

# To MMR or Not MMR: Medical Discourses Surrounding Parental Decision-Making for Pediatric Immunization

by

Jen-Yin Shao

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for the degree of Master of Sciences

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# To MMR or Not MMR: Medical Discourses Surrounding Parental Decision-Making for Pediatric Immunization

Jen-Yin Shao

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## Abstract

Coverage for the combined measles, mumps, and rubella vaccine (MMR) has been low since the publication of Wakefield's 1998 study associating MMR with the onset of autism. As a part of a larger project on risk communication, this study examined the medical discourse on parental decision-making for childhood immunizations to gain insight on why risk communication efforts have not been successful at improving uptake. The Public Understanding of Science (PUS) was used as a theoretical lens to guide Critical Discourse Analysis of texts from medical, pediatric, and public health journals, from which the analytic themes of Risk and Trust emerged. MMR uptake was framed mainly in terms of risk, indicating the dominance of the Deficit Model of PUS in the discourse. Future research and risk communication need to expand beyond current notions of risk; the Contextual Model of PUS can help highlight other factors that impact parental decision-making about MMR.

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# 1 Introduction

## 1.1 Aim of Research

This study is part of a larger project on risk communication and discourses on parental decisions concerning MMR vaccination. In this phase of the project, the discourse in the medical literature will be critically examined through the theoretical lens of Public Understanding of Science (PUS) in order to characterize and problematize the nature of existing assumptions about parental decision-making. The aim is to show through the Contextual Model of PUS how current medical discourse understands or constructs parental decision-making for MMR. It will be posited that any uptake strategies based on problematic accounts of parental decision-making about vaccination are not likely to be effective. Thus, the Contextual Model will be used to show the current medical discourse is problematic and to indicate potential areas to explore to improve risk communication strategies that go beyond the understandings in the medical discourse. The findings from this study will provide the background to the broader project on risk communication by informing the interview guide and identifying thematic areas for exploration in subsequent stages.

## 1.2 Background

Vaccinations have been widely hailed as one of the most important developments in medicine. Medical professionals generally agree that vaccines are effective in preventing potentially devastating illnesses, and many developed countries have systems for ensuring that the population is immunized during childhood for diseases such as measles and polio, among others (Bonanni and Bergamini 2002; Schmitt 2002). Since vaccines became widely administered, the rates of certain diseases have dropped drastically. Over the past 100 years in Canada, vaccines have helped reduce the incidence of diseases by 95% (Avis, Tan *et al.* 2007) while in the United Kingdom, measles was nearly eradicated (PLoS Medicine Editors 2006).

Vaccines have successfully eradicated devastating diseases such as smallpox and eliminated polio in most of the world, while significantly reducing the incidence and severity of numerous other illnesses (Upshur 2003). However, there has been difficulty in convincing some parents to

have their children immunized. As vaccine-preventable illnesses became less common in developed nations, immunization coverage among the population began to decrease. Parents' concerns appear to have shifted from the disease itself to the safety of the vaccine and associated complications (Gust, Kennedy *et al.* 2005). Unlike other medical interventions that are aimed at those who are ill, vaccines are administered to healthy individuals to prevent disease; thus the risk of an adverse event resulting from vaccination is much less "acceptable".

In particular, target uptake levels for the measles-mumps-rubella combination vaccine (MMR) have been difficult to achieve amidst concerns over its alleged link to autism in countries where uptake had previously been high, such as the United Kingdom, Canada, and the United States (Middleton and Baker 2003; Pearce, Law *et al.* 2008). The controversy surrounding the MMR vaccine makes it a good model for investigating how a public health initiative such as vaccination can become undesirable by some, when at one point in time it was considered a privilege (Brundtland 2002). Also, the MMR vaccine is discussed in a sufficiently large body of research, making it an ideal case for studying discourses on vaccine uptake.

Many have traced the origin of the MMR controversy to a study by Wakefield *et al.* (Wakefield, Murch *et al.* 1998) that was published in *The Lancet* in February, 1998 that investigated a hypothesized link between autism, bowel disease, and the MMR vaccine (Editors 2000; Stroud and Laura 2005; Offit 2008). While the authors stated that they found no evidence of the MMR vaccine triggering the onset of autism in children and conceded that vaccination is important and should be continued, Wakefield also recommended the separate administration of vaccines for measles, mumps and rubella. This recommendation was picked up by the media and was widely reported, stirring fear among the public as people began to question the safety of the combined vaccine (Casiday 2007; Elliman and Bedford 2007).

Other researchers tried to follow up on Wakefield's study, though the majority of studies found no support for the purported link between the MMR vaccine and autism (DeStefano 2007; Hornig, Briesse *et al.* 2008), and the paper was partially retracted in 2004 (Horton 2004). However, media coverage for the two sides of the argument was disproportionate, with equal weight given to both views, when in fact there has been much more evidence against a causal association between MMR vaccine and autism than for it (Horton 2004). Also, parents' concerns could not be adequately addressed with the little information that was available about the causes

of autism and the safety of the vaccine. While studies were conducted soon after the *Lancet* publication to investigate the link, these findings were not available soon enough to assure anxious parents. Uptake for MMR declined as a result.

The United Kingdom experienced the greatest impact to MMR uptake rates, which dropped from 90.4% in 1997 (ICES 2009) to a low of 79% in 2003 (Pearce, Law *et al.* 2008). With the fall in uptake, the number of measles cases increased, from 773 to 1004 between 2006 and 2007 (Middleton and Baker 2003). Some parents decided to switch to single antigen vaccines for measles, mumps, and rubella, while others opted out of vaccination altogether (Casiday, Cresswell *et al.* 2006).

While vaccination by single antigen vaccines is better than no vaccination, the use of single antigen vaccines is considered by medical experts to be less preferable than the MMR vaccine for a number of reasons. First, there is no scientific support for the benefit in using the single antigen vaccines, and little is known about their effectiveness relative to the triple vaccine (Harden and Shakespeare 2001; Pearce, Law *et al.* 2008). Also, the single antigen vaccines require more injections and more visits to the physician's office, which increases the likelihood for children to be incompletely vaccinated or not vaccinated on schedule and leaves the child vulnerable to infection between vaccinations (Harden and Shakespeare 2001). In the United Kingdom, uptake for single antigen vaccines cannot be tracked because they are only provided by private practices and the information does not get transferred to the national health database (Elliman and Bedford 2007).

According to the World Health Organization, a minimum coverage of 95% for MMR is needed to eliminate the diseases from Europe (Middleton and Baker 2003). A high level of coverage also helps to maintain herd immunity and minimize the risk of disease break outs. Herd immunity is important for protecting those who, for health reasons, cannot be immunized and those who are unable to develop immunity, as it ensures the people surrounding these individuals are free of disease. In Canada, the national target for immunization is 97%, though ICES data from 2009 showed that less than 67% of 2 year olds in Ontario had complete immunization coverage (ICES 2009). Although vaccination has been a highly successful public health initiative in Canada, mumps outbreaks were reported in 2005, with the majority of those infected found to be unvaccinated (Peltola, Kulkarni *et al.* 2007). The recent outbreaks in New Jersey

and Quebec among Orthodox Jewish boys who attended a summer camp in Sullivan County, New York, is a reminder that uptake levels still need improvement in some areas. In these cases, local religious leaders have spoken out and urged members of their community to immunize their children (Lerner 2009). While coverage at the national level may be high in Canada, immunization coverage varies widely at the community level. Thus, some communities are in fact more vulnerable to outbreaks than others, and the threat of disease re-emergence cannot be ruled out (Avis, Tan *et al.* 2007).

The most commonly proposed solution to improving uptake is to provide more information to parents about the benefits and the “real risks” of the vaccine (Ramsay 2001; Brundtland 2002). Nevertheless, uptake for MMR has been slow to recover. In the United Kingdom, coverage reached only 85% in 2007 (Pearce, Law *et al.* 2008), which is short of the 95% target for achieving herd immunity. Even among parents who had their children immunized, there were some who still had doubts about its safety (Casiday, Cresswell *et al.* 2006), which suggests that current methods of communicating risk have not been effective in addressing parents’ concerns.

Research by Borchelt and Hudson (Borchelt and Hudson 2008) has found that public reception of scientific information is influenced by the way in which scientific establishments communicate to and about the public. The call for more education for parents implies that parents chose to opt out of vaccination for their children due to a knowledge deficit (McGuire 1997; McGreevy 2005). However, some studies have found that many of the parents who refused the vaccine had in fact done their own research and were quite knowledgeable about the vaccine (Gullion, Henry *et al.* 2008). Parents refusing vaccination are usually educated, middle-class citizens who follow alternative beliefs and have low trust in the government. (Gullion, Henry *et al.* 2008)

Perhaps there is something wrong with the current approach to parental decision-making, and efforts to educate parents are misguided as the parents who are refusing MMR are often the ones who are most knowledgeable about it. This incongruence leads to the present study, which will attempt to provide a closer examination of the dominant medical discourse and how it constructs parents and their decisions regarding child vaccination. This study attempts to answer the following research question: what does the dominant, mainstream, medical discourse around

parental decision-making and uptake of childhood immunizations reveal about the construction of non-vaccinating and vaccinating parents?

As a part of a larger research project on risk communication (as shown in Figure 2 in the Methodology chapter), the purpose of this study is to critically examine the formal, written medical discourse in the journal literature through the lens of the Contextual Model of PUS. An analysis of the formalized, written discourse on parental uptake of childhood vaccines is a first step in understanding the disparities between medical and lay (parental) understandings of the science and risks pertaining to vaccination. It is therefore useful to explore the way in which the dominant medical discourse constructs the problem of declining vaccination uptake in order to understand why risk communication about vaccination has not been as successful in improving uptake as desired. This is important because the medical discourse is composed of ideas, attitudes, beliefs and practices that systematically construct the subjects of which it speaks. Once we have an understanding of what is contained in and what is problematic about this discourse, we can then go on to ask in the context of the broader research program: what is the role of this discourse in the wider context of MMR vaccination uptake, and parental decision-making? Hence, the aim of this thesis is to problematize the discourse, as it is a formalized system of thought that both reflects and constructs the dominant beliefs about immunization uptake and decision-making by parents. Secondly, the aim is to show how the Contextual Model of PUS can suggest alternative framings of the issue. In order to answer the research question, three objectives were set:

1. Compare constructions of vaccinating and non-vaccinating parents in the medical discourse by examining the medical journal literature in the decades before and after the 1998 Wakefield publication; that is, from 1988 to the present
2. Examine, through the lens of the Contextual Model of PUS, how the medical discourse understands parental decision-making for immunizations
  - What are the reasons given for parents' decisions (to fully vaccinate, to not vaccinate, to delay vaccination, or to vaccinate only partially)?
  - How does the discourse frame the issue of non-vaccination?

- What solutions does the discourse propose to the problem of non-/under-immunization for children?
3. Suggest possible and alternative framings of the issue of declining childhood immunization uptake using insights from the Contextual Model of PUS, based on the scientific understanding of the public (rather than the public understanding of science)

In examining the discourse in the medical literature around parental uptake of the MMR vaccine, particular attention will be paid to the way in which parental decision-making for childhood vaccinations is discussed in the medical discourse. For example: how does the discourse deal with the notion of expertise? What does it posit as the reasons for why some parents vaccinate and not others? These are the kinds of questions that are of interest in this study.

### 1.3 Chapter Overview

This chapter provided an introduction to the issue of immunization uptake, for the MMR vaccine in particular, a brief history of the MMR controversy and explained the aim of this study.

In the next chapter (Chapter Two), I will provide an overview of the theoretical framework guiding my analysis, Public Understanding of Science (PUS). I will discuss the two models within PUS, the Deficit and Contextual Models, and the assumptions they make about the public, science, and the “transfer” of knowledge.

Chapter Three describes the methodology of this study, including the methodological framework, Critical Discourse Analysis, and the procedures for data collection and analysis. I will also explain how the data were managed and organized.

The Results will be presented in Chapter Four, which seeks to answer the questions of what reasons are attributed by the discourse to parents’ decisions, how the issue of non-vaccination is framed, and what solutions are proposed by the discourse for improving vaccination uptake among parents.

The Discussion of the analytic categories that emerged from the process of categorical aggregation will follow in Chapter Five. The overarching themes that define the discourse will

be discussed in greater detail, and the medical discourse will be examined through the lens of the Contextual Model of PUS. There will be a discussion about the strengths and limitations of this study as well as the implications of the findings from this study for risk communication. At the end of the chapter, the major findings from this study will be summarized.

Chapter Six concludes this thesis with a brief overview of the next steps of the larger project on risk communication and suggestions for other possible directions for future research.

## 2 Literature Review

In this chapter, the theoretical framework that informs this study, Public Understanding of Science (PUS), will be outlined. The assumptions underlying the two models within this framework will be described, and it will be argued that a Contextual Model approach to the public understanding of science provides greater insight than does the more conventional Deficit Model.

### 2.1 Overview of the Public Understanding of Science

As science and technology advanced in the 20<sup>th</sup> century, it played a greater role in people's everyday lives, but it also became too specialized for non-scientists to understand. Western society became increasingly dependent on specialized roles and institutions that were associated with specialized knowledge and skills (Irwin and Wynne 1996). However, a number of controversies involving public resistance to specialized, expert knowledge, including concerns over bovine spongiform encephalitis (BSE) in the UK (Irwin and Wynne 1996), genetically modified foods (Irwin 2001), and vaccine safety, drew attention to the need to study the ways in which science and technology interacted with the lay public.

From the Sociology of Scientific Knowledge, Public Understanding of Science (PUS) emerged as a discipline focused on examining the relationship between science and the public. Much of the interest in PUS originated from the field of risk studies, from frustration among experts over the apparent inability of the public to comply with expert assessments of risk (Irwin and Wynne 1996). Accordingly, theories were developed that centred on perceptions of risk, expertise, and trust (Irwin and Wynne 1996). The Sociology of Scientific Knowledge has not been applied to the case of MMR uptake, though it may offer insights that the current medical approach cannot. The issue of MMR vaccine uptake can be framed as a disagreement between medical expertise and lay public understandings of the safety and value of the MMR vaccine, so the PUS is a good theory to use in this study as it has been used in other contexts to look at the differences between expert and lay perceptions of science (Wynne 1989; Irwin and Wynne 1996). There are two



models in PUS, the Deficit Model and the Contextual Model, which will be described in detail below.

## 2.2 Deficit Model of PUS

In 1985, the Royal Society published a report chaired by Dr. Walter Bodmer on the public understanding of science, in response to concern over waning public interest in, and support for, science (Sturgis and Allum 2004). The main message of the Bodmer Report was that greater scientific literacy by the British public was essential to the well-being of the nation, as “science and technology play a major role in most aspects of our daily lives both at home and at work” and “our industry and thus our national prosperity depend on them” (1985). In order to increase the public’s understanding of science, the Bodmer Report called for improved dissemination of scientific information by scientists and the media, stating that “there is scope for more science in the media” and that “scientists must learn to communicate with the public, be willing to do so, and indeed consider it their duty to do so” (1985).

Greater public understanding of science was said to be beneficial for a number of reasons. Efforts to educate the public and improve understanding about science and technology were justified with arguments about workforce requirements for technical literacy. For example, future generations of scientists needed to be trained to help solve the world’s problems. Greater scientific understanding by the public would also benefit modern democracy (Irwin and Wynne 1996), as a scientifically informed public would be in a better position to understand and negotiate policies with experts. People would be better able to assess competing technical arguments related to policy, and they would also be better at distinguishing between “logic and trivia” in government debates (Lewenstein 1992). Science was argued to be essential to human development as it “offers a uniquely privileged view of the everyday world” (Irwin and Wynne 1996).

Thus, in the beginning, PUS research was focused on measuring scientific literacy and attitudes towards science held by the public through survey questionnaires. By assessing and identifying areas where public knowledge of science was lacking, it was thought that initiatives could be taken to raise understanding in these areas to the levels needed to make informed decisions

regarding public issues. These surveys found that public knowledge was low for scientific concepts taught in high school and supported the view that the public was deficient in scientific knowledge (Sturgis and Allum 2004).

This perspective taken by the Royal Society on the relation between science and the public came to be known as the Deficit Model. The Deficit Model is aligned with the positivistic paradigm of the scientific worldview and shares the assumptions made by many biomedical scientists. Science is regarded as an objective and neutral process that allows people to discover truths, or “facts”, about the world. There is a clear distinction between “facts” and “values”. “Facts” are believed to be independent of the wider social, economic, and moral context (Irwin and Wynne 1996) and can be separated from “values” through objective, scientific methods.

