“Negative imagery and negative emotional reactions become closely linked with the mere thought of the product, place or technology, motivating avoidance behavior.” In the UK, many parents with autistic children were willing to speak of their conviction that MMR had caused the condition. The sheer number of these parents possibly indicated unmet needs for greater attention to the causes and management of autism.

Folklore about changelings from the British Isles, Germany and Scandinavia exhibits attempts by societies to understand the reasons for abnormal child development. The changeling was a child who exhibited remarkable and sudden changes in appearance and/or behaviour. Legends explained that supernatural folk exchanged a previously normal child for one of their own – the changeling.

Sometimes the fairies fancy mortals, and carry them away into their own country, leaving instead some sickly fairy child, or a log of wood so bewitched that it seems to be a mortal pining away, and dying, and being buried. Nineteenth century poet, James Russell Lowell, gave such an account. His poem, “The Changeling”, described a charming child with golden hair: “To what can I liken her smiling; Upon me, her kneeling lover; How it leaped from her lips to her eyelids; And dimpled her wholly over, Till her outstretched hands smiled also.” Then at 12 months a “troop of wandering angels” stole his daughter away. The poet lamented that he could not sing the new child to rest or “lift it up fatherly” and the child “smiles as she never smiled”.

In some changeling legends, the replaced child lives contentedly in paradise with the supernatural beings who stole him or her. Some tell of attempts to drive the changeling back to its kin with brutal acts such as setting the child upon hot coals or leaving him on a mound of manure overnight. In some tales, the normal child eventually returns to his parents, thus bringing hope. Most tales of changelings contain instructions on how to prevent the child being stolen, ways of determining whether the child is a changeling, and instructions on how to handle a changeling.
Modern accounts of autistic children describe similar changes to those observed in changeling children. Parents describe how their happy, responsive child who seemed to be developing normally, became fractious, unresponsive, or disruptive. They became a very different child who would not respond to affection or display normal communication skills.

The changeling legends and the MMR hypothesis attempt to make sense of, and cope with, child disability. Adhering to certain beliefs about the cause of the child’s condition gives parents a focus for blame. They can also share advice about prevention and treatment and receive and give hope. Perhaps the UK MMR-autism situation was not so much an issue of vaccination, but of how people deal with their grief. Unfortunately, as with the pertussis vaccine/encephalitis issue in the 1970s, vaccination became the scapegoat for autism with potential consequences that were not banal but put children at risk of suffering infectious diseases.

7.3.4 The seldom acknowledged role of providers

Although this thesis did not set out to test the hypothesis, public controversies about vaccine safety can also jeopardise the confidence of health professionals. Their lost confidence may affect parents. Cooperating health professionals are essential for the maintenance of vaccination programs since they form the focal point of the immunisation encounter. Through health professionals, age appropriate and opportunistic vaccination is delivered to children. Committed and confident health professionals maintain the vaccine cold chain, keeping up to date with current recommendations, and deliver accurate data to agencies. If their commitment is eroded by exposure to worrying new studies that cast doubt on the safety of vaccination, their subsequent uncertainty and/or fears of litigation might be part of the mechanism that reduces uptake.50
The significance of reduced provider confidence should not be underestimated. Although a primary focus in studies of vaccine controversy have been the mass media, the anti-vaccination movement, and parental attitudes and behaviour, the effect of negative reports on provider confidence and commitment might be an important trigger for a sustained decline in vaccination rates. This suggestion is based on three factors.

First substantial literature indicates the importance of provider recommendations in parental decisions about vaccination. Second, the focus group study indicated that parents refer to providers when they have media-generated concerns about immunisation. Third, evidence shows that sustained media coverage of hypothesised links between a vaccine and a serious disease affects providers. In 1976, two years after the negative television documentaries about a hypothesised link between pertussis vaccination and brain damage, a survey of 100 UK general practitioners found that one third were advising against pertussis vaccination, another third were leaving the decision to parents and the rest were promoting vaccination. Hence, it was not parents’ vaccine refusal alone that contributed to declining rates. Others have commented on the erosion of health professional confidence during this time.

More recently, anecdotal accounts report health professionals accepting Wakefield’s recommendation for separate measles, mumps, and rubella vaccines. The British Medical Journal has regularly published commentary on the issue along with studies refuting Wakefield’s hypothesis. In the journal’s rapid response section, increasing numbers of health professionals, including some paediatricians, have expressed their scepticism over studies rejecting an association between MMR and autism. A survey of UK provider beliefs about MMR showed a significant proportion thought it was either very likely, possible, or didn’t know whether the vaccine was associated with autism (22%) and Crohn’s disease (26%). Another smaller survey with a limited response rate showed an 18.5 per cent drop in the number of providers with “maximum confidence” in the MMR vaccine after the publication of Wakefield’s 1998 study.
If large numbers of providers become misinformed or their commitment to vaccination wanes, theoretically it is possible that this will have a more significant effect on vaccination rates since one provider will advise many parents.

### 7.3.5 Confused service delivery

Vaccine controversies also have the potential to confuse vaccine delivery systems. Repeatedly, evidence highlights the importance of service delivery in influencing vaccination coverage. Evidence also shows that vaccine controversies can negatively affect delivery systems. In explaining why MMR vaccination rates in the UK are yet to decline in the way they did with the pertussis vaccine controversy, Nicoll et al. state,

> In the 1970s immunisation had a low priority, and evidence based information from those doing the immunising was minimal. District immunisation coordinators did not exist, and vaccination rates slumped partially because it was unclear whose responsibility it was to do anything about them.\(^{14}\)

Recent data showed a temporary decline in the UK’s MMR vaccination rates and demonstrate the effect of disruption of service delivery on vaccination coverage.\(^{330}\) During the period January to July 2000, a decline of 1.6 per cent in vaccination rates was attributed to the introduction of the new meningococcal disease serogroup C vaccine (MenC) catch-up programme. Children were due for two vaccines (MMR1 and MenC) rather than one. This dual scheduling may have resulted in some children receiving MenC with receipt of MMR1 delayed. In this instance, the new vaccine temporarily disrupted service delivery and consequently produced a more visible decline than any negative media publicity during a similar period. However, this drop indicates that if negative publicity led to the adoption of separate measles, mumps and rubella antigens, the resulting disruption to standardised delivery systems would present a more serious threat to timely vaccination than negative publicity alone.

Finally, vaccination rates can be potentially influenced by significant policy changes that are triggered by negative media coverage and anti-vaccination lobbying. As noted in
chapter 1, the Japanese Ministry of Health and Welfare’s elimination of the entire whole-cell pertussis programme led to a pertussis epidemic;15 France temporarily suspended the Hepatitis B vaccination programme for adolescents after anti-vaccination and media lobbying.163 In the USA, the American Academy of Pediatrics (AAP) and the US Public Health Service released a joint statement suggesting that hepatitis B vaccination of infants born to mothers who were hepatitis B surface antigen negative should be postponed from birth until 2 to 6 months of age. This was due to concerns about the levels of thimerosal in the vaccine. Once a preservative-free vaccine became available, the AAP recommended that the standard hepatitis B vaccination programme resume. However, 38 per cent of hospitals in the study did not adopt this recommendation. In other words, a change in vaccination policy based on safety concerns had strong residual effects that were difficult to reverse.331

7.4 A model for the escalation of controversy

Researchers and commentators have proposed brief general explanations for the escalation of vaccine controversies. Streefland suggested that the process began with discussion among experts about the risks and benefits of a particular vaccine. The mass media take up the discussion. Parents seeking answers for their child’s illness begin to attribute it to the vaccine and discuss their ideas via Internet chat rooms. Once entering popular discourse, the evolved theory provides an explanation for parents seeking a reason for their child’s problems. For some, the story crystallises existing dispositions, for example, they move towards alternative medicine. Those particularly attracted to the theory then disseminate their beliefs, either as individuals or as a group.

Salisbury (2001) proposed a similar pattern where the media amplifies a contentious article published in the medical literature.332 This attracts the voices of parents who believe their children are vaccine victims. A general state of alert about a vaccine then arises and health officials must respond to mitigate the effects of public concerns.332
Gangarosa suggested that a background of high vaccine uptake and low perceived disease risks deters people from vaccination which consequently lowers uptake. Anti-vaccination advocates perpetuate this process via the media. Gangarosa’s explanation is unique because it identifies the role of expert opinion leaders in perpetuating vaccine controversies.\(^\text{15}\)

Figure 7.1, outlines a similar model for the escalation of a vaccine controversy. The model builds on Streiffland’s proposed mechanism,\(^\text{128}\) however, this model suggests that anti-vaccination lobbying increases the likelihood of media coverage and that lost provider confidence also influences vaccination rate downturns. Also, the model accounts for the influence of changed social contexts such as the rise of consumerism and alternative health practices. Finally it accounts for the importance of fright factors or “intensifying factors”, for example, the dreaded nature of a disease attributed to vaccination and credibility and trustworthiness of source.
Figure 7.1 Escalation of a vaccine controversy

**Intensifying Factors**

**Disease:**
- dreaded
- uncertain aetiology
- dissatisfaction

**Source:**
- prestigious
- seen as expert
- trusted

**Response:**
- is made
- is not made

- biomedical controversy
- lobby groups
- media
- popular consciousness
- providers
- delivery systems compromised
- lowered rates → outbreaks

- CONSUMERISM
- LESS VACCINE PREVENTABLE DISEASE

ALTERNATIVE HEALTH
7.4.1 Changing social contexts

Vaccine controversies do not occur in a vacuum. The wider context in which they occur influences whether they “catch fire”. Reduced public exposure to vaccine preventable disease creates a climate where people do not appreciate what vaccines prevent. Second, the rise in alternative health practices and in consumer demand for informed decision making means that people are less likely to accept medical recommendations at face value. These influences were discussed in chapter 2 and earlier in this chapter.

7.4.2 Cyclical process

In this discussion, the term “controversy” refers to a theory about a vaccine leading to a certain disease or condition that is unsupported by the most rigorous epidemiological studies but attracts considerable public attention and is entertained in the public arena. In figure 7.1, the vaccine controversy is presented as a cyclical process that affects the uptake of vaccination rates.

Similar to Streefland, the model identifies a biomedical discussion among experts as a trigger for media interest. Such a “discussion” usually occurs in the fairly insulated world of the medical literature. However, as chapter 3 identified, the anti-vaccination lobby, which is constantly attempting to perpetuate news of vaccine risk, alerts journalists and news producers to the issue. Alternatively, journalists become aware of the controversy through scanning prominent medical journals for newsworthy topics. They may seek a response from anti-vaccination spokespeople. Anti-vaccination spokespeople can provide compelling testimony as a hook anchor for journalists keen to give the story human interest. This exchange between media and the anti-vaccination lobby is represented in figure 7.1 with a two-way arrow.

Media interest intensifies with the presence of an articulate expert who lends more credibility to the issue than if the assertions were from one interest group. Sustained media interest leads to sensitisation where news that previously might not reach mass circulation now does. Sustained public exposure via the media makes the controversy
enter popular consciousness. Once this occurs, providers may see some validity in the controversy, possibly via the influence of opinion leaders within medicine.

Parents can be susceptible to the theory for a range of reasons. Some may already be ambivalent about the safety of vaccination. Others are ready to believe that vaccination caused their child’s problem. Some, with less initial interest, become involved through participation in conversations through their social networks. All parents who see or hear media stories receive high exposure to the hypothesised risk. The high availability of information about this alleged risk intensifies people’s concern.334

As noted in chapter 5, many parents defer to their health professional’s opinion as a way of negotiating the truth of the assertions. If health professionals have insufficient confidence in recommending the vaccine, parents might forgo or delay vaccinating. If delivery systems are compromised by the controversy creating confusion, a drop in vaccine uptake ensues and outbreaks occur. Because such debates tend to polarise audiences, and non-vaccination is a contentious issue, parents accepting the controversy’s hypothesis are forced to defend their decision. In seeking support, some parents form or join lobby/support groups. This maintains the movement which in turn feeds the next controversy.

7.4.3 Intensifying factors

Certain intensifying factors perpetuate the above process. These include the dreaded nature of the disease attributed to vaccination, whether there is existing uncertainty over its aetiology, or dissatisfaction with current explanations for the disease. The source of the biomedical controversy is usually a prestigious person, publication or institution that is trusted and consequently seen as a legitimate by parents, the media and providers. Depending on the context, an official response to the controversy may either intensify or calm the issue.
A response dilemma arises for those seeking to allay public concerns about vaccine safety. The next section discusses this dilemma in more detail. It then makes recommendations about how vaccine advocates in the public context and providers in the clinical context might respond to people’s concerns. These are based on the findings of this thesis and the literature reviewed in it.

7.5 Responding to vaccine controversies

The following recommendations are aimed at providers, campaign planners, policy makers and advocates. They arise from a synthesis of the literature, some results of this thesis and suppositions of the candidate. Therefore, the recommendations are not entirely evidence based but very general. Along with an intense focus on parental responses, these recommendations firstly acknowledge the importance of sustaining efforts at the level of service delivery and provider support. Addressing provider confidence and investing in the support of health professionals is likely to be more efficient, effective and within the control of agencies than dealing with widespread concern among lay people. In broader structural terms, well-supported service delivery provides a foundation of reinforcement for vaccination which will help pro-vaccination proponents “weather the storm” when media coverage is intense and public concerns are strong.

7.5.1 Facts are not enough

In the medical literature, suggested responses to erroneous beliefs about vaccination reflect the assumption that a public reiteration of “the facts”, provision of accurate well referenced statistics, and quantifiable risks and benefits should alone reassure parents. For example, one study suggested that, “failure to correct current misconceptions in the minds of parents and parents-to-be will likely lead to a larger proportion of parents questioning the value of childhood immunizations”. Gellin recommended that, “We need to help them (parents) to distinguish hypothesis from fact and provide them with the facts they need to help them make informed decisions about immunizations.” Others said, “Those advising families must make sure parents can
base their decisions on hard science and evidence". One journal article claimed that, “Evidence resolved the pertussis controversy and evidence has assuaged MMR fears,” but the author provided no evidence to support the claim. A recent *Lancet* editorial about the escalating demands for separate measles, mumps and rubella vaccines suggested that, “Doctors need to present all of the evidence to parents to allow them to make informed decisions, and that evidence comes down in favour of MMR.”

Underlying each of these responses is the assumption that people who express erroneous beliefs are simply mistaken and when exposed to counter-arguments will realise this (see Appendix 14). However, as cultural rationality theory suggests and empirical studies confirm, there is little support for the hope that decision making about vaccination is based on facts alone. Indeed, facts might have the opposite effect of polarising people into existing positions where those supportive of vaccination have their beliefs confirmed and those opposed become more entrenched and committed. Meszaros et al. presented parents opposed to the DTP vaccine with carefully prepared factual information about risks and benefits. These parents became more committed to their antipathetic position. Their response was moderated by their underlying values about death and chronic disability.

Since facts alone are likely to fail as a panacea for vaccination-related concerns, advocates of vaccination might consider the following recommendations when responding to safety controversies in the public arena. These recommendations are based partly on a risk communication approach, that is, they emphasise negotiation and avoid valuing one position over another. They are also based on an advocacy approach that aims to influence behaviour and policy. In this case, the behaviour is the maintenance of vaccination programmes which has been established in chapter 1 as a desirable outcome. Risk communication and advocacy approaches each have strengths and limitations. The extent to which health professionals adopt risk communication or advocacy is limited by their specific role. For providers in the medical encounter it may not be inappropriate to engage in the active persuasion that an advocate might attempt if persuasion conflicts with their medico-legal and moral responsibility to obtain valid consent from parents.
For immunisation advocates, persuasion is an inherent part of dealing with misinformation and actively maintaining public support for vaccine programmes. However, they must balance their use of persuasion against the need to safeguard scientific openness about vaccine safety.

7.5.2 A risk communication approach

In recent years, policy makers and clinicians have applied the principles of risk communication to public concerns about immunisation. As noted in chapter 2, risk communication is “the exchange of information about health or environmental risks between interested parties.” Effective risk communication has seven cardinal rules:

1. Accept and involve the public as a partner;
2. Plan and evaluate efforts;
3. Listen and be responsive to specific public concerns;
4. Be honest, frank and open;
5. Work with other credible sources;
6. Meet the needs of the media; and
7. Speak clearly and with compassion.

The next section applies some of these rules to vaccine risk communication.

7.5.2.1 The need for preparation

The first and most important point made in handling “events” (the term used in the risk communication literature) is to accept that crises in public confidence can and will occur. Hence, with vaccine controversies, it is not a question of whether they will arise but when and how. Good understanding and preparation are essential to a public health response. The post hoc, reactive, and indignant response to the public questioning of vaccine safety is usually ineffective and may contribute to the exacerbation of public concern.
7.5.2.2 The need to listen

Risk communication is a two-way process. Rather than communication about risk occurring as a monologue from expert to lay person, it should take the form of a discussion between both parties. All parents should be given the opportunity to communicate their values and concerns. In the focus group study reported in chapter 5, parents were suspicious of providers who brushed aside their concerns. They felt that this tendency might indicate a lack of knowledge about vaccination. In the provider study reported in chapter 6, the most effective role play encounters were when risk information was tailored to the mother’s background and the provider attempted to respond to her individual needs.