Irwin and Wynne (Irwin and Wynne 1996) identify three assumptions underlying the Deficit Model of the PUS:

- The public is ignorant in matters related to science and technology, and this ignorance leads to controversies over technical issues
- Science is important for improving quality of life; to quote Max Perutz (from Irwin & Wynne, 1996): “It is science alone that can solve the problems of hunger and poverty, of insanity and illiteracy...”
- Science is a value-free and neutral activity

The Deficit Model takes a science-centred perspective, where findings about people are based on the concept of the “typical citizen”, an average from the population under study. Accordingly, the public is generalized into an average individual and treated as a homogenous entity. People are assumed to be equally ignorant about science, and the same strategy for disseminating knowledge applies to everyone. The relevance of and social opportunities for using scientific knowledge are also assumed to be equal for everyone, without consideration of social structures of power and dependency. That is, the Deficit Model assumes that everyone has the same need for and is in the same position to employ scientific knowledge (Irwin and Wynne 1996).

In the Deficit Model, information flows in one direction, from experts to the lay public. The public is assumed to be “deficient” in knowledge about science, which is itself “sufficient” (Miller 2001), so knowledge needs to be provided to the public by experts, or scientists. The

scientific worldview is believed to be superior because it is based solely on the “facts” and is unaffected by values and emotions. The public is viewed as emotive and irrational, whereas science is objective and value-free, thus the local knowledge and experiences possessed by lay people are not recognized as legitimate. However, as the Contextual Model will argue below, local knowledge and experiences are important for assessing the relevance and applicability of science in real world conditions.

“Ignorance” is defined according to the Deficit Model as an absence of knowledge, as measured against scientific standards (Irwin and Wynne 1996). Scientific understanding requires that the facts, theories, and principles of science are taken up by the public exactly as they are provided (Miller 2001); in other words, knowledge is to be understood in scientific terms. Failure to take up scientific knowledge is treated as an indication of intellectual incapacity (Irwin and Wynne 1996). Resistance to science is believed to result from the public’s supposed inability to cope with the fact that risk and uncertainty are involved in everything and its demand for science to provide certainty and risk-free environments, which is acknowledged in science to be impossible (Irwin and Wynne 1996). In other words, the public is believed to lack an understanding about probabilities and uncertainties.

According to the Deficit Model, rejection of science stems from a lack of (accurate) scientific information, which makes the public susceptible to myths and irrational fears of the unknown and pseudo-science (Sturgis and Allum 2004). Acceptance of science and technology by the public is assumed to be directly correlated to the amount of knowledge that the public possesses about science. Thus, the rejection of science and technology is constructed as a simple information deficit, and all that would be required to remedy the problem is for experts to fill the public in on the appropriate information, or the “facts”.

By framing non-uptake of science as a problem of the public failing to understand and accept science, the operation of scientists and scientific institutions has not received much consideration (Irwin and Wynne 1996). Public trust in scientific experts, institutions, and the value of science is taken for granted as already established. The Deficit Model perspective assumes that the public shares the same values as scientists, in particular those relating to what is considered useful or relevant (Irwin and Wynne 1996). This assumption of trust in scientific experts and institutions will later be shown by the Contextual Model to be problematic.

## 2.3 The Deficit Model and Public Health

Many models that attempt to explain health behaviour share the positivistic perspective held by the Deficit Model and predict behaviour based on cognitive variables without taking into consideration social and contextual influences on decision-making (Tsutsui, Benzion *et al.* 2010). One of the more popular models used in health promotion, the Health Belief Model, is described below. It is relevant to this study because it is often the conceptual model underlying risk communication strategies in public health that aim to alter personal behaviour.

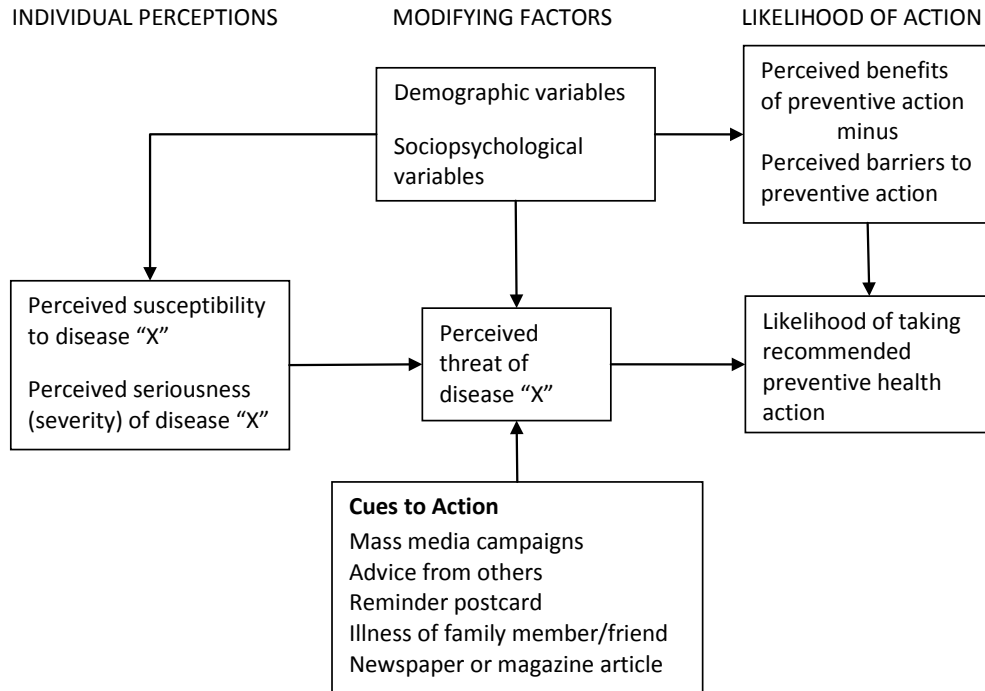
### 2.3.1 Health Belief Model

The Health Belief Model (HBM) is one of the most widely used frameworks for explaining health behaviours and for developing interventions to change health behaviours (Galvin 1992). It was developed in the 1950s by social psychologists to help explain why medical screening programs by the U.S. Public Health Service were not very successful (Glanz, Rimer *et al.* 2008).

The model predicts behaviour on the basis of six key constructs: (Glanz, Rimer *et al.* 2008):

1. Perceived severity of disease or health threat
2. Perceived susceptibility to disease or health threat
3. Perceived benefits of taking action to reduce health threat
4. Perceived barriers to taking a particular health action
5. Cues that trigger an individual to undertake a health action
6. Self-efficacy, or the perception that one can successfully implement a health action

Figure 1. Diagram of the Health Belief Model (Janz and Becker 1984)



The HBM is often used to inform the development of health interventions (Webb, Sniehotta *et al.* 2010) and to identify factors related to the uptake of health interventions (Petty, Callahan *et al.* 2010; Tsutsui, Benzion *et al.* 2010). For example, in a study by Petty, Callahan *et al.* (2010), a survey was conducted based on the HBM to determine the factors that were associated with parental acceptance of the cytomegalovirus (CMV) vaccine for their daughters. In this study, the desired health action was vaccination against CMV, which was measured using parental vaccination intention as a proxy. Perceived susceptibility to disease referred to a daughter's risk for becoming infected with CMV, while perceived severity referred to the consequences of a daughter or her unborn child contracting the disease. Perceived barriers were represented by how difficult it was to obtain the vaccine and perceived benefits was constructed as the expected benefits of having a daughter vaccinated. In this study, perceived benefits, as well as an additional domain consisting of normative beliefs, were identified as being positively associated with parental acceptance of the CMV vaccine.

We will see that there is also evidence of the HBM at work in the case of MMR immunization, where experts are trying to understand why some parents refuse to have their children vaccinated and non-uptake is discussed in terms of the perceived risks of the disease, the benefits of vaccination, barriers to access, and concerns about adverse effects. The HBM can be regarded as a formalized or codified version of the Deficit Model, as it assumes that there is a single definition of risks and benefits, and that the model can be applied equally to all individuals from populations that are similar to study samples without consideration of contextual factors that are not related to health but that could impact decision-making. Thus, people may sometimes behave in ways that are unexpected by the model, as in the case of smoking cessation, in which people continue to smoke despite awareness of the detrimental effects it has on health. Similarly, MMR vaccination uptake also cannot be explained by the HBM, as some educated parents refuse to have their children immunized despite well-documented evidence of the safety and benefits of the vaccine. Because the Deficit Model is unable to account for other factors involved in an individual's decisions about health interventions that are not directly health-related, a different approach to the public understanding of science was developed, known as the Contextual Model.

## 2.4 Contextual Model of PUS

The Contextual Model arose from a post-positivist, social constructivist theoretical tradition as a response to the Deficit Model. Drawing from the fields of sociology, history, and philosophy, the Contextual Model is a more reflective approach to the public understanding of science (Miller 2001). Researchers in the social sciences pointed out that it was useless trying to educate the public about science and to examine how information is disseminated to the public if the public is not first convinced that it is important to understand science (Lewenstein 1992).

Whereas the Deficit Model is concerned with public understandings of science, the Contextual Model of PUS does not regard the scientific worldview as unproblematic and as having a privileged position over other interpretations of the world. It is equally interested in studying how the public is understood by science as how the public understands science. Thus, with the Contextual Model, it is possible to critically examine how the medical discourse constructs parental decision-making and perceptions about MMR vaccination.

The superiority of the scientific worldview is disputed by the Contextual Model, which rejects the Deficit Model assumption that there is a reality that can be discovered only through the scientific method. According to the Contextual Model, the scientific worldview also comes with a set of social commitments and values, and what counts as science is shaped by social relations and institutions (Irwin and Wynne 1996). Unlike the Deficit Model, the Contextual Model asserts that knowledge is socially constructed, and scientific findings are a reflection of a particular set of social values. It argues that it is important for experts to recognize the limits of scientific forms of understanding, and that there are other “local”, or contextual, forms of knowledge (Irwin and Wynne 1996).

The Contextual Model argues that uptake of scientific knowledge is dependent on context. In particular, trust has been highlighted as an important determinant of whether or not the public accepts information from experts. That is, the public’s understanding of science is not necessarily influenced by scientific content but is related to (moral) understandings of persons and institutions associated with science (Gross 1994; Irwin and Wynne 1996). Whereas the Deficit Model presupposes that the public is already trusting of science and its experts, the Contextual Model posits that science does not automatically command trust, and that trust must be established (Gross 1994). Experts operating from a Deficit Model perspective may believe that knowledge has already been validated within the scientific community before dissemination to the public. When the public is not receptive to expert knowledge, the problem is constructed as one of public misunderstanding, and perhaps scientific miscommunication, rather than one of the organization, control, and/or conduct of “science” (Irwin and Wynne 1996). However, the Contextual Model states that knowledge is re-validated by the public.

In turn, according to the Contextual Model, people’s definitions of risk are tied to the perceived credibility and trustworthiness of the social institutions that provide risk information (Gross 1994; Irwin and Wynne 1996). Knowledge is not perceived independently of the context in which it is developed and communicated (Irwin and Wynne 1996). As McKechnie writes, “scientific expertise is identified, experienced, and responded to in terms of the institutional, cultural, and social dimensions in which it is always and inevitably embedded.” (Irwin and Wynne 1996) Expert risk assessments usually take the trustworthiness of relevant institutions for granted (Wynne 1991). There is a lack of reflexivity, or awareness of institutional interests on the part of scientists, which can lead the public to distrust science (Irwin and Wynne 1996),

where science may be viewed not as empowering for the public but as a resource for legitimating the social stance of certain privileged groups (Irwin and Wynne 1996).

For example, if the current discourse takes a Deficit Model perspective and privileges medical expertise over the experience and knowledge of parents, then perhaps the decision by some parents to opt out may be a form of resistance to the power of prevailing medical knowledge. Refusal of vaccination would then be a conscious choice that is made not out of ignorance, but for the purpose of resisting medical authority. If that is the case, it would be important to urge a re-evaluation of the ways in which parental understandings of diseases and vaccines are constructed in the medical discourse, as they might be contributing to the refusal to vaccinate among some parents.

On the other hand, low vaccine uptake stemming from a lack of confidence in vaccines among parents may be a response to distrust among medical experts of parents' "local" knowledge, or everyday experience, and their capacity to make reasonable decisions (Borchelt and Hudson 2008). It is important to examine the medical discourses about vaccine uptake decision-making by parents, as discourses both reflect and shape ideas about the lay public and vaccination, some of which may be problematic. The findings of this study may have implications for risk communication, as health promotion strategies that are rooted in problematic assumptions about the public may not be able to achieve the desired degree of success in communicating with parents about vaccines.

The Contextual Model also posits that the context and nature of the information providers also influences understandings and reception of information by the public. In one example of this, although visitors to a Food for Thought exhibit at the Science Museum in London were under the impression that the exhibit was authored by the food industry (and therefore possibly biased towards advertising sponsoring companies), they were also certain that scientists from the museum would ensure that the information presented was balanced (Irwin and Wynne 1996). The fact that the exhibit took place in the Science Museum, a respected and authoritative source for scientific information, modified visitors' perceptions of the credibility of the exhibit.

According to the Contextual Model, the way in which scientific information is perceived may also be affected by contextual factors of the receivers such as personal experiences. Certain risks will stand out more based on social norms (Sturgis and Allum 2004), so some information will



be perceived as more useful and relevant than others. Therefore, people's fears may not be irrational but reflect the norms of their culture and context, which shape ideas about risk and what can be considered acceptable (Irwin and Wynne 1996). People may also oppose science on the basis of particular core views and core beliefs. Rejection of science is not necessarily related to a lack of understanding about science (Sturgis and Allum 2004).

The Deficit Model approach assumes that the public receives scientific knowledge on a blank slate. However, according to the Contextual Model, people do not passively receive the information that experts provide to them; they actively learn about science and share their knowledge with others (Irwin and Wynne 1996). New scientific information interacts with other forms of knowledge that the public already possesses and is integrated with prior knowledge and understandings (Irwin and Wynne 1996). Thus, scientific knowledge is jointly constructed by experts and the public, as the public perceives, integrates, and modifies information according to their own needs, experiences and understandings of the world (Wynne 1991; Gross 1994). Public understanding of science is an interactive process between experts and lay people (Wynne 1991). While lay people are influenced by information from experts, experts can also be informed and influenced by lay people. Experts may select the information to share with the public, but public demands also shape future research directions (Irwin and Wynne 1996). Thus, the Deficit Model approach is criticized for its reliance on surveys that measure the public's understanding of science against an authoritative body of scientific knowledge, pitting a knowledgeable science against a deficient public (Irwin and Wynne 1996). Questionnaires may quiz the public about scientific facts and theories that are irrelevant to people's daily lives and may not allow respondents to express knowledge that they do possess, so they are not an appropriate measure of how much the public knows about science (Wynne 1991). Lay people may also possess knowledge that may not meet scientific standards of rigour, but are nevertheless consistent with scientific information.

The survey approach has also been criticized for treating people as "repositories" of information from which experts can simply take samples from and describe their contents (Irwin and Wynne 1996; Turner and Michael 1996). The level of scientific expertise varies among lay people as some information will stand out in people's minds more than others depending on their context (Irwin and Wynne 1996). The public is heterogeneous and made up of diverse groups, so there are in fact many publics, and the relevance of scientific information varies among different

groups with different information needs. Information is taken up according to its relevance to people's needs (Gross 1994; Irwin and Wynne 1996). What counts as relevant, useful, or necessary information also varies between individuals and situations (Irwin and Wynne 1996). Expert knowledge is often ignored by social groups because it has not been tailored to the needs, constraints, and opportunities that exist in their social situation (Irwin and Wynne 1996).

There is also variation in the kinds of information offered by different social groups in different situations (Irwin and Wynne 1996). The communication of science is not a value-free process of transferring information, as it involves selection and definition of what counts as science, as well as decisions about what kinds of understandings the public may make. These judgements may be influenced by institutional context, as shown in a study by MacDonald and colleagues on the development of the Food for Thought exhibition for the Science Museum in the United Kingdom (Irwin and Wynne 1996).

Thus, the Contextual Model presents both science and the lay public as diverse, and dynamic, as opposed to the more conventional, Deficit Model perspective of science as a unified and cleanly bound body of knowledge (Wynne 1991). Additionally, scientific knowledge is regarded as historically contingent, as demonstrated by the changes in dietary guidelines for controlling cholesterol levels and shifts in recommended cholesterol levels over the years (Irwin and Wynne 1996). However, the contingencies of scientific evidence are obscured in medical practice, where scientific evidence is treated as concrete facts (Irwin and Wynne 1996).