In the wider public arena, the responses of agencies to widespread concern over vaccine safety should first attempt to understand the extent and nature of people’s concerns. Importantly, parental beliefs, attitudes and values need to be considered when new policies are being implemented. Beyond having consumer representatives on policy committees, risk communication asks policy makers to consider the results of research that maps the perceptions and needs of parents as part of the policy formulation process. In Australia, the Federal Government conducts research on parental perceptions for immunisation campaigns. This could help inform policy directions.

Hearing the concerns of lay people does not deny the role of experts nor the value of specialised knowledge but recognises that policy decisions are often values-based and hence should be informed by the values of those who bear the risk. As noted in chapter 2, which discussed the role of fright factors in intensifying people’s response to risk, people are less likely to accept risks that are seen as outside of their personal control. The sense that people do not have control over risk in their lives is exacerbated when they feel their concerns are not considered.
Stone emphasised the importance of understanding and listening in the context of vaccination dissenters but the comment also applies to parents who are simply concerned about vaccination:

The point here is not whether the dissenters both professional and lay, are right or wrong but whether their objections are sufficiently understood by public health agencies and health care professionals. The absence of such understanding is bound to inhibit the formulation of an appropriate response to MCI refusers. 339

7.5.2.3 The need for pre-established networks

Risk communication suggests that a range of stakeholders be involved in the communication process. 338 In the public arena, preparing for urgent communication about vaccine safety requires pre-established networks between all stakeholders. It is too late to wait until an issue arises and captures public attention. This thesis warns that controversies have the potential to erode provider confidence in vaccine safety. Providers who have rapid access to accurate information and support will be less likely to formulate their own erroneous conclusions.

Access to accurate information can be fostered through pre-established networks. Existing relationships between “coalface” providers, immunisation coordinators and other vaccination experts, policy makers and the media might minimise harm in Australia from scares that have adversely affected public and professional confidence overseas. 149 291 Resolutions at the Public Health Association of Australia’s 2000 National Immunisation Conference suggested the establishment of a “national network of appropriately skilled personnel to respond to local media on vaccination issues” be set up. In this context, an e-mail list to disseminate information about impending controversies and to provide a forum for planning a coordinated response might be valuable. By doing so, it could facilitate the rapid and strategic dissemination of accurate information to providers and parents.
7.5.2.4 The need for accurate and accessible information

With the proliferation of misinformation on the Internet, parents and providers must have access to trusted sources of information which are regularly updated and responsive to contemporary controversies. Health professionals should also be aware of helpful international sources such as the World Health Organization website (http://www.who.int/vaccines-diseases/safety/index.html), the National Network for Immunization Information website (http://www.immunizationinfo.org), and the Centers for Disease Control in the USA (http://www.cdc.gov/nip/). These websites are extensive, well resourced and equipped to deal promptly with new issues. A website, relevant to the Australian context, responsive to current issues, and trusted as an authoritative source of information appears to be indicated. Most importantly, its existence must be well publicised to avoid lengthy web searches. The website of the Australian National Centre for Immunisation Research and Surveillance includes factsheets relevant to current controversies such as MMR and autism (http://www.ncirs.usyd.edu.au/facts/facts.html). Existing websites such as the Immunise Australia Program (http://www.health.gov.au/pubhlth/immunise/) could be developed further to meet all of the above criteria.

7.5.3 Responding to anti-vaccination lobbying

7.5.3.1 Responding indirectly to anti-vaccination claims

Recommendations for responding to the anti-vaccination lobby take two major forms. The first is an indirect response to the specific claims made in the public arena. The response must aim to maintain confidence in vaccination rates and takes an advocacy perspective. The second type of response requires direct engagement with anti-vaccination groups. This adopts a stronger consultative, risk communication perspective. This section first discusses the options for immunisation advocates who seek to respond to anti-vaccination claims in the public arena.
Many health professionals and vaccination experts are unsure of how to respond publicly to expressions of anti-vaccination claims. One concern is that a public response might unwittingly lend credibility or draw further attention to the claims. However, ignoring such claims poses its own risks. In the absence of expert voices refuting incorrect theories, some parents may uncritically accept information as legitimate, particularly when it is voiced by seemingly authoritative sources. Some may take the view that silence from authorities means they are unable to address the criticisms being made.

The local context will often determine whether it is appropriate to respond. For example, a February 2002 front page article in the Sydney Morning Herald rejoiced in the absence of measles in New South Wales since October 2001.\textsuperscript{340} Two days later, the president of the Australian Vaccination Network, Meryl Dorey, wrote a letter to the editor questioning the validity of case reports, presumably attempting to point out that recent campaigns had not been effective in reducing measles.\textsuperscript{341} In this situation, any public response would have given greater prominence to what might otherwise be ignored or seen as trivial. In situations where the media attention to a vaccine safety concern is widespread or intense, providing a response is usually necessary. For health workers who choose to do so, the following are suggestions based on risk perception and communication literature.\textsuperscript{113}

- Become familiar with the issue at hand.
- Ensure there is a credible vaccination advocate available to speak to the media.
- Acknowledge vaccines, like all other medical interventions, are not 100 per cent safe and effective. Trust is important in maintaining public confidence in vaccine programmes. Over confidence in vaccine safety estimates erodes trust.\textsuperscript{113} Promote the importance of adverse events reporting and making these data publicly accessible.\textsuperscript{18}
- Avoid fact-against-fact debates which risk losing audiences in arcane detail, may confuse or bore audiences, and appear reactive.\textsuperscript{337}
- Respond to the emotions raised by claims then reframe the debate to centre on protecting children from diseases. Vaccine controversies tend to draw attention away from this ultimate goal.
- Listen to community concerns about vaccination, and be open and responsive to these. Do not respond to questioning of immunisation in an admonishing way. Such responses tend to fulfil the medical arrogance frame regularly set by anti-vaccination spokespeople.
- Audiences with little familiarity of the vaccination issue (e.g. new parents) may more readily accept anti-vaccination claims as mainstream. Draw attention to the overwhelming medical and scientific support for vaccination.
- Have prominent community doctors and other credible sources like infant health nurses reinforce the importance of immunisation and give their own accounts of caring for those with vaccine preventable diseases.
- Use visual images and stories of those affected to jog the community memory of the effects of diseases like polio, pertussis and diphtheria. A story or picture can be more communicative than many risk-benefit equations.
- In order to broaden the coalition of voices supportive of vaccination, obtain the support of other parent organisations like SIDS groups who do not support anti-vaccination claims.

### 7.5.3.2 Responding directly to anti-vaccination groups

Australia needs a more explicit and consistent response to those who lobby against vaccination. Actively engaging with such individuals may intuitively appear unwise given their clear and unswerving opposition and sometimes unnecessary disruption. However, equally unwise is to fail to consider the option of engaging with the lobby on matters of policy, given that the vaccine safety issue is both complex and legitimate, and that such groups can advance their agenda in the political, media and community arenas.

It may be advantageous to involve anti-vaccination groups in policy forums as this can give them a voice while exposing them to the challenges facing policy makers. With
their involvement comes an opportunity to challenge the stereotype of ‘faceless bureaucrat’ or the juxtaposing myth that all people opposed to vaccination are deliberately malevolent in their intent. Those who protest vaccine policies are not homogenous and range from the fanatical to the reasonable. Engaging with the former would be fruitless but others can be highly attuned to system weaknesses. They could be share a desire to improve adverse events reporting and vaccine injury compensation even though such goals might arise from very different agendas.

The existence of other shared goals must also be considered. Australia’s main anti-vaccination lobby group, the Australian Vaccination Network (AVN), appears to concede no benefit whatsoever from vaccination, thus making it difficult to locate areas of common ground. Involving interest groups is time consuming, costly and will not guarantee a smooth risk communication process. There is also the possibility that some might broadcast their involvement in official forums to lend legitimacy to their claims when involvement is not intended to be an endorsement of them.

7.5.4 Responding to parental concerns

When parents in the focus group study were faced with conflicting messages about vaccine safety, their reassurances primarily revolved around a desire to protect their children from infectious diseases. In public debates about vaccination, not only do its opponents maintain a focus on the vaccines but its proponents also respond with information about the vaccines, their safety and efficacy. The focus on vaccines can eclipse a focus on the diseases. As noted in chapter 4, advocates need to re-frame debates away from vaccines and provide contexts that explain the need for vaccination. Stories of disease-affected children need to re-enter the public discourse via health professionals and those who have experienced the diseases. Stories are preferable to epidemics themselves as reminders of disease seriousness.

In the study, parents coped with disturbing messages about vaccination by keeping vaccine preventable diseases in mind. Trust in health professionals was also
fundamental. They included the general practitioner, medically trained friends, siblings who were nurses and the doctors who appeared on the anti-vaccination video. In deciding whether to believe a message, parents gave high priority to the question of whether the informant was medically trained. From their vaccine providers, mothers wanted a person they could trust, who was abreast of current recommendations, a person who was willing to discuss vaccine risk and benefit and a person who trusted them with this information. The notion of being an informed decision maker appeared important to many women, although the varying levels of interest in immunisation indicate that some have greater information needs than others. This suggests that providers should neither deny nor belittle fears about vaccine risks and that full information on risk and benefits should be available to parents. It appears, however, that the burden of providing all information should to some extent, be removed from the time pressured clinical encounter. Efforts to standardise risk-benefit information delivery may alleviate this.

Regardless of how information on risks and benefits is provided, the study identified and confirmed a number of reasons, beyond the ethical and medico-legal, about why vaccine risk information is important.

Firstly, parents who had only experienced vaccination being framed as beneficial expressed surprise, fear and anger at not feeling fully informed of risks. This led many to question their own previous unthinking adoption of the practice. The core claim by anti-vaccinationists that parents should be fully informed in decisions about their child's health clearly has some resonance for parents who do not want to feel they are careless in choices about their child's health. If parents have already been informed by their providers about risks, emotive press stories about vaccine-damaged children are likely to have less sway because parents have a supportive reference point with which to interpret them. This concept is supported by the process of “psychological inoculation” advanced by McGuire.342

Secondly, risk communication literature supports the importance of communicating uncertainty in the public arena.154 This is essential to maintaining public trust.343 In this
study, trust in clinicians and policy makers was an important aspect of support for vaccine programmes. In addition, the study indicated that parents see providers who convey risk information as being aware rather than doubtful of the evidence.

Finally, participants in the study expressed their abilities to compare vaccine risks with benefits and wanted to be trusted with such information. The exchange of risk information is also an exchange of trust. Parents speak about strong trust in health professionals and expected to be entrusted with information.

7.5.5 Recommendations for providers

For providers who are presented with immunisation-related concerns, the following recommendations are based on the findings presented in the previous chapter and the shared decision literature. Competencies or principles of shared decision making have been established by various authors. Shared decision making is defined as, “decisions that are shared by doctor and patient and informed by best evidence, not only about risks and benefits but also patient specific characteristics and values.” Towle and Godolphin’s guidelines can be applied to the immunisation encounter.

- Develop partnership;
- Establish information preferences;
- Establish preferences for role in decision making;
- Ascertain and respond to ideas, concerns and expectations;
- Identify choices;
- Present evidence according to established preferences;
- Make or negotiate decision and resolve conflict; and
- Agree on action plan and follow-up.

In the spirit of these competences, good communication includes first validating and acknowledging parental concerns. Second, providers should make an effort to understand the nature of the concern. Relevant and responsive risk information is
tailored to the individual circumstances and education levels of the parent. If initial
exploration reveals that immunisation is not a great issue for the parent, written
materials enhance informed decision making but free up valuable consultation time for
other matters. If however, a parent is an active information seeker, she or he needs the
risks put in perspective through mixing verbal estimates with quantified estimates where
possible. These should include disease incidence, disease sequela and specify vaccine
risks. Third, providers also need to consider the effects of framing. Where they are
uncertain about vaccine risks, providers should refer to The Australian Immunisation
Handbook as factual inaccuracies have the potential to erode trust.

When faced with conscientious objectors, providers should emphasise that it is their role
to outline the risks and benefits of their decision and then proceed to do so in a factual
and non-adversarial or manipulative manner. In terms of the stages of change model,
open questions such as, “Have you ever had any doubts about your decision” are useful
for diagnosing a parent’s readiness for change. Health professionals also need to listen to
cues. If it is clear that parents will not be swayed, providers should proceed with the
issue with which the patient presented.

Refusal to sign a conscientious objector form or refusal to treat the child because the
parents will not vaccinate raises challenging ethical issues surrounding the rights of the
child, parent and provider. While this strategy has been anecdotally reported as being
successful for vaccinating a child, some doctors in the study felt it risked further
alienation of people already sceptical of orthodox medicine. The worst outcome may be
that parents are less forthcoming when the child requires urgent medical care. In rural
areas, where access to GPs is already limited, treatment refusal based on vaccination
status might further limit this access.

If parents who state they are opposed to vaccination show an indication of changing
their mind, providers could consider a compromise where vaccination occurs in a way
that is different to the standard schedule. This might include delaying vaccination until
the child is older or missing vaccines of particular concern. An initial assessment of the
parent’s situation would reveal this. Although such a “harm minimisation” approach is not generally recommended and should not be promoted as policy, in cases where the choice is no vaccine or some vaccine, the latter is clearly preferable.

For parents doubting vaccination, an informed decision includes understanding the impact of their decision on the wider community. Altruism has been found to have a minor role to play in vaccination decisions. The focus groups study found that some parents valued the community benefit of vaccination. The impact of one parent’s decision on other children can be framed positively, for example, “Your child helps to keep diseases at bay so other children benefit”. It can also be framed negatively in terms of what would happen if all children were unvaccinated. However, this appeal should be expressed in a factual manner that avoids hypothetical scenarios that frame parents as potentially negligent should they not vaccinate.

Many GPs have a relationship with the news media. In the GP survey summarised in appendix 10, 12 per cent had been quoted in the press. This study indicates that GPs are required to deal with fallout from negative media stories. To be confident in dealing with patient queries initiated by media programmes, providers need rapid access to information. In the absence of information to refute plausible-sounding hypotheses like that of MMR and autism, health professionals may take on the information as is already indicated in the UK. Since patients raise media-sourced concerns with their providers, it could be argued that for every health professional reassured about vaccination many parents are reassured.

7.6 Summary

This chapter summarised the findings of this thesis, discussed the ways in which vaccine controversies may catch fire and made recommendations for improving responses to them. The next chapter briefly concludes this thesis.
Chapter 8 Conclusion

This thesis examined the different perspectives of participants in vaccine controversies. It found that parents and experts often speak different risk languages. While personal experiences, value systems and level of trust in medical authorities might be fundamental for parents in decision making, experts tend to rely on population-based and empirical estimates of risk.

Health professionals need to recognise the competing discourses in which vaccine controversies operate. Those making responses in public, especially through the mass-media, should re-frame debates away from powerful discourses appropriated by the opponents of vaccination and develop their own discourse which is not reactive but centres on the need for disease protection. Vaccination has been successful in significantly reducing the burden of a number of infectious diseases. Vaccination also holds the potential to eradicate some diseases. It is essential to maintain the commitment of parents, providers, policy makers, and wider society to vaccination programmes if we are to achieve disease control, elimination or eradication.
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Appendix 1