Another flaw with the Deficit Model is its treatment of public "ignorance" as a simple deficit of information, that is, there is an absence of information that can be filled through education (Gross 1994). Some studies have shown that "ignorance" is in fact actively constructed by people, based on their social and political contexts (Turner and Michael 1996). The public has been found to be capable of reflecting upon their relations to scientific knowledge and institutions, and are aware of their "ignorance". Thus, people may "choose" to be "ignorant" for various reasons, including the maintenance of boundaries between experts and non-experts. For example, interviews with Sellafield electricians found that ignorance served to help define their roles and responsibilities, with electricians claiming to have little knowledge of ionizing radiation because it was not their job to know about it (Turner and Michael 1996). Causes and reasons for "ignorance" can reflect perceived social relations between science and the lay public.

On the other hand, because the Contextual Model emphasizes the unique circumstances of individual cases, it may be criticized for its lack of more quantitative and rigorous methods such as survey measures and statistical analysis (Gross 1994). Nevertheless, Gross (1998) argued that the methodological rigour of case studies used by proponents of the Contextual Model can be improved through structured comparisons of carefully selected cases. As a result, the Contextual Model approach can generate knowledge that is no less legitimate than knowledge generated by scientific methods.

## 2.5 Summary

In the beginning, research in PUS served to identify and assess the gaps in the public's knowledge about science and technology, taking a Deficit Model perspective of public understanding. Science was deemed as essential to development, yet surveys have found the public to be lacking in knowledge about science and technology. Experts also encountered difficulties in communicating risk information to the public, which were attributed to public ignorance about science. A number of initiatives in the United Kingdom aimed to educate the public about science under the assumption that greater public understanding about science would lead to increased support for science. This approach, as will be shown in this study, is still prevalent in medical discourses and takes public trust in science for granted, at least with regards to vaccination uptake.

The Contextual Model of PUS takes a more complex perspective of both science and the public, viewing both as heterogeneous and dynamic, shifting with context. Indeed, context is considered essential to the uptake of information, and one important contextual factor is trust. Information from a source that is not considered by the public to be trustworthy will not be trusted or have credibility. Using the Contextual Model of PUS will help surface problematic issues and point to areas for further research when it comes to the understanding of parental uptake of the MMR vaccine.

### 3 Methodology

This chapter describes the process by which data collection and analysis was conducted in this study. As a part of a larger project, this study examined the written medical discourse found in the medical journal literature. An overview is given of Critical Discourse Analysis, which was used to analyze the texts from the top impact factor journals that comprised the medical discourse for this study. The data was coded in three stages and interrogated through the lens of the Contextual Model of PUS to identify emergent themes in the discourse.

#### 3.1 Discourse Analysis

During the 1950's there was a shift in the social sciences, known as "the turn to language", in recognition of the power of language and the insights it offers to social life (Wood and Kroger 2000). With the turn to language, or discourse, new methods were developed that comprised Discourse Analysis, on which there are many perspectives. The most commonly used version of Discourse Analysis is that described by Potter and Wetherell (Webb, Sniehotta *et al.* 2010). They regarded Discourse Analysis as not only a method, but as a collection of approaches to discourse including data collection and analysis, metatheoretical assumptions, as well as a body of research claims and studies (Wood and Kroger 2000). It is regarded as a perspective on social life that is concerned with ways of thinking about discourse as well as with ways of treating *discourse as data* (Wood and Kroger 2000). Discourse Analysis focuses on discourse as texts and talk in social practices, unlike other methods of studying language such as linguistics, in which language is conceptualized as a set of grammatical rules and vocabulary.

Other approaches to Discourse Analysis include the genealogical approach developed by Foucault, which looks at how texts are socially and historically located (Garoon and Duggan 2008), and the archaeological approach which is interested in structures and systems of thought that are manifested through discourse (Garoon and Duggan 2008). This study takes the latter approach.

### 3.1.1 The Nature of Discourse in this Study

Language, or discourse, is assumed to be not only used for description and communication; it is also a form of social practice, a way of doing things (Wood and Kroger 2000). Discourse is believed to both construct and reflect the world in which it exists.

Rather than a genealogical approach which examines the social and historical positioning of the medical discourse, this study will employ an archaeological approach. Thus, discourse in this study is taken to represent, to quote Lessa, “systems of thoughts composed of ideas, attitudes, courses of action, beliefs and practices that systematically construct the subjects and the worlds of which they speak.” (Lessa 2006) The medical discourse is taken to reflect the dominant way of thinking about and addressing childhood immunization uptake. For the purposes of this study, the dominant medical discourse is represented by articles from the top ten impact journals from the areas of medicine, paediatrics, and public health. A further discussion of the rationale for this follows in the subsequent section.

### 3.1.2 Critical Discourse Analysis

In order to analyze discourse through the lens of the Contextual Model, a matching “critical” methodological framework was needed. Within the field of Discourse Analysis, Critical Discourse Analysis (CDA) is a widely used qualitative method of inquiry that arose from the traditions of critical social theory (Powers ; Janz and Becker 1984). It can be applied to both written and spoken texts, and it allows for a critical examination of social and cultural practices (Wood and Kroger 2000). It is therefore ideal for a study on the ways in which parental decision-making about vaccination is constructed in the medical discourse, which is regarded as a form of social and cultural practice.

The way in which an issue is described and framed can contribute to the way people think about the issue (Rundblad, Chilton *et al.* 2006). CDA is an approach for studying bodies of knowledge to reveal how meaning is constructed and to problematize assumptions that were previously taken for granted. Some perspectives on CDA prescribe a set of steps for text-based analysis, while others argue that CDA is not a method with a strict set of rules but rather a flexible approach that can be applied to a wide range of research questions and theoretical orientations to study the “interplay of linguistic and sociological forces” (Fairclough 1992; Editors 2010). The

approach to CDA taken in this study will not be as diverse in scope as that described by Fairclough (Fairclough 1992). Instead, this study will take an archaeological approach to Critical Discourse Analysis as described by Garoon and Duggan (Garoon and Duggan 2008) and focus on content analysis of the texts that comprise the dominant medical discourse on MMR immunization uptake.

Within the “universe of discourse” (Garoon and Duggan 2008) on MMR vaccination uptake, which consists of all texts related to MMR uptake, there is a hierarchy of discourse, and it is assumed that at the top of the hierarchy are the discourses found in those journals with the highest ranking impact factors. In other words, journals with high impact factors are assumed to be representative of the dominant, mainstream medical discourse, as impact factors have a great deal of influence within the scientific community (PLoS Medicine Editors 2006). The aim of this study was to examine the mainstream medical discourse found in the texts published in the top ten impact factor journals in medicine, paediatrics, and public health. Since vaccination is considered a medical issue, the social science literature on MMR uptake was taken to comprise the marginal, alternative discourses to the dominant medical discourse within the “universe” of discourse and was not included in this study. Using the insights from the Contextual Model of PUS, the epistemological commitments underlying the discourse were identified, and assumptions that had seemed normal and natural, or taken for granted, were rendered visible and problematized. The context of the Wakefield study was used to help define this data set in a “critical” way by providing the historical setting in which the discourse takes place.

## 3.2 Methods

### 3.2.1 Study Design

This study is conducted as a part of a much larger research project on discourses on parental decision-making for vaccines that will examine the medical, parental, and media discourses. As a part of the larger research project on risk communication (Figure 2), this study will examine the written medical discourse, and the findings from this study will inform the next stage of the larger project in which interviews with primary health providers will be conducted. Later steps will compare the medical discourse with parental discourses on vaccination issues and highlight

the gap between parental and medical discourses to provide insight into why current risk communication efforts have not been successful.

Figure 2. Overview of larger project on childhood immunization and risk communication



This study focused on the “dominant” written medical discourse from journals whose impact factors ranked among the top ten in the fields of medicine, pediatrics, and public health. From these journals, texts related to parental decision-making and uptake for MMR vaccine were identified. Content analysis was used to code the data and identify prevalent themes in the discourse. The process was highly iterative, as it was necessary to cycle between coding stages when further analysis indicated a need to revise categories. The resulting themes were analyzed by Critical Discourse Analysis through the lens of the Contextual Model.

### 3.2.2 Inclusion and Exclusion Criteria

As mentioned above, the focus of this study is on the dominant medical discourse at the top of the hierarchy, which was taken to refer to the discourse found in the ten highest ranking impact factor journals in medicine, pediatrics and public health (a discussion of the limitations to this approach can be found in Chapter 5). All written texts published in the selected journals were included in the data set: editorials, studies, opinion pieces, letters, news, etc. However, the articles needed to address MMR vaccination decision-making by parents, for example, through discussions about parental concerns about the vaccine, trends in vaccine coverage, and strategies for increasing uptake. The articles also needed to be published between 1988 and 2010, or approximately ten years before and after the study by Wakefield that stirred up the controversy over MMR.

Articles were excluded from the data set if they were published before 1988 and if they were not related to parental attitudes and decision-making, or made no mention of possible explanations for vaccine uptake. Thus, papers that were concerned only with establishing or refuting a link

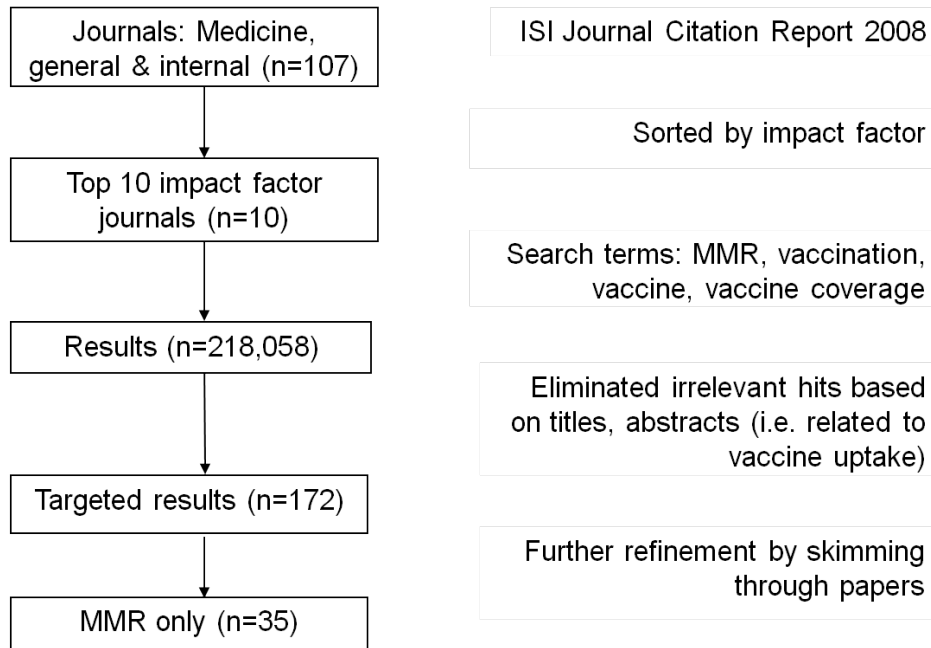
between MMR and autism, and those that focused on biochemical and pharmacological details of MMR, such as vaccine-induced reactions, vaccine efficacy, etc. were eliminated from the data set. Papers that discussed structural barriers to MMR uptake were also excluded, as those were not considered relevant to parents' decision-making.

### 3.2.3 Data Collection

The top ten impact factor journals in each of the disciplines of Medicine, general & internal; Pediatrics; and Public, Environmental, & Occupational Health were identified using the ISI Web of Knowledge Journal Citation Report for 2008, which was the most recent edition available at the time. A search was conducted through each journal by entering the terms "MMR", "immunization", "vaccination", "vaccine", and "vaccine coverage" for any field (which consists of title, abstract, and text), yielding a total of 229,420 papers from all three disciplines. The results were then narrowed down to 252 papers by scanning the titles and abstracts of the articles to ensure they were related to MMR uptake and decision-making by parents, which were then saved. A diagram of the search process for journals from the discipline of Medicine is shown in Figure 3 (the same process was repeated for journals in Pediatrics and Public, Environmental, & Occupational Health). Excel files were also created to keep track of the papers that were collected, including those that were subsequently eliminated from the data set, in case they provided useful, supplementary information for the analysis. After reading through the remaining papers, more papers were eliminated according to the inclusion/exclusion criteria described above, and the papers that fit the criteria were organized into folders according to journal discipline (medicine, pediatrics, or public health) and by journal title. Papers that were collected but that were excluded from the data set were kept in a separate folder for reference.



Figure 3. Diagram of search process for articles in top ten impact factor journals within the discipline of Medicine, general and internal



### 3.2.4 Description of the Data

As shown in tables 1 through 3 below, the majority of the papers came from journals in medical and pediatric journals, and only a handful of papers related to MMR uptake were found in public health journals. The final data set consisted of a total of 64 papers, with 35 from the medical journals, 24 from pediatric journals, and 5 from public health journals. A summary of the kinds of texts that were collected can be found in Table 4.

Before conducting keyword searches in each journal, some of the journals that were identified as top ten impact factor journals were removed from the data set because they clearly were not relevant to the issue of parental decision-making for MMR immunization. Journals such as *Pediatric Obesity*, *Journal of the Academy of Child and Adolescent Psychiatry*, *Birth Issues in Perinatal Care*, *Cancer Epidemiology Biomarkers & Prevention*, and *Tobacco Control* were concerned with entirely different health issues. Other journals were excluded because the issue of MMR uptake was not applicable to the populations that were covered in these journals, in which the individuals were either too young (*Seminars in Perinatology*) or too old (*Journal of*

Adolescent Health) to receive MMR. The numbers of articles from these journals were indicated as “N/A” in the tables to show that these journals were excluded from data collection.

Table 1. Distribution of articles from journals in Medicine, General and Internal

<b>Medicine, General &amp; Internal</b>	
<b>Journal Title</b>	<b>Number of articles</b>
New England Journal of Medicine	6
Journal of the American Medical Association	9
British Medical Journal	8
Lancet	9
Canadian Medical Association Journal	2
Annals of Internal Medicine	0
Archives of Internal Medicine	0
Annual Review of Medicine	0
Annals of Medicine	1
PLoS Medicine	0
<b>Total</b>	<b>35</b>

Table 2. Distribution of articles from journals in Pediatrics

<b>Pediatrics</b>	
<b>Journal Title</b>	<b>Number of articles</b>
Archive of Disease in Childhood	5
Archive of Pediatrics and Adolescent Medicine	5
Birth Issues in Perinatal Care	N/A
International Journal of Pediatric Obesity	N/A
Journal of Adolescent Health	N/A
Journal of the Academy of Child and Adolescent Psychiatry	N/A
Journal of Pediatrics	0
Pediatric Infectious Disease Journal	1
Pediatrics	13
Seminars in Perinatology	N/A
<b>Total</b>	<b>24</b>

Table 3. Distribution of articles from journals in Public, Environmental, &amp; Occupational Health

<b>Public, Environmental, &amp; Occupational Health</b>	
<b>Journal Title</b>	<b>Number of articles</b>
American Journal of Epidemiology	1
American Journal of Public Health	3
Annual Review of Public Health	0
Cancer Epidemiology Biomarkers & Prevention	N/A
Environmental Health Perspectives	0
Epidemiologic Review	0
Epidemiology	0
International Journal of Epidemiology	1
Tobacco Control	N/A
WHO Technical Report Series	0
<b>Total</b>	<b>5</b>

Table 4. Summary of article types from each journal discipline

<b>Article type/ Journal discipline</b>	<b>Medicine</b>	<b>Pediatrics</b>	<b>Public Health</b>	<b>Total</b>
Editorial	2	0	0	2
Letter	10	4	0	14
News	7	1	0	8
Research - Qualitative	1	3	1	5
Research - Quantitative	7	8	3	18
Review	8	8	1	17

### 3.2.5 Data Management

Computer software, such as NVivo, was not used because the data set was not very large and hence it was more efficient to code by hand.

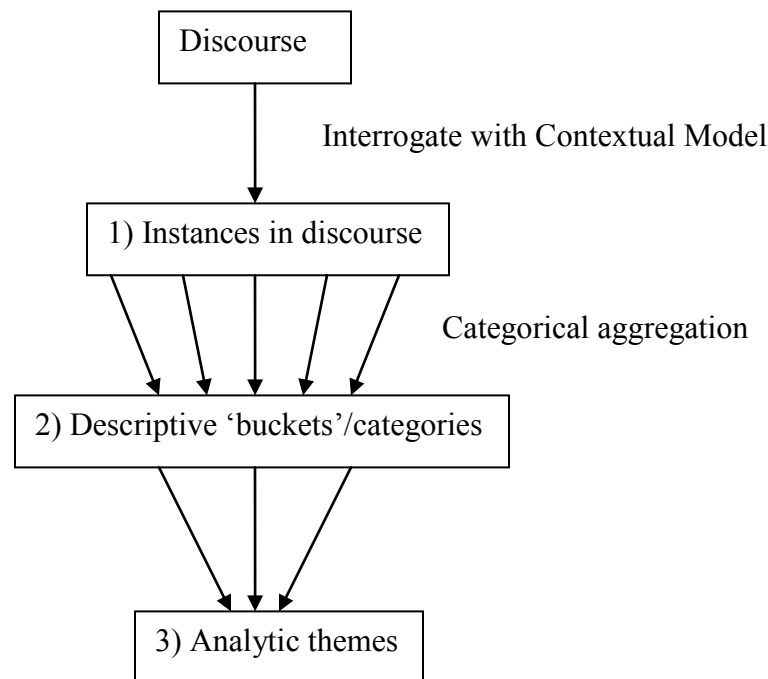
### 3.2.6 Data Analysis

The data were analyzed using Critical Discourse Analysis through the theoretical lens of the Contextual Model of PUS. A brief overview of the coding process is provided here, which consisted of three steps (Figure 4):

1. First stage coding: Highlighting parts of the text that were concerned with parental decision-making and that stood out through the theoretical lens

2. Second stage descriptive coding: Data generated in the first step were “bucketed” into descriptive categories based on a process of “categorical aggregation”. This stage was still descriptive and remained close to the data, as category titles were taken directly from the text.
3. Third stage analytic coding: Second level descriptive categories were further collapsed into theoretically informed analytic themes.

Figure 4. Diagram of coding process



### 3.2.6.1 Coding: Stage One

Initially, coding was broad and descriptive, so a large number of codes were generated based on words or phrases that stood out from the text, without any attempt to abstract any meanings. The first stage of coding consisted of reading and highlighting parts of the texts that stood out through the lens of PUS, keeping in mind the idea that models of the public understanding of science influence the way in which the medical discourse constructs MMR uptake. Parts of the texts were also highlighted if they were deemed relevant to parental decision-making. Phrases

that consistently appeared in the discourse were also noted. The aim of this stage was simply to collect “instances” from the data that could be organized into categories in the next stage, so coding was kept inclusive to avoid arriving at conclusions about the data too early in analysis. The highlighted data were then transcribed to Microsoft Word for ease of organization. Details about the source of the data (author, year, journal, page number) were also noted for future reference. The following is an excerpt from an article by Maldonado that illustrates how the first stage of coding was carried out:

The rare occurrence of vaccine-preventable illnesses in the United States and other developed areas of the world has left the public with a number of misconceptions regarding the continued need for vaccinations. In these areas, there exists a poor perception of the real and continued risk of exposure and illness due to vaccine-preventable infections. (Maldonado (2002) JAMA p3156) (Maldonado 2002)

Through the lens of PUS, the phrases “misconceptions” and “poor perception of the real and continued risk” stand out as they suggest that there is a conflict between the lay and expert understandings about vaccine risk that is expressed in the discourse. The underlined statement “poor perception of the real and continued risk of exposure and illness due to vaccine-preventable infections” was transcribed in Word, along with information about author, journal, year, and page number for later reference.

Early in coding, a question arose about whether there are any differences in the manner in which the discourse describes non-vaccinating, fully vaccinating, and partially vaccinating parents, and parents who believed their children developed autism as a result of MMR. In order to address this question, the data were divided on the basis of the group of parents that was described by the data. There was some difficulty in organizing the data in this manner, however, as it was not always stated explicitly in the texts what vaccination decisions were referred to, as parents were sometimes referred to as one general group. The solution was to create another group, “Parents in general,” or “General”, to contain all the instances of the discourse where it was not clear what kind of decisions were made by the parents described. Whereas non-vaccinating parents received the most discussion in the discourse, this “General” group of parents was also referred to quite often. The incomplete and late vaccinators, parents of children with autism, and parents who vaccinated were rarely mentioned in the discourse.

### 3.2.6.2 Coding: Stage Two

In the second stage of coding, the data highlighted in the previous step were bucketed into descriptive categories in a process known as “categorical aggregation” (Cresswell 1997), in which phrases containing similar ideas or meanings are grouped together, or categorized. It should be noted here that the categories didn’t emerge from the data on their own, but were brought out through the use of the theoretical lens of PUS. Thus, it is possible that with another theoretical lens that looks for different things in the texts, a different set of categories might have been elicited. Analysis at this early stage was still descriptive and stayed close to the data as the titles of the categories were taken from the text, as informed by the PUS theoretical framework. Taking the Maldonado excerpt from the previous section as an example, the highlighted text from stage one was placed under the “bucket” of “risk perception.” The descriptive nature of this stage can be seen in the name of the “bucket,” which came from the text: “perception of [the real and continued] risk...”

Because the coding process was iterative, there was some overlap between first and second level coding. For example, as first level coding progressed, some recurrent terms became apparent, so during first level coding there was eventually some organization in which highlighted text containing similar terms were grouped together. Second level descriptive “buckets” were continually revised as first level items were rearranged and moved around between “buckets” to ensure that the items within each bucket were coherent and similar. New “buckets” were also generated to accommodate items that did not fit adequately in existing “buckets”.

The list of second level, descriptive codes generated from the data are shown in Table 5. Some of these codes were common to all parent groups, whereas others were unique. The codes were continually revised; major changes are shown in Table 5, where some codes were collapsed into one code, and others were newly generated after further analysis. Others were eliminated, in particular those concerning socioeconomic status, as it was decided that these explanations for MMR uptake are not so much a matter of parents deciding to vaccinate or not vaccinate, but more about whether or not they are even able to access the vaccine. Strikethrough font indicates when codes were eliminated from the data set.

Table 5. Lists of Stage Two codes: evolution from intermediate codes to final codes

Stage Three Codes	Stage Two Final Codes	Stage Two Codes- 22/04/2010	Stage Two Codes - 18/03/2010
			<del>Access</del> <del>accuracy of self report of immunisation status</del> <del>demographics</del> <del>education</del> <del>income</del> <del>social inequality</del> <del>socioeconomic</del>
Risk		Risk	risk
	Risk Management	Morals/responsibility	morals, responsibility
		<del>Non uptake factors (terms)</del>	non-uptake factors (terms)
		<del>Non vaccination (terms)</del>	non-vaccination (terms)
		Conflict	conflict misunderstanding
	Education	Risk communication	risk communication communication media
	Risk Perception Credibility of Information Assigning relative weight to risks	Risk perception	link with autism disease severity perspective risk perception vaccine safety (concerns) side effects
		Anxiety	anxiety, fear
		Beliefs	beliefs
		Health beliefs	health beliefs medical
		Government/expert response	Government, expert response
	Evidence	Evidence	evidence decision-making
		Information source	information source information request
Trust	Credibility of Science	Trust	trust in vaccine trust in government
	Control Coercion	Control	control
	Irrationality Trusting the Public		
	Physician-patient relationship	General Practitioner	general practitioner
		<del>Miscellaneous</del>	Miscellaneous
		<del>Wakefield</del>	Wakefield

### 3.2.6.3 Coding: Stage Three

After the descriptive categories from the second stage were finalized, they were further condensed into broad analytic themes that could be used to capture “what was going on” in the discourse. Questions were posed of the data set to interrogate the data and to identify emergent themes. The following questions were asked:

1. What are the reasons given for parents’ decisions (to fully vaccinate, to not vaccinate, to delay vaccination, or to vaccinate only partially)?
2. How does the discourse frame the issue of non-vaccination?
3. What solutions does the discourse propose to the problem of non-/under-immunization for children?

The first question allowed for an examination of the assumptions that the discourse made about parents and how it constructed their decision-making for childhood immunization. The second question helped with focusing on the way in which non-vaccination was constructed as a problem within the discourse and with drawing out the central themes in the discourse. In other words, how did the discourse describe the impact and consequences of non-vaccination? The third question enabled an exploration of what needed to be done to improve uptake, according to the discourse.

To continue with the example using the Maldonado excerpt, the second stage code of “risk perception” was collapsed into the third stage analytic theme of risk.

After coding was completed, theory was brought back into the analysis to show how the analytic themes related to the Deficit and Contextual Models of PUS. The issue of MMR uptake was reframed from the critical social science perspective of the Contextual Model to problematize assumptions held in the medical discourse, which will be discussed in the next chapter.



### 3.3 Summary

In this chapter, the methodology of this study was described, and detailed explanations of the data collection and analytic processes were provided. The method of analysis used in this study was Critical Discourse Analysis, which is an approach to textual analysis that allows the researcher to problematize ideas in the text that seem natural. It is therefore useful for interrogating the medical discourse on MMR uptake through the critical lens of PUS and identifying problematic assumptions in the medical discourse that could be contributing to the issue of declining MMR coverage. Because impact factors are a measure of the importance of journals in a field, texts were collected from high impact factor journals in medicine, pediatrics, and public health as representative of the mainstream medical discourse. After three stages of coding, broad analytic themes were identified within the discourse, which will be discussed in the following chapters.

## 4 Results

The final data set consisted of a total of 64 papers, with 35 from the medical journals, 24 from pediatric journals, and 5 from public health journals. The distribution of articles from each journal and discipline can be found in Tables 1 through 3 in the Methods chapter. Most of the texts from the medical journals were letters, news, and reviews, and almost all the primary studies were quantitative (Table 4). The articles from the pediatric and public health journals were roughly equally represented by research and review papers. Because the vast majority of the papers were published after 1998, it was not possible to compare the discourse on MMR decision-making by parents before and after the Wakefield publication. A possible explanation for the paucity of texts on MMR uptake before 1998 is that MMR uptake had not been considered a problem and therefore did not need to be addressed in the journal literature.

Content analysis was performed on the texts using the Contextual Model of PUS as a lens, and evidence for the Deficit Model of PUS was found in the discourse discussion about reasons for refusing MMR vaccine. Non-vaccination was attributed to parents' lack of evidence-based information, skewed risk perceptions, and misinformation from their physicians, which all followed the assumption that parents resist what they do not understand (Sturgis and Allum 2004). The issue was framed by the discourse as that of risk communication, conflict between lay and expert perceptions of risk, control over health, and trust. In order to solve the problem of non-vaccination, the discourse proposed more education for parents, as well as more respectful communication between parents and health care providers.

By answering the questions listed in the previous chapter to interrogate the data set, the third level analytic themes of Risk and Trust were abstracted. Under the theme of Risk were the second level descriptive categories of risk perception, risk management, evidence, and education. Trust was abstracted from patient-physician relationships, credibility of science, trusting the public, and control and coercion. These two overarching themes will be discussed in greater detail in the following sections.

## 4.1 Risk

Much of the discourse has framed non-vaccination as an issue of risk: parental perceptions of the risks of disease and vaccine adverse events; risk communication from experts to parents about the risks versus benefits of vaccinating; evidence about vaccine risks; and conflict between expert and lay assessments of risk. It will be argued that the concept of risk in parental decision-making for childhood immunizations is rooted in a PUS Deficit Model approach to understanding the public.

The presentation of the term “risk” will revolve around notions of evidence, expertise, education, risk perception, and risk management. The way in which the discourse constructs evidence, experts, and the roles of education, risk perception and risk management will be examined. The results will also focus on how lay assessments of risk conflict with expert assessments, as what counts as legitimate evidence for making risk assessments is under dispute between parents and experts.

### 4.1.1 Risk Perception

According to the discourse, parents refused to have their children immunized for MMR because they had a skewed perception of risk. In other words, their perception of risk was not aligned with risk assessments that were made by medical experts and that were based on current scientific evidence. In order to help remedy parents’ faulty risk perception, it was recommended in the discourse that experts provide accurate scientifically-supported information to parents through risk communication. The solution to the problem of skewed risk perception, according to the discourse, was to give parents the right information in order to help them form “balanced” perceptions of the risks of vaccinating versus not vaccinating:

Although parents almost always seek to act in the best interests of their children, their decisions are influenced greatly by the information they receive from many sources. We should all help parents understand the risks and benefits of any medical intervention, including continued vigilance, follow-up, and assessment of reported adverse events. Providing parents with an accurate and balanced perspective will help them make best choices for their children’s future. (Freed, Katz *et al.* 1996, p.1872)

In accordance with the Deficit Model, the assumption was that parents were opposed to MMR because they lacked the “right” information, or the ability to distinguish between “right” and “wrong” information.

#### 4.1.1.1 Assigning Relative Weight to Risks

By treating parental risk perception as skewed, the discourse also implied that parents were not seeing the whole picture. The discourse suggested that parents were overly concerned with the vaccine-related adverse events that were extremely rare and failed to acknowledge the greater likelihood of their children contracting a vaccine-preventable disease if unimmunized. This implied that experts, whose assessments of risk were based on statistics, had a better grasp of the risks of vaccinating and were in a better position to judge whether vaccination was appropriate for children.

The explanation offered by the discourse for the tendency by parents to place more attention on the risks from MMR vaccine than from the diseases was that they had never experienced these diseases which were nearly eliminated, ironically, by the vaccines. According to the discourse, younger parents questioned the need for continuing immunizations because they thought the diseases prevented by the vaccines were no longer a threat.

The rare occurrence of vaccine-preventable illnesses in the United States and other developed areas of the world has left the public with a number of misconceptions regarding the continued need for vaccinations. In these areas, there exists a poor perception of the real and continued risk of exposure and illness due to vaccine-preventable infections. (Maldonado 2002, p3156)

As a result of substantial gains in reducing vaccine-preventable diseases, the memory of several infectious diseases has faded from the public consciousness and the risk-benefit calculus seems to have shifted in favor of the perceived risks of vaccination in some parents' minds. (Omer, Salmon *et al.* 2009, p.1986)

On the other hand, the discourse also explained that the public placed disproportionate attention on claims about vaccine related reactions, which, combined with the perception of low disease severity, resulted in a skewed perception of risk that favoured non-vaccination. Parental

perceptions of vaccine risks were also described as easily influenced by media scare stories about vaccine adverse events that were widely publicized and highly visible, compared to scientific studies supporting the safety of MMR.

Instead, attention has been diverted to concern about adverse events related to vaccines, real or otherwise. Today, when the topic of vaccines appears on the news, reports often focus on potential adverse events. More recently...it has been hypothesized that the measles-mumps-rubella vaccine (MMR) is linked with autism. Although these hypotheses have not been substantiated, they have affected vaccination coverage in other countries. (Bardenheier, Yusuf *et al.* 2004, p569)

Statistically, the likelihood of encountering a vaccine adverse event is much smaller than the risk of contracting disease. Complications from measles, mumps, or rubella have the potential to be serious and life-threatening, and worse than the child developing autism. However, this risk seemed to be ignored or was considered miniscule by parents (Bellaby 2003).

#### 4.1.2 Misrepresentation of Evidence of Risk

As we have seen, the discourse described non-vaccinating parents as basing their decisions on emotion and intuition rather than on reason and evidence (Marcovitch 2009). Anxiety over Wakefield's claims of a putative link between the MMR vaccine and autism (Wakefield, Murch *et al.* 1998) was identified by the discourse as a factor in the decision-making of both vaccinating and non-vaccinating parents. Despite findings by other researchers that refuted this link and a partial retraction of the 1998 *Lancet* paper, parents remained worried about the safety of the vaccine:

Criticisms of the study and Wakefield's interpretation of the data have followed. But public fears have remained, and private clinics offering the single shots have been besieged with requests from anxious parents. (Ramsay 2002, p590)

Parents who refused MMR were described as ignoring the evidence about the safety of the vaccine and basing their decision on emotions. Without "evidence" to support decision-making, the resulting decision was deemed irrational, with the underlying assumption that a rejection of scientific evidence was irrational. On the other hand, parents who independently sought out

information about vaccines and formed perceptions that led to non-vaccination were dismissed in the discourse as misled by “wrong” information.

Many parents have little awareness of the various organizations that offer immunization information, and even less awareness that the information offered by different organizations may vary considerably in terms of its scientific basis. An organization with a credible-sounding name—even if fictitious—may be mistaken by some proportion of parents as offering valid information. (Gellin, Maibach *et al.* 2000, p.1101)

New organizations and Internet sites portraying selves as official resources for credible information continue to appear. Unfortunately, many provide flawed or biased information that serves to fuel public concern regarding the safety of childhood immunizations, leading to increased immunization refusal rates by families. (American Academy of Pediatrics 2003, p.994)

#### 4.1.2.1 Emotion and Intuition vs. “Fact”

It was suggested in the discourse that parents gave more weight to emotional accounts than to objective findings when forming perceptions and making decisions about immunization. The subsequent decline in MMR uptake was interpreted as indicative of parents’ tendency to act on emotions rather than reasoning:

There is also the conundrum of the conflicts between perception and fact and between intuition and logic. Clearly, judging by the fall in uptake, a large minority of parents acted on the former concepts rather than the latter, surely common behavior. Countering perception with factual argument requires that the facts are clear-cut, accessible and well communicated. Replacing perception by logic may be more difficult, even impossible. (Marcovitch 2009, p.828)

Thus, parents were described as acting on their anxiety and thereby refusing MMR, rather than making a logical decision based on the scientific facts that stated the vaccine was safe relative to the diseases it prevented.