### Appendix 2

**Summary of Australian Vaccination Network newsletter “Vaccination? The choice is yours!”, 1997 to 2001.**

<table>
<thead>
<tr>
<th>Issue</th>
<th>Activity initiated</th>
<th>Outcome</th>
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<tbody>
<tr>
<td><strong>Pre- 3(4) (outcome reported in subsequent issues)</strong></td>
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| Announcement of plans by Federal Government to implement the linking of Maternity Allowance Payments and Child Care Assistance to vaccination status | AVN objected to the Bill on two major bases: 1. the Bill didn’t recognise children who had “developed natural immunity” 2. the Bill required that a provider approve whether or not somebody is a conscientious objector. This involved being counselled by a provider about the benefit and risks of vaccination. AVN engaged experienced lobbyist 2 days in Canberra in late 1997 Saw 12 senators, 4 MPs and 2 aides including the Health Minister, Michael Wooldridge’s policy adviser. Obtained support of democrats, Greens, Independent senator Harradine, and “tentative support from Labor”. Request for members to lobby senators | From issue “We Did It”:
Bill was unopposed in House of Representatives 11th November 1997 Senate voted 2 out of 3 amendments to the Bill so that children who had natural immunity were exempted. Senate also widened the definition of conscientious objector. From 4(1):4, linking to Maternity Allowance legislation was passed under Veteran’s Affairs legislation. Wording is same as original for Child Care Payments bill before their amendment. Requested senator Dee Margett’s office try to change wording. November 27 John Herron (QLD minister for Aboriginal and Torres Straight Islander Affairs) “last week in the Senate the Australian Vaccination Network circulated a false and mischievous document which has influenced people against immunisation” 4(1):23 |
<p>| Asthma and vaccination | “2 children a day die from asthma and it’s brought on by vaccines” Lobbied media and sent press release | |</p>
<table>
<thead>
<tr>
<th>Issue</th>
<th>Activity initiated</th>
<th>Outcome</th>
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<tbody>
<tr>
<td>Social security benefits linked to vaccination</td>
<td>Lobbied media regarding people who don’t realise that they can still receive social security allowances.</td>
<td>Practical Parenting magazine published a piece about a “Vaccination Information Kit for Parents” It included a 500 word text box on how parents are entitled to conscientious objections and information on the kit. Members urged to thank the editor of Practical Parenting for publishing above.</td>
</tr>
<tr>
<td>Volume 3(4) November 1997</td>
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<tr>
<td>Measles campaign</td>
<td>Measles booklets produced</td>
<td>Approx. 11,000 copies distributed in North Coast 12 local schools near Mudgee with one agreeing to send booklet home to all parents 4(3):15 Members visited principals of state schools in the Brisbane area “many printing our 1800 number in the school newsletter and promoting our new MMR booklet”. Members stood outside schools handing booklet to parents. 150 measles booklets sent to Brisbane Parents and Citizens’ Associations</td>
</tr>
<tr>
<td>Measles campaign</td>
<td>Lawsuit pending against federal government in the Administrative Appeals Tribunal.</td>
<td>Federal Health Minister, Michael Wooldridge issues press release denying that any action had been lodged with both the Federal Court and the Administrative Appeals Tribunal. In response, AVN asks their solicitor to write to government claiming a case is pending in the Administrative Appeals Tribunal.</td>
</tr>
<tr>
<td>Measles campaign</td>
<td>Tasmanian mother, Janet Cragg’s son vaccinated without permission. Case reported as being lodged in Federal Court naming Hobart City and Health Minister, Michael Wooldridge as defendants.</td>
<td>5(3) case moved to Supreme Court in Hobart</td>
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<tr>
<td>Issue</td>
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<tr>
<td>Adverse events reporting</td>
<td>1800 number publicised</td>
<td>“Our 1800 number has been very busy.”3(4):1 Members asked to thank Mother and Baby magazine for advertising 1800 number and Vaccination Roulette.</td>
</tr>
<tr>
<td>The promotion of vaccination</td>
<td>Members urged to write to Today Tonight, A Current Affair and The 7.30 report for story on “blatant pressure” being put on parents</td>
<td>Members asked to thank Mother and Baby magazine for advertising 1800 number and Vaccination Roulette.</td>
</tr>
<tr>
<td>Members urged to write to Sydney’s Child newspaper to encourage editor. She was allegedly being rebuked for publishing an article by Meryl Dorey, AVN president. Request for members to distribute publication to increase its reach.</td>
<td></td>
<td>Members asked to thank Mother and Baby magazine for advertising 1800 number and Vaccination Roulette.</td>
</tr>
<tr>
<td>Volume unnumbered</td>
<td></td>
<td>Members asked to target 60 Minutes to do program on the dangers and ineffectiveness of vaccines.</td>
</tr>
<tr>
<td>Title: “We Did It”</td>
<td>Members asked to target 60 Minutes to do program on the dangers and ineffectiveness of vaccines.</td>
<td></td>
</tr>
<tr>
<td>General</td>
<td>Members asked to target 60 Minutes to do program on the dangers and ineffectiveness of vaccines.</td>
<td></td>
</tr>
<tr>
<td>Social security benefits linked to vaccination</td>
<td>Child care payments bill: members asked to write to local MP and local papers.</td>
<td>Members asked to target 60 Minutes to do program on the dangers and ineffectiveness of vaccines.</td>
</tr>
<tr>
<td>“We get NO media coverage despite numerous press releases and phone calls to the press. The fear of the pharmaceutical companies and the wrath of the medical community is too great.” “We all have the power to change the way the media deals with (or doesn’t deal with) this issue. Please, let’s get active and make sure that our voices are heard!”</td>
<td>Members asked to target 60 Minutes to do program on the dangers and ineffectiveness of vaccines.</td>
<td></td>
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<tr>
<td>Plan to charter buses bringing families of maimed children to a protest on the steps of parliament house April 6&lt;sup&gt;th&lt;/sup&gt;. Buses hired from Brisbane, Sydney, Melbourne, Adelaide.</td>
<td>From 4(2):3 “I have gotten many calls from members to ask how the Canberra march went. Well, it didn’t. Lynne Grimsey, Jim Townley and myself went to Canberra and lobbied for a week.”</td>
<td>Members asked to target 60 Minutes to do program on the dangers and ineffectiveness of vaccines.</td>
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<tr>
<td>Issue</td>
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<tr>
<td>Adverse events reporting</td>
<td>Plan to ask Senator Brown to request legislation requiring doctors to report vaccination status in all cases of notifiable infectious diseases</td>
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<tr>
<td>Measles campaign</td>
<td>$10 measles packs available. Members urged to write to local papers: “The AVN continues without success to try and attract media coverage by posting press releases on all these issue. Through advice and our own experience, we feel that writing letters to the editor would be the most effective way to achieve this goal.”(p25)</td>
<td></td>
</tr>
<tr>
<td>Alternatives to vaccination</td>
<td>Plan to produce quarterly journal called “Healthy Families Naturally” to reach beyond the AVN membership.</td>
<td>From 4(1):23 Senator John Herron quoted in Hansard 27 November 1997 “it was in the hands of one of my parliamentary colleagues the other day. The poor chop believed that some of the material in that was also verifiable”. 4(2):13 Queensland members sold copies to Mary Ryan’s book stores and held book launch in city mall. Blue Mountains NSW group donated book to Blinky Bill Preschool library. 4(2):20 Canberra launch of Vaccination Roulette in a Senate Committee Room hosted by Greens party senator Dee Margetts. 4(3):2 $35,000 made which would cover costs of printing Vaccination Roulette (at $25 and less per book that is 1400 books sold)</td>
</tr>
<tr>
<td>Social security benefits linked to vaccination</td>
<td>Call for Spanish, Chinese, Vietnamese etc speakers to translate a document about compulsory, school attendance, vaccine ineffectiveness, maternity and childcare allowances.</td>
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<tr>
<td>Child care restrictions</td>
<td>Call for a network of parents able to mind kids</td>
<td></td>
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<tr>
<td>Social security benefits linked to vaccination</td>
<td>Maternity Allowance: Booklet produced by Centrelink allegedly failed to outline the option of becoming a conscientious objectors to vaccination. Contacted Jocelyn Newman’s office requesting public correction be made and not just promise to revise the next booklet. Contacting three Centrelink agents (possibly to test their knowledge) Contacted Baby Health Centres and doctor’s offices – not seen (they were asked within 1 month after legislation went into action Contacted Commonwealth Ombudsman Contact solicitors looking into “misleading the public and violating the TPA Section 52.”</td>
<td></td>
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<tr>
<td>Childcare restrictions</td>
<td>- Senator Belinda Neal established childcare funding inquiry Concern over access to federally funded daycare for parents of unvaccinated children; “your children are healthy and no threat to other children”.</td>
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5(2):18 “The staff (at local library) were very happy to receive the book as they often have students requesting information for assignments and have few resources covering this topic.”

5(3) planning the placement of advertisements in Practical Parenting and Nexus Magazines.