...This careful and convincing study shows that there is no association between autism and MMR vaccination. Other studies have also found no such association.

Unfortunately, objective data are not likely to put an end to the controversy. Strongly held beliefs are difficult to change. (Campion 2002, p.1474)

By the standards of science, judgments based on emotions were flawed and inaccurate. In the context of scientific paradigms, the construction of parental decisions as based on emotions implied that such decisions were based on invalid kinds of information and were therefore flawed.

#### 4.1.2.2 Inability to Distinguish Misinformation from Fact

Because most parents were assumed to lack training and knowledge of scientific processes, it was also assumed that they were unable to discern the quality of the information that they found. According to the discourse, parents' inability to evaluate the validity of information led some parents to base their decisions on "myths" and "misconceptions" while ignoring the advice of medical professionals. Parents who refused vaccination were often reported to base their decision on information from sources such as anti-vaccination web sites, the media, and magazines that promoted alternative health practices, all of which had content that was opposed to vaccination, such as claims of a link between the MMR vaccine and the development of autistic symptoms (Wolfe, Sharp *et al.* 2002; Benin 2006; Levi 2007). However, these sources were described as not always "credible" (in medical science terms) and liable to provide "flawed" information.

Although this study did not formally evaluate the accuracy of medical references provided on antivaccination Web sites, a separate review found that sites that contain citations to scientific papers often misrepresent their contents. (Wolfe, Sharp *et al.* 2002, p1718)

According to the discourse, parents found information about vaccine adverse events more persuasive because it was more visible to parents. News media reported more on vaccine adverse events, or "scare stories", because they stood out and were more interesting. Also, the

Internet made it easier for parents to access information about vaccines from websites of various groups, both for and against vaccination, that didn't necessarily qualify as scientific evidence.

Despite the success of routine childhood immunizations, parental resistance continues to grow... In part, this resistance is because of a proliferation of articles, books, and Web sites questioning the safety and value of routine childhood immunizations. (Levi 2007, p.19)

Some parents were also assumed to value anecdotal reports of a link between MMR and autism over peer-reviewed findings that refuted such a link. The discourse described parents as being swayed by emotional accounts of children who developed autism following MMR vaccination, giving them greater weight than cold scientific facts.

Fifty-five percent of the [antivaccination] sites provided personal accounts written by parents who believed that their child was killed or permanently harmed by vaccination, and almost one fourth of the sites included pictures of the affected children. Such visual images of purported adverse consequences can be unsettling to parents facing vaccination decisions. In social psychology terms, these parents may be swayed by "false consensus bias," a tendency to rely on personal experience as opposed to scientific evidence. (Wolfe, Sharp *et al.* 2002, p.3247)

#### 4.1.2.3 Defining Valid Evidence in Science

Vaccinating parents were treated as no better at evaluating the quality of information, but they were able to make the right decision because they trusted the right source: their physicians. In the case of parents who did trust the advice of their physicians and were influenced to not vaccinate, the physicians were also described as misinformed and not up to date with current evidence about the vaccines. Some physicians were described as holding misconceptions about vaccine contraindications and safety, which caused them to advise against vaccinating with MMR.

Parents most frequently cite healthcare professionals, particularly health visitors, as their source of advice on immunization. However, healthcare professionals have been found to be poorly informed about vaccines. Shortly after publication of the 1998 case series, some healthcare professionals reported having lost confidence in the safety of MMR



vaccine. A more recent investigation ... found that, although the vast majority had positive attitudes to the safety of MMR vaccine, they demonstrated significant gaps in knowledge about both contraindications to the vaccine and adverse side effects. This could have the effect of denying the vaccine to children on the basis of a non-existent contraindication and could also result in parents being given inconsistent advice by different professionals leading to confusion or mistrust. (Elliman and Bedford 2007, p.1056)

Thus, the discourse posited that “wrong” conclusions, defined as decisions to not vaccinate, were not based on scientific evidence. Scientific evidence should always lead to the “right” decision; that is, the decision to vaccinate. The ability for evidence to lead to the right answer was not questioned in the discourse. For example, one article mentioned the British public’s experience with the poor handling of the BSE crisis by their government as possibly contributing to the British public’s distrust in the United Kingdom government and influencing parental attitudes towards government policies on MMR (Elliman and Bedford 2001). In defence of the government’s promotion of the combination vaccine, the author claimed that the cases of MMR and BSE were different, as the handling of the BSE crisis was not based on evidence, whereas efforts to communicate the safety of MMR were supported by evidence. These issues will be taken up in the Discussion chapter.

Some of the terms found in the discourse for describing evidence included: “substantial”, “real”, “credible”, and “scientific”. Other similar terms referring to data included: “valid”, “stringent”, “objective”, and “reliable”. Within the discourse, there was a hierarchy for the kinds of information that were considered valid within the discourse. At the top was scientifically based evidence, which was knowledge that has been validated through rigorous, peer-reviewed, scientific studies (Offit and Moser 2009). Scientific, peer-reviewed findings were not as accessible for the general public because these findings required subscriptions to journals and an understanding of the scientific content in the articles. Information that was more accessible for parents, such as that which can be obtained over the Internet, through the news media, magazines, books, and acquaintances, were not considered valid unless they agreed with “scientific” information about vaccines. The validity of other kinds of information varied to the extent that they drew from and were consistent with scientific evidence.

While scientific findings were favoured by the rules of this hierarchy as the most valid type of evidence, even within scientific evidence, some sources were considered more rigorous than others. Certain study designs were considered superior on the basis of replicability, validity, sample size, and so forth. Findings also needed to have expert consensus about the legitimacy through peer review:

In the latter sections, Sears often takes the position that, if parents think that a vaccine is problematic, then the vaccine is problematic. He believes that parents' fears should be indulged by offering alternative schedules, not countered by scientific studies, and he fails to explain that good science is the only way to determine whether a vaccine causes a particular adverse event. Instead, Sears alludes to evidence on both sides of any issue, failing to distinguish studies on the basis of their quality, internal consistency, or reproducibility and failing to distinguish those that are accepted by the scientific community and those that are not. (Offit and Moser 2009, p.e166)

The knowledge that people develop in everyday life, known according to the Contextual Model of PUS as local knowledge, do not meet these strict criteria that define the only acceptable forms of evidence within the discourse. Nevertheless, the Contextual Model suggests that other forms of knowledge may count as evidence for parents, such as personal experience. (Wynne 1991) This will be further discussed in the next chapter.

### 4.1.3 Risk Management

#### 4.1.3.1 The Public Health Perspective

Conflict arises between experts and parents over the real risk of vaccines and diseases and what counts as evidence to support risk assessments. Also, experts are more concerned with the health and safety of the entire population, while parents value the health of their children over that of the general population. The concern for public health expressed in the discourse was that herd immunity will eventually be compromised as the number of vaccinated individuals decreases, which increases the risk for outbreaks of measles, mumps, and rubella.

Although a few unimmunized individuals are most likely protected by herd immunity, growing numbers of unvaccinated individuals could eventually pose a risk to both themselves and society. (Wolfe, Sharp *et al.* 2002, p3248)

Part of the decline in vaccination uptake was attributed to anti-vaccine groups, who were highly vocal about their opposition to immunizations.

The large number of approved vaccines and the laws that require vaccination for school entry only increase the tension. Some anti-vaccine groups have received wide publicity, and they try to convince worried parents that avoiding vaccination is “playing it safe.” (Campion 2002, p1475)

#### 4.1.3.2 Parental Perspective

Although the MMR vaccine protects most of the population from potentially serious diseases, it is also believed by some researchers and parents to cause autism in certain susceptible children. When parents suspect that their child might develop serious adverse reactions to the MMR, their responsibility to their own children’s health may conflict with health officials and their responsibility to ensure the safety of the public. While the aim of public health is to protect the health of the population, parents aim to protect their own children. However, this perspective was absent in the discourse. This issue was more often framed as one of moral failing, as the discourse implied that parents who didn’t vaccinate were selfish, taking advantage of herd immunity from other vaccinated individuals around them and endangering the public health.

In essence, a *de facto* social contract exists among parents who immunize their children. They provide individual protection to their children as well as contribute to the overall protection of other children for whom the vaccine is ineffective or those who cannot receive vaccines due to true medical contraindications or religious exemptions. Because of the skewed perceptions of risk, parents of healthy children who do not have their children immunized violate this social contract. (Freed, Katz *et al.* 1996, p.1871)

#### 4.1.4 Education as a Risk Communication Strategy

The discourse claimed that correct scientific information was needed in order to educate parents about the facts about the MMR vaccine so that their perceptions of the risks of immunization can be “normalized”, that is, aligned with the medical perspective.

This finding indicates that current public health education campaigns on this issue [concern over association of vaccines with autism] have not been effective in allaying the

concerns of many parents. Officials must attempt to develop more effective and targeted education campaigns that focus directly on this issue if their goal is to match parents' level of concern with the available scientific evidence. (Freed, Clark *et al.* 2010, p.657)

The discourse included descriptions of how physicians played important roles in educating parents because they were often cited by parents as a source of information for making decisions about immunization. As in the Deficit Model, parents were assumed to lack information about vaccines, which had to be provided by physicians, who had more expertise in the matter.

Because most parents receive information about vaccines from their doctors, and because these recommendations carry substantial weight with parents, providers must be knowledgeable when addressing parents' concerns. (Offit, Quarles *et al.* 2002, p.124)

Physicians, in turn, were thought to be informed by experts, who were the researchers. The flow of information followed the top-down direction posited by the Deficit Model, that is, information flowed from researchers at the top to the lay public below. However, not all physicians were deemed to have accurate knowledge about vaccines, which suggests that there were gaps along the chain of risk communication. Information from experts was not taken up by some physicians, and information from physicians was not accepted by some parents.

The discourse framed low immunization uptake as a problem of risk communication, but risk communication may not be the only cause. Knowledge of scientific evidence alone does not ensure that parents will favour vaccination. By framing the problem as one of risk communication, the discourse ignored domains other than knowledge, such as ethical and political concerns (Gross 1994). This is consistent with the Deficit Model assumption that uptake of knowledge is not socially mediated or contextually situated. Non-uptake of science was constructed as a result of ignorance, therefore it followed that education would improve acceptance of science. It was assumed in the discourse that if experts can only accurately communicate risk information to parents, then parents would realize that vaccination is beneficial.

Major reasons for vaccine refusal in the United States are parental perceptions and concerns about vaccine safety and a low level of concern about the risk of many vaccine-preventable diseases. If the enormous benefits to society from vaccination are to be

maintained, increased efforts will be needed to educate the public about those benefits...  
(Omer, Salmon *et al.* 2009, p.1987)

One determining factor in the effectiveness of risk communication suggested by the discourse was the quality of the patient-physician relationship, which will be discussed later in this chapter.

## 4.2 Trust

According to the Contextual Model of PUS, trust is central to the uptake of information from experts by parents, and to parents' decisions to follow expert advice to vaccinate. The presence of the theme of Trust in the discourse suggests that the discourse is not based only on the Deficit Model but also has elements of the Contextual Model of PUS. That is, rather than framing parental decision-making solely in terms of parents' knowledge and understanding of the evidence for vaccine safety, contextual factors such trust were also recognized in the discourse as important. This is consistent with the assumption in the Contextual Model that the public does not already trust experts; trust must be built. (Gross 1994) However, this insight is not applied in the discourse beyond the relationship between patients and physicians, while the trustworthiness of vaccine researchers is taken for granted. In the absence of trust in medical authorities, parents are not likely to relinquish control over their children's health to physicians and to heed recommendations made by experts. Thus, trust needs to be established first before experts can attempt to convey information and to make recommendations to parents. Experts' trust in parents and the lay public will also be discussed.

### 4.2.1 Scientific Credibility vs. Credibility of Science

In science, the credibility of findings is not based on trust. Instead, the validity of evidence is determined on the basis of features of the study's design and the precision and accuracy of measurements. Findings generated through the scientific method are believed to be able to stand on their own and to be replicable regardless of who conducts an experiment. Although parents were described as lacking in understanding about the scientific method, they were expected to trust that the scientific method will lead to the "truth". In other words, the credibility of science itself was presupposed and not questioned. In this case, parents were supposed to trust that

findings of a lack of association between MMR and autism were true because they were based on “objective” and “neutral” scientific experiments.

Additionally, concern in the discourse over parents’ distrust of government regulatory bodies suggested that experts had previously taken for granted that parents trusted them to follow the scientific method. Parents were expected to trust that experts had reported all of the findings on MMR safety, both for and against MMR.

Furthermore, there is a pervasive sense of distrust, expressed in beliefs that governmental oversight bodies suppress reports of adverse vaccine reactions and collude with the pharmaceutical industry to profit from vaccine sales. (Wolfe, Sharp *et al.* 2002, p.3247)

Even though this mistrust was acknowledged in the discourse, it was assumed that scientific validity was enough to establish the credibility of science and its institutions.

#### 4.2.2 Role of Trust in the Patient-Physician Relationship

Because experts, or researchers, do not directly communicate with parents, physicians are responsible for disseminating current evidence about vaccines to parents. Information is distributed from researchers to physicians, and in order for physicians to convey accurate information to parents, it was recommended in the discourse that physicians kept up with the latest findings and had good relationships with parents. The discourse claimed that one of the problems for MMR uptake was a lack of trust in health care providers, where parents did not view health care providers as allies in protecting their children’s health.

For decades, pediatricians and parents have generally maintained a unified commitment to childhood vaccination; for the most part this continues to be true. Unfortunately, signs suggest a decline in this unity. The National Immunization Survey revealed that the rate of unvaccinated children has risen significantly since 1995; while most parents continue to believe that vaccination is important, a large number express concern about vaccine safety. (Flanagan-Klygis, Sharp *et al.* 2005, p.929)

The decision to vaccinate was not based on an assessment by parents of the available evidence itself, but on whom parents trusted to give them recommendations that were in their children’s best interest. It was assumed in the discourse that the majority of parents lacked in-depth

knowledge of scientific principles and reasoning, so they needed to look to an expert that was knowledgeable about the vaccine and that they trusted to have their children's best interests in mind. Trust determined the credibility of information for parents. If the source was considered trustworthy, then the information provided by the source should also be credible. Thus, trust and credibility are linked, with trust acting as a proxy for scientific knowledge in assessing the credibility of information.

In direct contrast to how these mothers [late vaccinators] felt, those mothers who were vaccinators had decided to trust the doctor. For example, one mother said, "You know I really ... feel that I've made a decision to trust our pediatrician ... So that, you know, I'm kind of ceding the responsibility of getting more information over to them, trusting her." ... These mothers did not want too much information, because they trusted the doctor. (Benin 2006, p.1537)

The discourse posited that a strong patient-physician relationship would help facilitate risk communication and improve compliance. As mentioned earlier, parents were assumed to be unable to identify evidence-based information, so they needed to rely instead on a source that they trust. This would ideally be their physician, who was knowledgeable about the scientific evidence on vaccines and was able to communicate with them directly.

According to the discourse, parents needed to trust that their physician had a thorough understanding of the vaccine and that their physician valued their child's health over profit from the pharmaceutical industry and government pressure to meet uptake targets. In order for physicians to convince parents that they had their children's best interests in mind and to gain parents' trust, they needed to listen to parents concerns and to be able to address parents' worries in a respectful manner. Parents who had a good relationship with their physicians were described as more likely to trust the information provided by their physicians, and to accept their physicians' recommendations to have their children immunized.

Most often, parents who changed their minds after considering delaying or refusing a vaccine for their child gave credit to the child's health care provider... Other research has also found that health care providers who are able to communicate effectively and with respect can positively affect patient satisfaction and adherence... Therefore, a trusting, respectful, provider-patient relationship can help offset the negative impact of

misinformation on parents' decisions concerning immunizations for their children. (Gust, Darling *et al.* 2008, p.724)

The attitudes of physicians in addressing concerns raised by parents were discussed as an influence on parents' perceptions of immunization. It is interesting to note that while parents tended to be described in the discourse as lacking in information, their efforts to obtain more information from health care providers were sometimes met with negative attitudes. The discourse suggested that negative physician attitudes may have contributed to parental dissatisfaction with health care and to unfavourable attitudes towards immunization.

Though pediatricians and family practitioners have a reputation as friendly and approachable, there are reports of parents having their concerns dismissed and/or disparaged, sometimes aggressively so. ...But when parents' concerns are not effectively addressed, often the end result is that children do not get the medical care they need and deserve. (Levi 2007, p.19)

Thus, parents' decisions about vaccination were described as being influenced by interpersonal factors such as the quality of their relationships with their health care providers, suggesting that there were also elements of the Contextual Model in the discourse.