Hervey Bay, Bundaberg, Gold Coast, Kalgoorlie, Bunbury, Lismore libraries have copy.
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<th>Issue</th>
<th>Activity initiated</th>
<th>Outcome</th>
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<tr>
<td>Parent entitlements</td>
<td>Conscientious objector pack (188 pages) available for purchase to give to providers during required encounters.</td>
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<tr>
<td>Acellular pertussis vaccine</td>
<td>Sydney Morning Herald, Courier-Mail and Australian report on Infanrix vaccine eliminating side effects. Complaint lodged with Press Council about this reportage misleading the public.</td>
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<tr>
<td>General</td>
<td>Tasmania group hosted Isaac Golden seminars. Tasmania group leader attended 2 outdoor Immunisation Clinics handing out information. Member also went through the motions of being vaccinated but stopped at the end and informed the doctor of her position.</td>
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<tr>
<td>Volume 4(2) May 1998</td>
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<tr>
<td>Adverse reactions</td>
<td>Proposals sent to every Australian politician supporting legislation introduced in Parliament at next sitting. This included mandatory reporting of adverse events, that notifications include vaccination status of child, and the availability of a 1800 number for parents and others to report reactions. Hand delivered to 13 senators with discussions with each of their advisers. Also talked with ADRAC and AEFVSS about weaknesses in the reporting systems and linkage which they reportedly agreed about.</td>
<td></td>
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<tr>
<td>Privacy – “A Child’s Smart card is being considered for use in Australia”</td>
<td>Write to Qld, VIC Council for Civil Liberties, All newspapers, Senators Harradine and Brown, Human Rights Council of Aust, HREOC (listed all numbers, addresses, faxes, emails) 5(1) call for members to write to Privacy Committee of the Attorney General’s Department.</td>
<td>5(1):2 Attorney General’s Dept of NSW “not aware and seeking further information from the SA privacy committee.”</td>
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<td>Issue</td>
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<tr>
<td>Measles vaccination campaign</td>
<td>MMR vaccination in schools where 22 Tasmanian children were allegedly vaccinated without parental permission. Form letter published in newsletter to send to school principals warning them not to allow a child to be vaccinated and if they do, threatening legal action.</td>
<td>By 5(2) database commenced with details of whether the centre accepted unvaccinated children and if they don’t, whether they accept a child with a medical exemption.</td>
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<tr>
<td>Childcare restrictions</td>
<td>Calls for details of private daycare centres that accept unvaccinated children so they can be put on national database and circulated to members wanting to find childcare.</td>
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<td>Issue</td>
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<td>Creutzfeldt Jacob Disease</td>
<td>Members urged to write to the Community Affairs References Committee, a “parliamentary body with power to activate a Senate Parliamentary Hearing into the investigations of issues”, asking the chairman to investigate everything about vaccine risks, public funding, adverse reactions etc.</td>
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<tr>
<td>Measles campaign</td>
<td>Claimed to be taking Federal Government to court over “blatant untruths and discrimination”. Legal action taken in Administrative Appeals Tribunal. Federal Court application being prepared. Five media releases about the abuse of parent’s rights and discrimination sent to major outlets.</td>
<td></td>
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<tr>
<td>Adverse reactions</td>
<td>1800 number established</td>
<td>Number promoted via local groups – Parents and Citizens groups, school newsletters, local newspapers</td>
</tr>
<tr>
<td>Measles campaign</td>
<td>Allegedly, letter sent by Health Department’s Media Unit to all editors warning them about the AVN. Calls for members to write to all newspapers informing them about the AVN, calling the editor and asking if they have heard of the group with threats to call for boycott of newspaper if material is not published.</td>
<td>Letter box drop to 5,633 homes in Hunter NSW area about measles.</td>
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<tr>
<td>The Natural Family Fair</td>
<td>Run via Healthy Families… Naturally a registered sub-group of the AVN.</td>
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<tr>
<td>Measles campaign</td>
<td>Considered taking out an injunction against the campaign</td>
<td>Unable for financial reasons</td>
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**Volume 4(3) August 1998**
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<tr>
<th>Issue</th>
<th>Activity initiated</th>
<th>Outcome</th>
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<tr>
<td><strong>Volume 5(1)</strong></td>
<td><strong>February 1999</strong></td>
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<tr>
<td><strong>Federal Health Minister, Michael Wooldridge’s alleged statement “you could fit all the AVN supporters in one phone booth.”</strong></td>
<td>Meryl Dorey requested photos of members crammed into and overflowing from booths published.</td>
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| **Instructions on “pro-choice” candidates; members can vote for:**   | - Alan Corbett from A Better Future for Our Children party in NSW parliament.  
- Earth Save Australia is run by a naturopath  
- Australians for a Better Community                                                                                                                                 |                                                                                                                                                                                |
| **Entitlements**                                                      | Reported difficulties for members in accessing conscientious objector forms, privacy invasion, procedure, need to consult a doctor.  
Write to federal members, Commonwealth Ombudsman, Privacy Commission, QLD Council for Civil Liberties, Rosemary Crowley and Belinda Neal                                                                 | 6(3) presented concerns to Senator Newman. Letter sent back was printed in issue. Letter sent back 1 year after letter to Rosemary Crowley.                                    |
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<th>Issue</th>
<th>Activity initiated</th>
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<tr>
<td>Hepatitis B vaccination</td>
<td>call for 10 members to see their MPs with information about the vaccine</td>
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<tr>
<td>Hepatitis B vaccination</td>
<td>Undertaking mail drive to union reps, schools, committees, companies, doctors and MPs.</td>
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<tr>
<td>Volume 5(2) May – July 1999</td>
<td>“We have contacted the Federal govt. and the RACGP to talk to them about the fact that doctors are either refusing to sign the conscientious objection forms or were harassing parents who had taken the forms to be signed.”</td>
<td>6(3) copy of letter from Grant Tambling to Rosemary Crowley: “The AVN has distributed contact details for the NIC and a staff rep from Imm Sect. of DHAC to all its member. …….To date, neither of the contacts have received any enquiries in this regard.”</td>
</tr>
<tr>
<td>Doctors refusing to sign conscientious objector forms</td>
<td>Calls for all members to write to Peter Brooks, Diana Terry, and copy AVN.</td>
<td></td>
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<tr>
<td>Childcare</td>
<td>Surveyed many centers regarding acceptance of unvaccinated children. Stated aims of doing above: -to link member needs for childcare with appropriate centers -to put centres on notice that parents know their rights. AVN will send letter about discrimination etc. -to give the impression that “quite a few parents” don’t vaccinate</td>
<td>Database commenced.</td>
</tr>
<tr>
<td>Free choice</td>
<td>National Freedom of Choice Day instituted by the AVN 12th September to encompass health, vaccination, breastfeeding, birthing choices, complimentary medicine, environmental interests, animal protection.</td>
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<td>Issue</td>
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<tr>
<td>Volume 5(3) August – October 1999</td>
<td>Membership at “about 1500 nationally”</td>
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<tr>
<td>Free choice</td>
<td>Write to your federal MP asking to support freedom of choice – guarantee not to vote to require proof of vaccination for school entry.</td>
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<tr>
<td>WA select committee</td>
<td>Write to media asking why 90 page AVN document submission was ignored</td>
<td></td>
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<tr>
<td>Adverse events</td>
<td>TV Community Service Announcement aired in Wollongong and South West NSW.</td>
<td>Health Department wrote to stations and commercial was pulled.</td>
</tr>
<tr>
<td>Autism</td>
<td>AVN Supported “Mind of a Child” autism conference in Sydney run by Robyn Cosford. Healthy Families Naturally held seminars on Attention Deficit Disorder, Autism, in Sydney, Lismore, Gold Coast and Brisbane.</td>
<td></td>
</tr>
<tr>
<td>Free choice</td>
<td>Case against Municipal council in Tasmania where a person was not appointed to a position due to refusing the tetanus vaccine.</td>
<td>no progress</td>
</tr>
<tr>
<td>Free choice</td>
<td>Tasmania – Cerebral Palsy Association “threat to dismiss staff who did not have a tetanus and Hepatitis B vaccine by a certain date. Head of AVN’s Tasmanian group called and had “heated discussion” with manager of organisation.</td>
<td>Provided a disclaimer for any not wishing to be vaccinated.</td>
</tr>
<tr>
<td>Hepatitis B vaccine</td>
<td>Tasmanian group contacted media regarding ban in USA for vaccine.</td>
<td>ABC radio contacted an expert who delayed interview. Interview then went ahead without member.</td>
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<tr>
<td>Issue</td>
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<tr>
<td>Press releases</td>
<td>Simon Chapman&lt;br&gt;Rotavirus removed&lt;br&gt;Oral polio vaccine removed&lt;br&gt;Hep B removed&lt;br&gt;US congressional hearings re Gulf War Syndrome</td>
<td></td>
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<tr>
<td>5(4) Nov-Jan 1999</td>
<td>Free choice&lt;br&gt;Write any accounts of discrimination for not vaccinating to the authorities.</td>
<td></td>
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<tr>
<td>Entitlements</td>
<td>More complaints to Centrelink.</td>
<td></td>
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<tr>
<td>Free choice</td>
<td>Write letters to Members of Parliament, Premier, Ministers of Health and Education and Civil Rights Association.&lt;br&gt;Contact 5 Child Care Centres re accepting unvaccinated children.&lt;br&gt;Information to local health food stores.&lt;br&gt;Promote professional membership&lt;br&gt;Local bookstore Vaccination Roulette&lt;br&gt;Calls to share contacts of “open minded doctors”</td>
<td></td>
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<tr>
<td>Seminar</td>
<td>Sutherland Seminar on Vaccination</td>
<td>Letter published in Orange Newspaper thanking Simon Chapman for his support in advertising session to medical students.</td>
</tr>
<tr>
<td>General Practice Incentive Initiative</td>
<td>Demonstration at Ballina Island Motor Inn where SmithKline Beecham held meeting for general practitioners on the Australian Childhood Immunisation Register and the incentives scheme. Demonstration included placards.</td>
<td>Demo held</td>
</tr>
<tr>
<td>Volume missing 6(1)</td>
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<tr>
<td>Issue</td>
<td>Activity initiated</td>
<td>Outcome</td>
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</tr>
<tr>
<td><strong>Volume 6(2)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Entitlements</td>
<td>Press release about links to allowances</td>
<td>Article published in Sydney Morning Herald on 4\textsuperscript{th} May 2000 and in the North Shore Times suburban newspaper.</td>
</tr>
<tr>
<td><strong>Volume 6(3)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>August – October 2000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adult measles campaign</td>
<td>Press release about vaccine never being tested. Target universities, TAFEs, radio stations and newspapers.</td>
<td>“sent to many, many media outlets without much success”</td>
</tr>
<tr>
<td>Call for research projects- asking for researchers. Plan to seek funding from government and private sources.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Entitlements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A Current Affair did a story on a child “expelled at 17 months of age”</td>
<td>Members urged to write to A Current Affair to tell them about their dissatisfaction with their coverage of the story.</td>
<td></td>
</tr>
<tr>
<td><strong>Volume 7(1)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>January to March 2001</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Conscientious objection for nurses</td>
<td>Wrote to Head of Australian Nurses Federation to have a conscientious objector form for nurses available to sign if they object to vaccination.</td>
<td></td>
</tr>
<tr>
<td>Issue</td>
<td>Activity initiated</td>
<td>Outcome</td>
</tr>
<tr>
<td>-----------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Hepatitis B vaccine</td>
<td>Letter sent to Professor Margaret Burgess, director of the National Centre for Immunisation Research asking about the Hepatitis B vaccine.</td>
<td>Request for members to write to media saying that Professor Burgess did not reply to their questions.</td>
</tr>
</tbody>
</table>
| Volume 7(2)                       | Contact list is at 35 groups  
ACT = 1; NSW = 13; NT = 1; QLD = 12  
Victoria = 2; WA = 6  
Professional members 91 include chiropractors, ear candling, herbalists, midwives, naturopaths, printers, vets, sound therapists etc. |                                                                                                                                                                                                      |
| Child Safety Handbook distributed in all schools of NSW | Members protested chapter on Personal Safety - Child Abuse where “not immunised against illness” is listed as a sign of neglect. Alan Corbett informed. He wrote to Chairman of Police Legacy. |                                                                                                                                                                                                      |
| School entry requirements         | Letters sent to parents about immunisation requirements implied they needed to be immunised.  
Meryl Dorey wrote to principal requesting a letter correcting mistake should be sent to all parents.  
Dept. of Education and Training took over correspondence assuring Dorey that letter would be less misleading next year  
Dorey maintains request for letter to be sent and requests involvement in future forums to standardise letters sent from schools. |                                                                                                                                                                                                      |
| MMR autism on 60 minutes           | “Thank you to those who contacted Channel 9 to thank them for airing these programs. If the media gets strong messages of support from viewers when they put on shows like this, they will continue to do so. |                                                                                                                                                                                                      |
Appendix 3
Explicit claims made in opposition to vaccination. Australian newspapers 1993 to 1997

<table>
<thead>
<tr>
<th>Main Arguments</th>
<th>Minor Arguments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Vaccination can lead to a variety of major diseases</td>
<td>IMMUNISATION GENERALLY:</td>
</tr>
<tr>
<td></td>
<td>• Immunisation is dangerous to health</td>
</tr>
<tr>
<td></td>
<td>• Immunisation is linked to leukaemia, cancer, epilepsy, dyslexia, asthma, GBS,</td>
</tr>
<tr>
<td></td>
<td>eczema, diabetes</td>
</tr>
<tr>
<td></td>
<td>• Cot death in Australia has decreased following the reduction in vaccination</td>
</tr>
<tr>
<td></td>
<td>rates.</td>
</tr>
<tr>
<td></td>
<td>• Some vaccines have been linked with HIV</td>
</tr>
<tr>
<td></td>
<td>• Some vaccines have been linked with polio, the disease</td>
</tr>
<tr>
<td></td>
<td>PERTUSSIS VACCINE</td>
</tr>
<tr>
<td></td>
<td>• In Japan, the rate of SIDS dropped dramatically as a result of raising the</td>
</tr>
<tr>
<td></td>
<td>age of pertussis vaccine to 2 years of age</td>
</tr>
<tr>
<td></td>
<td>• is linked to SIDS</td>
</tr>
<tr>
<td></td>
<td>MEASLES VACCINE</td>
</tr>
<tr>
<td></td>
<td>• Measles vaccine causes deaths</td>
</tr>
<tr>
<td></td>
<td>• Causes ‘atypical’ measles</td>
</tr>
<tr>
<td></td>
<td>• Measles vaccines causes Crohn’s disease</td>
</tr>
<tr>
<td></td>
<td>POLIO VACCINE</td>
</tr>
<tr>
<td></td>
<td>• may cause SIDS</td>
</tr>
<tr>
<td></td>
<td>• caused HIV</td>
</tr>
<tr>
<td></td>
<td>• Jonas Salk has attributed all cases of polio in the US to the polio vaccine</td>
</tr>
<tr>
<td></td>
<td>31</td>
</tr>
<tr>
<td></td>
<td>• polio cases mainly come from the vaccine</td>
</tr>
<tr>
<td>Vaccines can damage children</td>
<td>• Vaccines can cause brain damage</td>
</tr>
<tr>
<td></td>
<td>• Vaccines cause SIDS</td>
</tr>
<tr>
<td></td>
<td>• They erode the immune system</td>
</tr>
<tr>
<td></td>
<td>• In the US 400 million has been paid out in vaccine related damages</td>
</tr>
<tr>
<td></td>
<td>• Can cause childhood behavioural problems</td>
</tr>
<tr>
<td></td>
<td>• Some children develop meningitis from the measles vaccine</td>
</tr>
<tr>
<td></td>
<td>• Polio vaccine can cause paralysis</td>
</tr>
<tr>
<td>Vaccine effectiveness</td>
<td>• Vaccines are ineffective in disease prevention</td>
</tr>
<tr>
<td></td>
<td>• Mandatory vaccination in the Us has been ineffective, in fact, diseases</td>
</tr>
<tr>
<td></td>
<td>have been on the increase</td>
</tr>
<tr>
<td></td>
<td>• Vaccination puts kids at higher risk of catching the disease than those</td>
</tr>
<tr>
<td></td>
<td>not vaccinated.</td>
</tr>
<tr>
<td></td>
<td>• Smallpox stills exists in the Third World</td>
</tr>
<tr>
<td></td>
<td>• Vaccine preventable diseases occur in the vaccinated</td>
</tr>
<tr>
<td>Vaccine-preventable diseases</td>
<td></td>
</tr>
<tr>
<td>------------------------------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------</td>
</tr>
<tr>
<td>They were on the decline before vaccines</td>
<td>• Were on the decline prior to vaccinations</td>
</tr>
<tr>
<td></td>
<td>• Have declined due to better sewage, water, hygiene and nutrition.</td>
</tr>
<tr>
<td>Alternatives to allopathic vaccination</td>
<td></td>
</tr>
<tr>
<td>It’s better to get the disease than to be vaccinated</td>
<td>• Side effects of vaccines are as bad as diseases</td>
</tr>
<tr>
<td></td>
<td>• Measles, the disease, provided a lifetime immunity to a range of diseases including forms of cancer.</td>
</tr>
<tr>
<td></td>
<td>• Acquiring the diseases naturally gives better protection</td>
</tr>
<tr>
<td></td>
<td>• Are not fatal in their natural state</td>
</tr>
<tr>
<td></td>
<td>• Sickness cleanses the body Medication thwarts this process</td>
</tr>
<tr>
<td>Homoeopathy is an alternative to vaccination</td>
<td>• Homoeopathy is an alternative to vaccination</td>
</tr>
<tr>
<td>A healthy lifestyle is adequate to fight off the diseases.</td>
<td>• Adherence to natural health principles is how to prevent disease</td>
</tr>
<tr>
<td></td>
<td>• Good diet, exercise and clean water and fresh air will keep the immune system able to fight off the infections</td>
</tr>
<tr>
<td>Prevent disease through religious observances</td>
<td>• Prayer, Christian living is an alternative to immunisation.</td>
</tr>
</tbody>
</table>
Appendix 4
Immunisation questionnaire

How many children do you have?

What are their ages?

Have you ever had any concerns about vaccination? What sort of concerns are they?

Focus group information

Able to attend?
Date
Time
Place
$20
Voluntary
Taped

Need for childcare
how many children?
any special needs?

Name
Contact number
address
Info sheet given
Consent form signed
Appendix 5
Participant information sheet

Department of Public Health and Community Medicine

The University of Sydney

Faculty of Medicine

Associate Professor Simon Chapman
Dr Penny Hawe
Professor Margaret Burgess
Ms Julie Leask

Edward Ford Building A27
NSW 2006 AUSTRALIA
Telephone +61 2 9351 7800
Facsimile +61 2 9351 4381
Email: JulieL@pub.health.usyd.edu.au

RESEARCH STUDY: EXPLORING ATTITUDES TO CHILDHOOD IMMUNISATION

INFORMATION FOR PARTICIPANTS

You are invited to participate in a discussion group with other parents about the issue of childhood immunisation. In this study, we will be interviewing parents of young children. Like you, these parents have agreed to be part of a small group discussing immunisation. We want to try to better understand how parents are affected by different arguments about immunisation. The study is being conducted by Associate Professor Simon Chapman, Dr Penny Hawe and Ms Julie Leask from the Department of Public Health and Community Medicine at the University of Sydney along with Professor Margaret Burgess at the National Centre for Immunisation Research at The New Children's Hospital.