#### 4.2.3 Control and Coercion in the Absence of Trust

Although the link between control and trust may not be immediately apparent, it will be argued that the need for control stems from an absence of trust. The discourse posited that immunization decisions were influenced in part by the degree of control that parents perceived to have over their children's health and in their lives. Vaccinating parents were described as having a sense of personal control whereas non-vaccinating parents didn't, and so they resisted the advice of the medical establishment as a way to obtain some sense of control (Prislin, Dyer *et al.* 1998). It therefore follows that allowing parents a bit of control would reduce resistance.

Very often misinformation can be corrected, and even very resistant parents will respond to being allowed some small degree of control, such as delaying some vaccinations by a few months. (Wolfe 2002, p.1718, in reply to letter by Davies 2002)



According to the discourse, some parents wished to have more control over their health instead of allowing the physician to decide what was best for their children. *The Vaccine Book: Making the Right Decision for Your Child* is a popular book written by Dr. Robert Sears that provides a formula allowing parents to plan out alternative immunization schedules from the schedule recommended by government health authorities, on the premises that physicians didn't necessarily know more about vaccines than do parents. (Offit and Moser 2009)

Implicit in Sears' premise is the idea that doctors do not know much about vaccines and that if parents educate themselves they will know more than their doctors. For some parents, this admission can be quite reassuring, allowing them to negate their doctor's advice and take control of a worrisome situation. (Offit and Moser 2009, p.164)

The discourse described parents as siding with the anti-vaccine activists against the dominant and untrustworthy government in order to obtain a sense of empowerment to compensate for the lack of control they had over their lives. A study by Wolfe *et al.* (Wolfe, Sharp *et al.* 2002) on characteristics of anti-vaccination web sites noted that electronic vaccine registries had been likened to "Big Brother".

"Violation of Civil Liberties." Seventeen (77%) of the sites mentioned civil liberty concerns associated with mandated vaccination. Electronic vaccine registries, designed to allow tracking of childhood immunizations, were attacked as an example of "Big Brother" intruding into the lives of citizens." (Wolfe, Sharp *et al.* 2002, p.3247)

Other parents who were opposed to MMR out of the belief that it triggered autism in their children were portrayed as helpless and desperate, grasping at straws to explain their children's condition. Because the etiology of autism is poorly understood, parents have little control over the condition.

Additionally, Offit addressed, but did not flush out, what it is about autism that drives victims to search for extraordinary causes of the disease. Recent studies have shown that people who lack control of their lives will make causal connections and detect completely illusory patterns where there are none. Perhaps it is the lack of control these families suffer that drives a vocal minority to pursue so tirelessly the eradication of the vaccine... (Alverson 2009, p.396)

However, some parents who believed they were able to control the course of disease in their children were also found to be less likely to vaccinate.

Previous studies have identified important promoters and inhibitors of parents' acceptance of vaccines. Promoters have included... Inhibitors have included...a perceived ability to control child's susceptibility to and outcome of the disease... (Benin 2006, p.1533)

Control was closely associated with trust in the discourse. Parents who had low trust in health professionals were described as having a low sense of personal control, which in turn determined their decisions about vaccination.

In comparison with nonrecipients, respondents receiving [AFDC] aid were more likely to believe in natural immunity and to distrust medical professionals. The resultant less favorable attitudes and diminished sense of personal control combined to eventually cause low immunization rates. (Prislin, Dyer *et al.* 1998, p.1825)

By problematizing parents' autonomy to decide what is best for their children and framing non-vaccination in terms of parents' personalities, the discourse fails to acknowledge that risk and vulnerability that are inherent to trust (CanPREP 2009). By trusting and following the advice of health experts, parents and their children also become vulnerable to harm from experts who might be mistaken or do not have their best interests in mind. In other words, it is possible that some parents refuse MMR not because they want more control, but because they feel that they cannot trust the experts.

In the absence of trust, there may be a struggle for control, which leads to conflict. Parents wish to maintain control in order to ensure the best health care decisions for their children, whereas physicians would like parents to relinquish control to them because they are more knowledgeable about vaccines and diseases. Each side feels that they know what is best for the child. This idea was illustrated in a response to a letter about measles outbreaks in Japan resulting from declining uptake of measles vaccination:

The experience that Drs. Noble and Miyasaka describe is sobering. People want more independence and more control over all health care decisions. However, if the rate of

childhood vaccination declines substantially, the result will be needless harm to young children. (Campion 2003, p.953, in response to letter by Noble and Miyasaka)

In some cases, rather than trusting parents to have their children immunized, they are compelled to do so by policies for school entry. In most states in the United States and most provinces in Canada, children are required to be fully immunized before being allowed to register for public school. It was recognized in the discourse that there were some cases when the decision to vaccinate was not voluntary but mandated for school entry.

School entry laws also may have an impact; 11.7% of case parents and 6.3% of control parents reported that they had received a vaccine they did not want because it was required. (Gust, Strine *et al.* 2004, p.e21)

This suggested that there was concern in the discourse that even among vaccinating parents, there was potential for them to decline vaccination if given the opportunity. While coercive measures for vaccination such as school mandates are effective for ensuring compliance among parents, some parents may choose to opt out of vaccination if given the choice.

Besides being mandated for school entry, vaccination was also socially mandated. Although it was claimed in the discourse that the role of experts was to support parental decision-making and to provide parents with the vaccine information that they needed, parents' choices were in fact constrained by social expectations. Thus, there was a false sense of choice within the discourse. A significant number of pediatricians reported that they would be willing to dismiss families from their practice for refusing a vaccine, leaving these families with very few alternatives (Flanagan-Klygis, Sharp *et al.* 2005). It is interesting to note the contrast between the constructions of lower and middle class families. While low immunization uptake among families of low socioeconomic status was constructed not as a choice but as inequalities in access to health care (Middleton and Baker 2003), middle class families were constructed as having a choice. In fact, it can be argued that middle class families also have limited options, though in their case they are limited to choosing vaccination as the only acceptable decision.

### 4.3 Summary

While the construction of parents' decisions in the discourse was generally based on the Deficit Model of PUS--as irrational and emotional, and informed by skewed perceptions and flawed information--it also incorporated a Contextual Model approach in acknowledging that poor interactions with health care providers and the government could also affect uptake. The desire for more control over health; misinformation from physicians; and coercion to vaccinate were also discussed as reasons for parents' decisions to vaccinate or not vaccinate.

Overall, the problem of non-vaccination was described in terms of conflict between parents and medical experts about control over health, trust, and risk. Consistent with the Deficit Model assumption that vaccine resistance results from inadequate knowledge, education was commonly proposed as a solution to improving uptake. At the same time, the Contextual Model was also evident in the recommendation for more trusting patient-physician relationships. Thus, the construction of parental decision-making for immunizations can be viewed from the context of two overarching themes in the discourse: Risk and Trust.

## 5 Discussion: Medical Discourse through the PUS Lens

In the Results chapter, Risk was shown to be the dominant theme throughout while the theme of Trust was weakly present, indicating that the medical discourse was rooted in the Deficit Model of PUS. In this chapter, the medical discourse on parental decision-making for pediatric immunizations will be re-examined through the lens of the Contextual Model to offer a critical perspective on the medical discourse around parents and their decisions regarding MMR vaccine. It will be shown that the Contextual Model offers an alternative perspective on the problem of ineffective public health risk communication.

First, the lack of differentiation in the discourse between groups of parents may explain why risk communication efforts have not been successful. As shown in the Results chapter, parents are not a homogenous group, and those who decline vaccination do so for a number of reasons. Risk communication that is based on an over-simplified definition of the public is unable to address the various reasons that parents have for declining the MMR vaccine, and the subsets of the population they make up.

The definition of risk in the discourse has also been overly narrow, as it deals only with disease-related risks. Parents and medical experts operate in different contexts, so they may assess risk and frame immunization decisions very differently. While decision-making about immunization has been framed in the discourse in terms of risks from diseases and risks from vaccines, parents may be concerned with other risks such as pain caused by vaccine administration. There is a failure to recognize the perspectives of parents in the discourse, and parents who don't have their children immunized may well be insulted by the suggestion that they are putting their children and society in danger. Thus, the concept of risk in the discourse needs to be expanded to account for other kinds of risks, such as pain, that may impact parents' decision-making so that risk communication, which draws from the discourse, will be able to address parents' concerns.

While trust was also cited in the discourse, hinting at some recognition in the discourse that knowledge was not the only determinant of vaccine uptake, the discussion of trust was also limited. Besides the provision of more vaccine information to parents, the development of trusting relationships between parents and physicians was also proposed as a solution to improving vaccine uptake. However, trust in the government and the pharmaceutical industry

can also impact parents' decisions to vaccinate, and there was no discussion about improving trust in these areas. Also, the notion of trust was one-sided; that is, while parents were expected to trust medical experts, experts did not demonstrate much trust in parents in the discourse, as parents who refused the MMR vaccine were considered irrational.

The relationship in the discourse between the themes of Risk and Trust is interdependent, as trust was assumed to influence parents' perceptions of the credibility of information, which in turn affected their assessments of risk. The implications of these findings for risk communication will be discussed at the end of this chapter.

Throughout this discussion, it should be kept in mind that the call in this study for improved understanding of why some parents refuse MMR is distinct from a legitimization of their decisions.

## 5.1 Lack of Differentiation between Groups of Parents

It is interesting to note that "parents in general" constituted the second largest group with respect to the amount of attention they received in the discourse on vaccination uptake, as the discourse often discussed parents without explicitly stating which group it referred to (e.g., vaccinating or non-vaccinating). However, it appeared that discussions in the discourse about "parents in general" were in fact concerned with non-vaccinating parents, giving the impression that the majority of parents are refusing vaccination. Although only a small fraction of parents actually declined the MMR vaccine (MMR coverage in Canada in 2002 was at 95% (Spooner 2002) and about 88% in the United Kingdom in 2001 (Middleton and Baker 2003) the discourse often described non-immunization by parents as though it was a widespread trend among parents.

In the discourse, there were few differences between parents who vaccinated, didn't vaccinate, delayed vaccination, or vaccinated incompletely. The fact that the discourse often did not differentiate between the various vaccination decisions made by parents is indicative of the Deficit Model, in that it constructed parents as a homogenous group. The lack of differentiation between different groups of parents can be problematic for risk communication efforts, because attempting to target all of them with one general message will likely be ineffective. For

example, as shown in the Results chapter, section 4.1.3, the discourse described parents who refused to vaccinate as taking advantage of herd immunity and breaking a social contract to contribute to herd immunity. At the same time, non-vaccinating parents were also described as a very vocal group that opposed vaccination and tried to convince other parents of the evils of vaccination (see Results 4.1.2.2). It would not make sense for parents taking advantage of herd immunity to dissuade other parents from vaccinating, as that would destroy the very herd immunity they were benefitting from. Logically, parents who “hide in the herd” should be a different group from those who hold anti-vaccination beliefs, yet the discourse has not differentiated between these parents.

Parents are not homogenous as assumed in the Deficit Model, so it is important to be aware of different groups of parents and to tailor risk communication messages to address each of these groups. Those parents who “free-ride” off herd immunity from others around them likely do acknowledge that vaccines are effective in preventing disease, but they do not see the need to have their own children immunized since the disease prevented by the vaccine is so rare in their environment. In contrast, parents who are opposed to vaccination may not believe that vaccines are effective at preventing disease, or they distrust government motives in promoting the vaccine. As the Contextual Model of PUS asserts, the public, or parents, is in fact heterogeneous and composed of diverse groups (Gross 1994), so very different approaches would be needed to convince each of these groups of parents to have their children immunized.

Little was discussed about the non-traditional parents (late and incomplete vaccinators) and those whose children developed autism following immunization. It is possible that because incomplete vaccination was not considered a choice in the discourse, but a result of poverty and poor access to health care (Senier 2008), there was a lack of data about MMR decision-making among these parents. There was also little mention in the medical journals of parents of children with autism, and of the small amount of data about them that were gathered from the discourse, most came from pediatric journals.

Perhaps the top ten medical journals were more entrenched in the Deficit Model perspective than were the pediatric journals, and so the discourse in these journals failed to distinguish between incomplete and non-vaccination, treating incomplete vaccinators as part of the non-vaccinating group. That is, parents who did not vaccinate appropriately according to the vaccination

schedules set forth by government health organizations, whether by delaying vaccination or by refusing vaccination altogether, were constructed as one homogenous group. As well, the content in the top ten medical journals is more general, covering all areas of medicine, whereas the pediatric journals are more specialized and are probably able to examine the issue of childhood immunization uptake more closely. It is possible that there was more coverage for these groups of parents in other journals. However, using the top 10 medical journals, as defined by impact factor, allows one to characterize the discourse as being constitutive of the formalized, and dominant system of thought within the medical community as defined by their own standards of what counts as “dominant” or most authoritative.

Surprisingly, parents of children with autism also did not receive much attention in the discourse on MMR uptake, presumably because their children’s condition was assumed to be unrelated to MMR. While the discourse did discuss parental concern over the alleged link between autism and MMR, the medical community generally agreed that autism was not triggered by MMR. Thus, it would follow for the medical community that the decision-making of parents of children with autism is no different than other parents. It is possible that based on this line of reasoning, parents who opposed MMR out of the belief that it caused their children’s autism were simply grouped with the other non-vaccinating parents.

There were also few data on vaccinating parents, presumably because they were not considered a problem group. They already made the “correct” choice to vaccinate, so their decision-making was not problematized, and the only concern was to ensure that these parents continued to vaccinate.

On the other hand, non-vaccinating parents received the most discussion in the discourse because they were of greater concern for public health than were the other groups. However, despite the need to improve uptake among these parents, the discourse did not propose many solutions beyond recommending more education for parents. This is because the discourse is rooted in a Deficit Model framework that assumes that non-uptake for vaccines results from inadequate or flawed knowledge. Parents were assumed to have concerns about the safety of the vaccine because they didn’t know enough about it; thus, the problem can be remedied by providing them with more information (Results 4.1.4). The discourse assumed that all of the scientific evidence pointed to the benefits of vaccinating (those findings that did not support MMR were judged to



be flawed), so once parents were provided with the evidence, the only rational decision was to have their children immunized. This assumption excludes other considerations that parents must make, as will be seen later.

## 5.2 Risk

### 5.2.1 The Role of Risk

The way in which an issue is framed constrains its analysis. In the case of MMR uptake by parents, the discourse mostly focused on risk assessments by parents and risk communication. By framing the issue of MMR uptake by parents as one of risk, the discourse ignored what it would consider other “non-risk” factors that might have played a role in parents’ decisions. For example, the level of pain experienced by children during administration of the vaccine is not considered a risk factor in the discourse. This highlights the fact that the discourse fails to acknowledge that risk itself is a subjective variable, as what is considered an undesirable outcome, and its significance, varies among individuals (Shiloh 1996). Many parents may well decide that causing pain to their children during immunization is a risk. However, the notion of risk presented in the medical literature was an attempt to present risk as an objective variable. We know from other areas of medicine, such as genetic counselling, that the definition of risk is limited to probabilities for specific outcomes, which are taken to represent risk in general (Shiloh 1996). In other words, there is a simplification and narrowing of the definition of risk which fails to take into account the risk probabilities for alternative outcomes and individual differences in perceiving risk. As a result, predictions about patient decisions often do not correlate well with subsequent behaviour, and counsellors are unable to anticipate the information that patients need (Halperin, Eastwood *et al.* 1998).

As in other areas of medicine, health care providers must provide support for parents to make optimal decisions about immunizations for their children. It is likely that the medical discourse on childhood vaccination decisions by parents was based on a similar scientific definition of risk as in genetic counselling; thus, risk communication efforts have not been successful in persuading some parents to vaccinate. In other words, risk communication efforts have not successfully elicited the intended behaviour by parents to vaccinate (Halperin, Eastwood *et al.*

1998), because predictions of parental decisions did not take into account how risk assessment varies among parents.

As mentioned earlier, one factor that the discourse neglected entirely was the impact of pain on parents' decision-making, because the discourse framed the issue of vaccine uptake in terms of disease risk, adverse reactions, and risk communication. While pain is considered by the discourse to be unrelated to the risks of diseases or vaccine adverse effects, it is considered an adverse event by parents. As Taddio *et al.* have demonstrated, the immunization process can be painful and distressful for children, parents, and vaccine providers, which can lead to non-adherence to vaccine schedules in an effort to avoid pain in children (Taddio, Chambers *et al.* 2009).