What will happen?

On (insert date), we would like you to come to (insert location) at (insert time). There, you will join up to 8 other parents who are also assisting us with this study. An interviewer will spend about 90 minutes asking you to talk about your opinions. You will also be shown some short pieces of TV film about immunisation and asked some questions about what you saw. The discussion and footage might raise some questions or concerns about immunisation. There will be an opportunity at the end of the session to discuss any concerns you might have.

What about cost of getting there?

We will pay you $20 to cover any expenses such as travel to the interview.

The interview will be tape-recorded

To help us in writing a report on this study, the interviews will be tape-recorded. You will not be asked to identify yourself by giving your full name on the tape. The tapes will be transcribed (typed out) and the tapes then erased. The tape transcripts will be stored securely for 5 years in an office within the University. No one other than the research group will be allowed to hear the tapes or read the transcripts.

Can I leave the study?

Your participation in this study is completely voluntary. If you decide that you no-longer wish to take part, you are free to withdraw at any stage.
Who can I speak to about this project?

If you have any questions about any aspect of the project, please call Associate Professor Simon Chapman on (02) 9351 5203.

If you have questions or concerns about vaccination and would like to discuss them with a medical practitioner, please call:
Professor Margaret Burgess,
Director,
National Centre for Immunisation Research
Phone (02) 9845 0520 (during business hours)

This study has been approved by the Ethics Review committee (RPAH Zone) of the Central Sydney Area Health Service. Any person with concerns or complaints about the conduct of this research study can contact the Secretary on (02) 9515 6766.
Appendix 6
Participant consent form

RESEARCH STUDY:
EXPLORING ATTITUDES TO CHILDHOOD IMMUNISATION
PARTICIPANT CONSENT FORM

I ...........................................................................................................................(name)
of ....................................................................................................................(address) have read and understood the Information for Participants on the above named research study and have discussed the study with ..........................................................................................................................
I hereby agree that I have voluntarily agreed to be interviewed with a small number of other parents about childhood immunisation.

I freely choose to participate in this study and understand that I can withdraw at any time.

I understand that I will not be identified in any report or publication arising from this research, nor in any other way.

I understand that I will be paid $20 to compensate me for any cost involved in attending the interview.

I hereby agree to participate in this research study.

NAME: ...........................................................................................................

SIGNATURE: ...................................................................................................

DATE: .............................................................................................................

NAME OF WITNESS: .......................................................................................

SIGNATURE OF WITNESS: .............................................................................
Appendix 7

Appendix 8
Survey of focus group participants

Background Information

Office use only

Date: ____________________________  
Group code number: __________  

What is your postcode? ...............

What is your age? .................

Country of birth: ....................... 

What language do you usually speak at home? ........................................

What is your highest level of education reached? ........................................

What is your occupation? ............................................................................

Is your job:  full-time ( )  part-time ( )  casual ( )

Are you currently on maternity leave? yes ( ) no ( )

If not currently employed, what was your previous occupation? ....................

What is your partner's current occupation? ......................................................

If your partner is not currently employed, what was his last occupation? ..............

Your child/ren:

<table>
<thead>
<tr>
<th>Child's age</th>
<th>Vaccination status for age (tick one)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>full ( )  partial ( )  not at all ( )</td>
</tr>
<tr>
<td></td>
<td>full ( )  partial ( )  not at all ( )</td>
</tr>
<tr>
<td></td>
<td>full ( )  partial ( )  not at all ( )</td>
</tr>
</tbody>
</table>
Appendix 9
Focus group interview guide

"Immunisation" - what comes to mind?

What kinds of things reassure you about vaccination?

What kinds of things give you doubts or concerns about vaccination?

Prompt 1 "think about people you know who are parents - friends, family, a parent's group you might go to - and whether anyone has ever mentioned concerns about vaccination."

Prompt 2 "for example, some people hear things about vaccines causing serious health problems."

Prompt 3 "or that vaccines erode the child's immunity"

TV documentary about immunisation (Play Quantum part 2. (3-7.47 mins): Impressions?

Today Tonight 26 January, 1996: Impressions?
Appendix 10
General Practitioner survey

Presented at 7th National Public Health Association of Australia Immunisation. Gold Coast, QLD 2-3 August 2000

TITLE: Provider encounters with immunisation-ambivalent parents

PRESENTER: Julie-Anne Leask
AUTHORS: Julie-Anne Leask, Margaret Burgess, Han Wang, Simon Chapman

ABSTRACT: This study aimed to investigate GP encounters with parents concerned about childhood immunisation and their level of confidence in addressing these concerns. It is also intended to provide background information for further in-depth interviews with providers.

A self-administered postal survey was sent to 1000 randomly selected GPs in NSW and QLD. Of 516 (52%) who responded, 471 (91%) identified themselves as being immunisation providers. Just under half (48%) of these respondents had encounters at least monthly with parents concerned about, or opposed to, immunisation. The most commonly occurring concerns related to generalised vaccine reactions. Concerns about vaccines causing more specific conditions such as SIDS, concerns about the effect on the child’s immunity, vaccine effectiveness and whether homoeopathy was preferable were encountered less frequently. When parents raised concerns 43% of respondents found it difficult to reassure them.

Within the limitations of a low response rate, the results support the provision of strategies to address parental concerns about vaccination.
November 17, 2000

«Q10_Name_»,  
«Address_1»  
«Address_2»

Dear «Name»,

Re: Responding to parents' concerns about childhood immunisation.

We would like to invite you to participate in a study about the issue of childhood immunisation. In this study, we are interviewing GPs who responded to a survey sent by our team last year. We have chosen respondents who said they saw parents with concerns about immunisation fortnightly or more. We want to try and better understand how doctors and parents communicate with each other about the issue of childhood vaccination.

The study is being conducted by myself, Prof. Penny Hawe, Prof. Margaret Burgess and Ms Julie Leask from the Department of Public Health and National Centre for Immunisation Research, University of Sydney.

The interview would involve a brief role play of four typical 'concerned parent' scenarios with a research assistant (Julie Leask) and would end with a follow-up discussion. The interview would not be a test of knowledge but an attempt to describe the range of communicative strategies used by immunisation providers when responding to parents' concerns about immunisation. Interviews generally take 20-30 minutes.

This letter will be followed up with a telephone call inviting you to participate in the study. If you have any questions please do no hesitate to contact me on 9351 5203 or Julie Leask on 9351 7739.

Yours sincerely,

Simon Chapman  
(Associate Professor)
Information Sheet
Responding to parents' concerns about childhood immunisation.

Thank you for agreeing to participate in an interview about the issue of childhood immunisation. In this study, we are interviewing some GPs who responded to a survey sent by our team last year. We want to try and better understand how doctors and parents communicate with each other about vaccination.

The study is being conducted by Professors Simon Chapman, Penny Hawe and Margaret Burgess and Ms Julie Leask from the Department of Public Health and Community Medicine and National Centre for Immunisation Research.

The interview will involve role playing some typical ‘concerned parent’ scenarios. I will play the role of the parent and you shall be asked to respond in role and then given an opportunity to comment on your approach at the end. The interview will not be a test of knowledge but an attempt to describe the range of communicative strategies used by immunisation providers when responding to parents' concerns about immunisation. The interview will take about 30 minutes.

To help us in writing a report on this study the interview shall be tape recorded. You will not be asked to identify yourself on the tape. The tapes will be transcribed and the tapes erased. The transcripts will be stored securely for 5 years in an office within the University and then destroyed. All aspects of the study, including results, will be strictly confidential and only the investigators named above will have access to information on participants. A report of the study may be submitted for publication, but individual participants will not be identifiable in such a report.

Your participation in this study is completely voluntary. If you decide that you no-longer wish to take part, you are free to withdraw at any stage. If you have any questions about any aspect of the project, please call me on 9351 7739 or Simon Chapman on 9351 5203.

This study has been approved by the University of Sydney Ethics Committee. Should you have concerns or complaints about the conduct of this research study you can contact the Manager of Ethics and Biosafety Administration, University of Sydney, on (02) 9351 4811.

Yours sincerely,
Julie Leask (Research Assistant)
Appendix 13
Consent form for general practitioners

The University of Sydney

NSW 2006 AUSTRALIA

RESEARCH STUDY:
RESPONDING TO PARENTS' CONCERNS ABOUT CHILDHOOD IMMUNISATION.

PARTICIPANT CONSENT FORM

I hereby agree that I have voluntarily agreed to be interviewed about immunisation.

I understand that the conversation will be tape recorded but that I will not be identified in any report or publication arising from this research, nor in any other way.

I hereby agree to participate in this research study.

NAME: ________________________________
SIGNATURE: ___________________________
DATE: _________________________________
NAME OF WITNESS: _____________________
SIGNATURE OF WITNESS: ___________________
Appendix 14