Pain has been found to be the main reason why mothers didn't return for follow-up injections (Thompson 1988), and it has also been reported by parents to be the reason for delaying immunization (Taddio, Chambers *et al.* 2009). Thus, improving uptake and complete immunization may have as much to do with parents' perceptions of vaccine and disease risks as with risks associated with aspects of vaccine administration, such as the vaccine provider's injection technique. Aside from looking only at educating parents more about vaccines, experts might improve vaccine acceptance among parents, for example, by ensuring that pain during vaccine administration is minimized through good technique on the part of the vaccine administrator and through the application of local anaesthetics (Taddio, Ilersich *et al.* 2009).

While the discourse has acknowledged that other contextual "non-risk" factors that are not related directly to the disease or the vaccine, such as trust, also influence parents' decisions (Results 4.2), there remains a great deal more that experts need to understand about parental decision-making. The Contextual Model would suggest that there are likely a host of other influences besides trust that seem irrelevant to disease prevention *per se*, but that carry as much weight in parents' minds; injection pain is but one example. Other issues related to the immunization process can play a role. For example, in some states in the United States, the procedure for providing documentation indicating compliance with state immunization requirements was more complicated than requesting an exemption, which made exemption a more preferable option to parents, especially in light of the scarcity of diseases and the low

perceived need to vaccinate (Omer, Pan *et al.* 2006). Thus, convenience may also be an important, non-risk factor.

One observation about the presentation of risk in the discourse was that many of the descriptive categories that fell under risk were similar to concepts found in the popular Health Belief Model (HBM). Basically, the model posits that the likelihood of an individual adopting a particular health practice is related to 1) the perceived susceptibility to the health concern, 2) the severity of the health concern, 3) the perceived benefits of taking action, 4) the perceived barriers of the action, 5) cues to action, and 6) self-efficacy (Glanz, Rimer *et al.* 2008). As discussed in the Literature Review chapter, the HBM can be considered a formalized version of the Deficit Model, as both models overemphasize factors related to disease and overlook social, contextual factors. Consistent with the tenets of the HBM, the discourse discussed vaccine uptake in terms of parents' perceptions of their children's susceptibility to disease, disease severity, and the safety and efficacy of the MMR vaccine.

Explaining parents' decision-making using the HBM can be problematic, though. The model is unable to account for factors that are not health-related but that nevertheless influence health behaviour. One of the weaknesses of the model lies in its assumption that people always behave in a "rational manner". Smoking cessation was an example of a health behaviour that could not be completely explained by the HBM, as factors such as physiological and psychological dependence also influence the success of any intervention (Galvin 1992). The Contextual Model would explain that this is because people do not base decisions on just "the facts." In the case of childhood immunizations, where parents are making choices on behalf of young children, there are undoubtedly emotional factors involved in decision-making. The definition of rationality in the discourse is also rather narrow, as it can be argued that parents who "hide in the herd" are behaving rationally, because the threat of disease in their environment is indeed low; their decision may be viewed as selfish, but it is nevertheless rational.

The point is that parents who opt out of immunizations probably don't frame their decisions in the same way that the medical discourse has described them. If that is the case, it would be understandable that they feel offended by experts labelling them as selfish and taking advantage of herd immunity for opting out of a vaccine that they believe to be dangerous to their children's health and that people in general are better off not having. As social theories of risk argue, risk

is socially constructed by groups and institutions, and what is considered a risk by one group may not be a risk for a different group. (Senier 2008)

### 5.2.2 Risk Assessment

As mentioned earlier in the Results chapter (4.1.3), experts and the lay public operate in different contexts. Experts would like the public to evaluate information according to the criteria for identifying scientific evidence; however, this is not necessarily the case. Experts are responsible for ensuring the health of the population, while parents are responsible for their own children. Hence, they have different ways of assessing risk. According to Senier, experts base decisions on probabilistic risk-benefit calculations, whereas parents use possibilistic, worst-case thinking, though they do also employ probabilistic thinking. Experts assess risks according to scientific theories, experiments, and findings based on simplified models of what actually occurs in everyday life. For parents, probabilistic thinking is but one among many “tools” that they use in decision-making (Senier 2008): “Ordinary people, including physicians and parents, have a much more complex view of reality.” (Heller 2001)

One reason for the disparate perceptions of risk between experts and parents is that experts and parents possess different kinds of information. The Contextual Model suggests that there are other variables in the lives of individual parents that are not accounted for by simplified models but that may still impact risk assessment and decision-making by parents. Parents assess whether their child should receive a vaccine based on other knowledge besides medical evidence about vaccines and biology. They might make observations about their children that cannot be explained by current science and that would be dismissed by experts because they have not been validated by scientific studies. (Senier 2008) “Anecdotes can only serve as hypotheses to be verified through experiments” (Heller 2001), but while their veracity is as yet undetermined, it also cannot be ruled out that they do have the potential to be true.

The discourse suggested that parents were focusing on the wrong issues when considering vaccination, while worrying excessively about the safety of the vaccine and not enough about the diseases prevented by the vaccine (Results 4.1.1.1). By constructing parents as having skewed perceptions of risk, the discourse denies the legitimacy of parents’ worries, as though it was unreasonable to be also concerned about potential side effects. It is true that statistically, the risk

for vaccine adverse events is very low, but the fear among parents is that their child happens to be that one in a million children that will have a serious adverse reaction to the vaccine.

Scientific calculations generalize and average their subjects out, but in reality, the average represents no one in the population from which it was derived. Assessments of vaccine risk may apply to an “average” individual, but which people actually fall into that category? To quote Wynne, “the objectivist discourses and rationales of science are often experienced by lay people as alien and impoverished models of human nature, values and social relations, clashing with people's own lived and embodied experiences, values and localized knowledges.” (Wynne 1996)

Non-vaccinating parents were described by the discourse as an irrational and especially difficult group to reach through risk communication. They were deemed irrational because, despite having been provided with information about the risks of the vaccines and the diseases, they did not form perceptions of vaccine risk that favoured vaccination and that were consistent with expert assessments.

The discourse assumed that acceptance of vaccination was the only logical outcome that parents can arrive at, once they are provided with scientific evidence about vaccines. Thus, if parents remain unconvinced of the benefits of vaccination, they must be irrational. This view of vaccination decisions is very narrow and inflexible, as it excludes the possibility that parents might have other considerations besides those that the experts have addressed. For example, the decision to not vaccinate and “hide in the herd”, while selfish, can be seen as very rational. It can be argued that there is no need to put children at risk for vaccine-related adverse reactions to protect against a disease that they are not likely to be affected by, thanks to the existing herd immunity.

#### 5.2.2.1 Expertise and Validity of Risk Assessment

Experts were defined in the discourse as those who conduct research on vaccines and diseases and government officials who regulate and run immunization programs (Offit and Moser 2009). Health care providers were sometimes included in this group, though at other times they were considered non-experts, particularly when they were found to possess knowledge that was contrary to current scientific evidence about vaccines and were reluctant to recommend MMR to parents. Conversely, non-experts were defined as those who were not knowledgeable in

scientific theories and processes related to vaccine research, or have not kept up to date with new findings. This group included parents, the media, anti-vaccine groups, and sometimes health care providers.

By constructing parents as incapable of distinguishing evidence from unsubstantiated claims, as seen previously, parents were placed in a dependent role. Scientific evidence was identified in the discourse as the only valid basis for decision-making, and in order to determine which information counted as scientific evidence, knowledge and understanding of scientific processes was required. Scientific expertise, which parents were assumed to lack, was privileged over other forms of expertise that parents did have (such as knowledge of the idiosyncrasies of one's own child). The experience and knowledge that parents possessed were rendered irrelevant by the discourse when it came to making health care decisions. Thus, parents needed to rely on medical experts who were able to identify valid scientific evidence and thus provide them with the necessary information for making decisions about immunizations.

### 5.2.3 Risk and Morality

Another problem with framing vaccine uptake as an issue of risk was that parents who did not have their children vaccinated were implied to be acting immorally, because they broke the social contract to immunize and thereby put their children and others at increased risk for disease (Results 4.1.3). Good health has been defined as both an individual responsibility and a social obligation, as failure to maintain good health may potentially harm or burden others (Peterson and Lupton 1996). Non-vaccinating parents were therefore seen as neglecting their responsibility to take preventive measures (i.e., vaccination) to ensure the health of their children and to minimize harm to other children. However, it can be argued that parents who refuse vaccination are also acting in their children's best interests, according to their understandings of their children's health and social context. Casting parents as "good" versus "bad", for vaccinating completely and not vaccinating completely, respectively, forces parents to choose vaccination if they wish to be regarded as competent, responsible parents by the rest of society.

The Contextual Model would argue that the social aspect of science and technology is ignored. Chapter 2 discussed the idea that science, according to the Contextual Model, is institutionally, socially, and culturally embedded (Irwin and Wynne 1996). Science and technology may in themselves be neutral, but they can be used by people for good or for ill. Even if science is

neutral, its application is not always so, and regulations need to be in place to ensure that it does not harm people. Certainly, vaccines were never intended to harm anyone, but to make vaccination compulsory without listening to the concerns of those affected seems to stretch the good intentions of the vaccine program. That is, although mass vaccination is meant to protect the population from the threats of disease, it does not necessarily justify indiscriminately imposing it on everyone, including those who believe the vaccine will, or has potential to, do more harm than good to their children.

While the discourse described non-vaccinating parents as taking advantage of herd immunity, herd immunity may not be on the minds of these parents at all; for them, vaccinating is simply too risky compared with the disease or with the probability of contracting the disease. Additionally, the Contextual Model points out that the public does not necessarily trust in science, so it is possible that some parents don't even view vaccination as beneficial to society. If this is the case, their decision to opt out cannot be considered selfish since they don't perceive themselves as benefitting from others who do vaccinate. Indeed, anti-vaccination activists may view themselves to be doing a social good by highlighting the dangers of vaccination. Interviews with vaccine critical groups have revealed that some of these groups opposed vaccination out of concern that vaccines were simply a "quick fix" that allowed the government to ignore problems in social equality (Hobson-West 2007).

#### 5.2.4 Risk Communication

Since parents who opt out of immunization do not necessarily frame their decisions in terms of the relative risks and benefits of the vaccine and diseases, risk communication that focuses on educating parents about vaccines and diseases will be irrelevant for some non-vaccinating parents. However, this issue was not acknowledged in the discourse, and parents who didn't vaccinate were assumed to lack valid scientific information about immunizations. This is consistent with the Deficit Model assumption that science is rejected by the public because of a lack of knowledge about it. According to the discourse, the flow of information from experts to the lay public was interrupted at certain points, as information from experts was not taken up by some physicians, and information from physicians was not accepted by some parents (Results 4.1.4). A lack of scientific information was equated in the discourse to having no relevant information for the assessment of immunization risks.

What about the flow of information from the public to the experts? It seems information does not move in this direction. The discourse assumes vaccination decisions belong in the medical science domain and should be governed by scientific principles; thus, from the perspective of the discourse, the lay public doesn't have any helpful information to contribute.

This line of reasoning also assumes that science is all good; rejection of a technology is not because it has the potential to be harmful, but because people misunderstand or are afraid of what they don't know much about. The information that the discourse identified as "scientific evidence" about MMR favoured the benefits of immunization over the risks and costs. It follows from this "evidence" that the only logical course of action for parents is to have their children immunized. Parental opposition to MMR is assumed to result from parents' ignorance about the scientific evidence and to be influenced by inaccurate information or misconceptions.

## 5.3 Trust

### 5.3.1 The Role of Trust

The Contextual Model-based construct of Trust was also identified in the discourse, which suggests that perhaps the discourse is starting to evolve away from a Deficit Model approach to improving vaccine uptake. However, it should be noted that trust cannot be used to explain all aspects of risk communication, as numerous other social, cultural, and cognitive variables are also involved in the ways in which people process information (Frewer 2003). Also, the concept of trust that has been described in the discourse so far has been limited to the patient-physician realm and has neglected the wider processes around vaccination policy and regulations. Trust in physicians alone may not be enough to persuade parents to immunize; improving trust in these wider processes should receive more attention in the discourse, as distrust in the government and pharmaceutical industry is a major reason why some parents have refused MMR vaccine (Davies 2002; Wolfe, Sharp *et al.* 2002).

### 5.3.2 Relationship between Parents and Physicians

The discourse consistently emphasizes vaccination as the only way to prevent disease. In other words, the discourse implied that disease prevention was unrelated to parenting skills but was



affected only by whether or not the child was vaccinated. Thus, the child's health is placed fully under the jurisdiction of medicine; only vaccines developed by medical researchers and administered by medical professionals are able to protect children from diseases. This is indicative of the Deficit Model assumption of a "deficient" public and a "sufficient" science. Parents are expected to cede control over their children's health to medical experts and follow recommendations to have their children immunized. However, in order for parents to relinquish control, parents need to trust that experts have their children's best interests in mind.

It was often reported in the discourse that trusting and respectful relationships between physicians and parents can lead to increased willingness by parents to have their children immunized (Results 4.2.2). However, would it not be difficult to foster trust, when on the one hand vaccine decisions are expected to be based only on scientifically validated evidence, while on the other hand physicians are asked to listen to parents' concerns, which aren't recognized as legitimate? What would physicians do about these concerns, now that they are aware of them? Do the concerns go anywhere, outside of physicians' offices? If the concerns expressed by parents manage to reach the experts, will the experts heed their concerns and follow up on them, or will it be only their physicians who listen?

Currently, physicians who listen to their patients' concerns (e.g., about contraindications) and negotiate an alternative schedule are labelled by the discourse as being misinformed and not up to date with current evidence (Results 4.1.2). This begs the question: by what means are physicians allowed to address parents' concerns, besides showing understanding and answering their questions? A study by Brownlie with general practitioners and health visitors in the United Kingdom found that target-setting for vaccine uptake constrained health professionals' ability to make clinical judgments for individual cases (Brownlie and Howson 2006). Pressure from central government to meet uptake targets meant that some children whom health professionals believed should have been exempted from vaccination on the basis of medical contraindications were administered the vaccine anyway. Unless they diverge from government guidelines, primary health providers are allowed little flexibility to negotiate with parents and establish trusting relationships. If the discourse is proposing that physicians simply listen to parents' concerns without allowing them to do anything else, such as negotiating an acceptable middle ground, to demonstrate that their concerns have been taken seriously and to ease their worries,

then it seems that what the discourse is really proposing is for physicians to “humour” parents, as opposed to addressing their concerns directly.

The lack of options available to physicians to address parents’ concerns likely hinders the establishment of trust between physicians and parents, as parents may feel that their physicians are not taking their concerns seriously. Thus, although the discourse described parents who did not vaccinate according to recommended schedules as wanting control over their children’s health decisions because they did not have a sense of personal control (Results 4.2.3), it is possible that they simply did not trust physicians to act in the best interests of their children. It follows from this that there are barriers to establishing trust in medical practice that have not been recognized in the discourse.

Interestingly, trust itself has been constructed by vaccine critical groups as a problem, that is, parents who trusted recommendations from their physicians to have their children immunized were simply taking the easiest option (Hobson-West 2007). In other words, vaccinating parents were not putting the effort into learning more about the vaccines and making their own decisions. Indeed, a study on advocacy coalitions for and against vaccines found that parents who vaccinated held weaker beliefs about vaccines compared to parents who opposed vaccines (Wilson, Barakat *et al.* 2008). Vaccinating parents simply accepted and trusted information provided to them without seeking additional information on their own, so they were susceptible to persuasion from coalitions against vaccination.

### 5.3.3 Trusting the Public

As shown in Results 4.1.1, parents were suggested to be in need of a great deal of guidance from experts. While parents had the best intentions for their children, it was assumed in the discourse that they lacked accurate information about vaccines and diseases to make informed choices. It was therefore best for them to defer to the advice of physicians.

What the discourse recommended as guidance for parents making decisions about MMR can also be reframed as paternalism, and a neglect of personal autonomy. While the suggestion to help parents navigate the sea of information that is available and identify what was valid and accurate seemed to allow parents to become better informed to make the best choices for their children, in the end it was really the experts who determined about what was best for the child and the

population. In setting the bounds for which information was legitimate to consider in decision-making, the best possible choice had already been pre-established by the experts.

The proposal to provide parents with balanced perspectives regarding the MMR issue (Results 4.1.1) implied that parents were incapable of thinking and making sound judgements for themselves. This is suggestive of the Deficit Model's assumptions that the lay public lacks expertise in scientific matters and that people cannot make rational and informed decisions without scientific expertise. Certainly, experts should explain to parents the benefits and the risks of vaccination, but to tell them what to make of the information takes away parents' autonomy to form their own perceptions about vaccination. The description of parents as ignorant and in need of a great deal of guidance also shows that experts have little trust in the public.

### 5.3.4 Transparency

Criteria for defining evidence within the discourse were not always consistent, and experts did not always agree with each other, so it was misleading when science was presented to the public as a neutral, constant force. It may not be necessary to disseminate all the technical details of scientific findings to the public, nor to present all the competing views held by scientists on a particular subject since it is likely irrelevant to most people's needs and too specialized for lay understanding. However, when disagreements arise among researchers and are made public, as in the case of MMR, it may be wiser to acknowledge the existence of dissenting voices instead of attempting to dismiss them as illegitimate. Despite uncertainty among members of the scientific community, health messages for the public were oversimplified in claiming that there was expert consensus that there was no association between MMR and autism. At the same time, the public was aware that there was in fact other research suggesting the opposite. Thus, it can be argued that one of the causes for public distrust of scientific evidence in favour of MMR is that public health messages presented MMR safety to the public with too much certainty and not enough transparency.

Another problem with the certainty expressed in public health messages about the safety and the benefits of MMR immunization was the failure to acknowledge that the evidence may potentially change with further research. Researchers are aware of this, and scientific studies are careful to propose hypotheses that are falsifiable and to speak tentatively about the certainty of their findings. However, it seems that when findings are shared with the public through public health

messages and the media, they are presented in a simplified manner to suggest that current research uniformly concludes that MMR definitely is not related to autism, when in fact there are dissenting views among scientists. The public image of science abandons the scientific principles of uncertainty: that while the current data suggest there is no link, one should always be open to the possibility. Perhaps what causes parents to distrust experts is not because they refuse to link vaccines with autism, but because they refuse to be open to such a possibility when communicating with the public and responding to public demands for more research.

## 5.4 Interdependence of Risk and Trust

At times, it was difficult to separate Risk and Trust, as the two concepts were clearly interdependent. Risk perception may be influenced by trust, as when parents trust information from medical experts that influences them to perceive the risk for vaccine-related adverse events as low. On the other hand, trust in medical experts may be adversely affected when parents believe that experts are putting their children at risk of being harmed.

### 5.4.1 Credibility

Trust and credibility have been recognized as important contextual factors influencing the uptake and understanding of scientific messages by the public, as well as the public's perceptions of risk (Irwin and Wynne 1996). People are more likely to believe information from a source that they trust. In turn, risk perception is influenced by information that people believe to be true, or credible. However, in science, the credibility of findings is not based on trust. As shown earlier (Results 4.2.1), the validity of evidence in science is evaluated based on features of the study's design and the precision and accuracy of measurements. Scientific findings are assumed to be able to stand on their own and be replicable regardless of who conducts an experiment; the personal characteristics of the experimenter are considered irrelevant.

However, examining the MMR debate through the PUS lens helps bring to light the subjectivity in science, of how findings don't necessarily reflect discovered truths about the world and how the validity of findings is in fact negotiated among scientists. In the case of MMR, Wakefield's findings were deemed invalid because of the study design used and because the gut samples used in the study might have been contaminated, as gut samples containing measles virus had also

been sent to the virology laboratory where Wakefield's samples were analyzed (Elliman and Bedford 2001). However, the fact that the study was conducted for vaccine litigation cases was also believed to influence the findings and interpretations. Requirements to declare funding and conflicts of interest in research can be viewed as acknowledgements that the outcome of a study may be coloured by the researcher's motives. If findings from studies truly were independent of social context, then the purpose for which they were intended should not have any effect on their validity. The fact that critics of the study bring up the issue of conflict of interest in a way recognizes that science is also a social undertaking.

While the credibility of findings in the discourse was assessed based on the journals in which they were published, with better credibility associated with peer-reviewed journals, the Wakefield study was not considered valid by most members of the scientific community even though it was published in *The Lancet*, a highly respected peer-reviewed medical journal. The requirement for publication in a peer-reviewed journal is undermined, which leads to the question: exactly what criteria do experts use in evaluating evidence?

Inconsistency in the criteria for evidence is further illustrated by that fact that what counted as evidence at one point in time may later be found to be incorrect. At the time of publication of the Wakefield study, there may not have been findings from other studies that refuted the proposed MMR-autism link, and the findings seemed to be accepted. Later, when the association between vaccines and autism was widely reported in the media, researchers investigated this hypothesis and concluded that Wakefield was wrong, that there was no link. But if experts had once made a mistake in accepting the findings from Wakefield's study, how can the public be assured that they have not made a mistake in approving the other studies that refuted a link between MMR and autism? The "facts" can change with time and so are also contextual.

Thus, the basis for determining the quality of research findings is unclear, and while scientific experts do not expect parents to understand scientific reasoning, parents are expected to simply trust that scientific findings reflect the "truth" about vaccine risks. Experts also take for granted parents' trust in experts to make objective assessments of risk that are based on evidence (though it is beyond the scope of this study to assess whether experts actually follow the processes they claim to follow, and whether they are truly done in the public's interest). This is problematic

when the means by which experts establish whether a finding constitutes evidence is unclear to the public, and possibly to scientists themselves. Lack of transparency in how experts arrive at conclusions about evidence that impact the health of the population may lead to distrust, as the public is unable to determine the credibility of expert judgments.

#### 5.4.2 Expertise

The discourse assumed that parents needed to rely on medical experts who were able to identify valid scientific evidence to provide them with the information they needed to make decisions about immunizations, because they lacked the scientific expertise to distinguish between valid evidence and “wrong” information for themselves (Results 4.1.2). One problem that is overlooked is that experts are only experts in their field of specialization; they do not have expertise in the public domain and do not really know what information parents need. Information provided to parents by experts is filtered out by experts according to what they believe parents should know, though it is possible that the information does not address all of the questions and needs of parents. As mentioned above, expert risk assessments can tell parents nothing about their particular child’s risk, which is likely the information that parents want.

The discourse also overlooked the fact that experts do not have knowledge of each family’s unique circumstances and the considerations that parents must make in light of their situations. Vaccination is a technology that extends into the daily lives of lay people, so while scientists may have specialized knowledge about vaccines under experimental conditions, individual parents also have specialized knowledge of their children’s health, how they react to medication, and the situations in which they live (Moore and Stilgoe 2009). Moore argues that when the authority of science is contested, as in vaccination, experts attempt to maintain the boundary between experts and non-experts, or scientists and non-scientists, through the construction of “anecdotes” and “anecdotal evidence” (Moore and Stilgoe 2009). “Anecdotal evidence” defines what science is not; that is, subjective and susceptible to misreporting and bias (Moore and Stilgoe 2009). Thus, information brought forth by parents about potential harm from MMR is dismissed as “anecdotes” from the lay population, as opposed to legitimate scientific evidence. The label “anecdotal evidence” performs the social function of separating the knowledge of lay people from that of experts. Similarly, the concept of expertise is also socially defined and lends credibility, trustworthiness, and authority to expert risk assessments (Irwin and Wynne 1996).

The proliferation of Internet websites on vaccine safety can be viewed as a democratization of information and decision-making about vaccines. Before, physicians and government were the only sources from which parents could obtain information, and there could be difficulties in accessing information. With the Internet, most people are able to access a variety of sources on their own and have the freedom to find and select sources that they perceive to address their concerns and that provide the information *they* deem to be relevant to the decision-making process.

Perhaps it is, as the experts say, that many online sources contain numerous inaccuracies about science, but it may also be that they help raise important questions that would otherwise be ignored or overlooked by the medical community. The paradigm in which one operates will make one more aware of certain problems and less of others, and a different perspective can offer new insights. Criticisms of the MMR vaccine from people outside of the medical field may highlight problems that those within the field are blind to. Unfortunately, for the most part, the discourse has not acknowledged that there are other ways of looking at the vaccine uptake problem other than through the medical lens, so it has not granted dissenting viewpoints any legitimacy. Perhaps, more importantly, there has been no dialogue between these two disparate groups.

If the legitimacy of evidence can only be determined with expertise in scientific concepts and processes, then parents are not in a place to decide for themselves what to make of vaccines. They are made dependent on what experts tell them, and they have no way of knowing when the experts have made a mistake, which they sometimes do. The requirement to base decisions on scientifically supported evidence puts parents in a position of dependence on experts.

The question of whether or not to accept MMR immunization can be characterized as an unfair argument between parents and experts, since the knowledge that parents possess about their children's health, which may determine whether or not vaccination is appropriate for their children, is not acknowledged by experts. It is possible that this was why some parents simply refused vaccines altogether, since they felt it was impossible for them to negotiate any other outcomes with experts.

### 5.4.3 “Evidence-Based” Decision-Making

According to the discourse, immunization was objectively determined by scientific evidence about vaccine risks and benefits as the best choice for parents. The kinds of information that count as evidence to support best choices, however, are determined according to a set of socially-defined criteria. This leads to the question: is evidence always “true” or “right”? As noted earlier, the hierarchy of evidence itself is not stable among scientists as the criteria for valid evidence are not always clear, and scientists do not always agree on whether a study should be deemed good or poor (Wynne 1991). Moreover, findings that were once believed to be true at a certain point in time may be refuted in later studies. As parents are constantly receiving health information, some of which may contradict each other and change over the years, their perceptions and decision-making about vaccination may change over time, and they may also feel uncertain about which information to believe.

The example of the BSE crisis in Results 4.1.2 illustrates the transient nature of “evidence”. Although the British government initially tried to convince the public that it was safe to consume beef, it eventually realized its mistake. It appears that the actions of the government were only ruled as not “evidence-based” after they could no longer be defended. In contrast, risk communication about MMR safety is currently considered evidence-based. If scientists should one day discover that there was an association between the vaccine and autism, would they, looking back at present MMR promotion, still consider it “evidence-based”? Evidence was used as an indicator of “the truth” to justify expert risk assessments, and it seems to also help distance experts from previous mistakes in risk assessment. The image of scientific unanimity and certainty over the safety of MMR is maintained by denying the legitimacy of research that was not consistent with the general position and classifying it as “non-evidence”.

Since what counts as evidence is variable, is there really a hierarchy of evidence? In other words, how is it possible to establish a hierarchy if the criteria for what counts as evidence are not consistent? As the Wakefield controversy shows, findings aren’t necessarily classified as evidence because they have been published in reputable, peer-reviewed journals. The channel that information is distributed from (e.g. academic journals, books, news media), which was previously thought to be an indicator of the credibility of the information and whether it constituted “evidence”, turned out to have no bearing on its status. It appears that findings are



given the status of “evidence” if they are consistent with the majority of the studies in scientific journals that support the views held by government institutions (Upshur 2003). Indeed, as Upshur (Upshur 2003) has found, the hierarchies of scientific evidence themselves have not been empirically supported but are based instead on expert opinion.

## 5.5 Strengths and Limitations

The decision to limit the data set to the top ten impact factor journals was somewhat arbitrary, as there are other journals that fall outside of the top ten range that contribute to the discourse. While journals with high impact factors were used to characterize the medical discourse, discourse is also shaped by journals outside of this data set, as well as “grey” medical literature, such as the Medical Post that is distributed to physicians. However, the focus of this study was on the *dominant* discourse in the universe of discourse, which is defined by medical journals themselves as those journals that have high impact factor.

One may also question the decision to limit journals by impact factor, as the usefulness of impact factors as a measure of a journal’s quality has been disputed by some (Cresswell 1997). It should be kept in mind that the aim of this study was not to evaluate the quality of the journals or the “truthfulness” of the studies selected, but to examine the discourse within journals that characterize the mainstream, dominant medical discourse. Furthermore, since the purpose of this study was to analyze the medical discourse, the actual reasons behind parents’ decisions were not examined, and no attempt was made to propose alternative explanations for parents’ decisions. Indeed, the strength of this study lies in its use of critical theory and methodology to explore the medical discourse, which was able to highlight assumptions that were taken for granted in the discourse while pointing to other possible interpretations of the MMR uptake issue.

Some, who are unfamiliar with qualitative research, may say there are also some limitations to the methodology, in particular the subjectivity of CDA, where the findings from a study are an interpretation of the data made by the researcher. Another researcher with a different theoretical perspective will arrive at somewhat different results. It is therefore important to maintain complete and transparent records of the research process, or an audit trail, so that another researcher following this trail should be able to arrive at the same results. However, it should be

noted that this kind of qualitative research does not claim to be objective in the classic sense of objectivity where the researcher is free from bias. The theoretical propositions that guide a study require the researcher to make certain epistemic commitments. The validity of the findings is located in their authenticity and faithfulness to the data, which is why the “audit trail” is of importance. Thus, the notion of validity is called reliability, dependability, or confirmability in constructivist qualitative research.

## 5.6 Implications for Risk Communication

In order to increase the likelihood of successful risk communication, trust must first be established between parents and information providers, as parents need to perceive the source to be credible. However, it should be kept in mind that trust is not static and may increase or wane as contexts change. Because trust is contextually contingent and should not be taken for granted, risk communication should take account of events that could affect trust between parents and the medical establishment.

As a few authors have suggested, risk communication should also be tailored to individual parents’ needs. The current medical discourse has not differentiated between different groups of parents, which could explain why risk communication messages are not taken up by all parents. As discussed earlier, parents have various reasons for declining vaccination and make their decisions in diverse contexts, so public health messages will not be perceived in the same manner by all parents. Future risk communication should be more aware of different groups of parents and their reasons for vaccine refusal so that their concerns can be more accurately addressed.

However, personalized risk communication alone may not be sufficient to increase uptake. Although risk communication, or education about the risks of diseases and vaccines, has often been proposed as the solution to improving vaccine uptake, it is based on a Deficit Model account of parental decision-making, which attributes non-vaccination to a lack of knowledge about vaccines and diseases. As shown in this study, there are other ways of framing the issue of vaccine refusal besides risk, and communication that focuses only on risk is unable to address other parental concerns that are not disease-related.

Communication with parents should assume that parents are not necessarily lacking in knowledge about vaccines, as some parents have been found to actively search for information on their own. The knowledge that parents possess about their children's health and their environment should also be acknowledged, rather than discounted as "anecdotal" evidence. As suggested by the Contextual Model, communication between parents and medical experts should not be a top-down process in which parents passively receive information from the experts. It is also important to keep in mind that the ways in which people perceive information is influenced by the context of communication.

## 5.7 Summary

The construction of immunization decision-making by parents in the medical discourse can be described by two overarching themes in the discourse: Risk and Trust. Of these two themes, Risk was found to be the dominant theme, with Trust playing a relatively minor role in the discourse. Thus, in answer to the objectives set out at the beginning of this study (Chapter 1), parents were assumed in the medical discourse to be lacking in understanding about vaccines, whether or not they chose to have their children immunized. Parents who vaccinated made the "correct" choice by following the advice of their physicians, while non-vaccinating parents were misled by "wrong" information and reports that focused on adverse events related to MMR. In essence, parents needed guidance from medical experts.

Parental decision-making was understood mainly in terms of Risk. Parents were assumed to base their decisions by balancing disease risks against the risks of vaccine-related adverse events. This is consistent with the Deficit Model's focus on knowledge as the main determinant of uptake for science and technology. Also consistent with the Deficit Model was the generalization in the discourse of parents as a homogenous group, which yielded seemingly contradictory results. For example, parents who refused MMR vaccination were described as free-riding off herd immunity while vocally opposing the vaccine and lowering herd immunity. This is a shortcoming of the Deficit Model assumption that the public is a uniform, homogenous entity. A more nuanced look at different groups of parents through the Contextual Model helps explain the discrepancies observed through the Deficit Model, and could be useful for developing more tailored messages to parents.

The framing of parental immunization decisions in terms of risk (which itself is narrowly defined) is a limited approach to the problem of vaccine uptake. Injection pain, while not considered a disease risk in the discourse, was regarded as a risk for parents and health care providers, as it was distressing for all parties involved in the immunization process. Other factors that are unrelated to health risks, but that nevertheless influence parental decision-making, are overlooked. Other research has also reported convenience as a factor in parents' decisions about vaccination, as it was easier in some parts of the United States and Canada to request vaccine exemptions than it was to provide proof of compliance with school immunization requirements.

Moreover, the concept of risk, as defined by the discourse, fails to consider that risk is socially constructed, and that there are other interpretations of what constitutes risk. The kinds of information drawn upon and the assessment of risk differ between parents and experts. Parents, with their focus on their children, will more likely employ possibilistic, or worst-case, thinking in their decision-making about vaccination, whereas experts calculate risks using probabilistic assessments that can be applied to a large population. Parents also possess more knowledge about their children's health, and may decide, based on that knowledge, that their children do not fit the profile of the "average" individual for which expert risk assessments were calculated. Yet, parents who declined MMR were described in the discourse as acting immorally for putting their children and others around them at risk for disease. Alternative perspectives on immunization were not acknowledged in the discourse as legitimate and needed to be "corrected" through education or risk communication.

While the discourse was mostly rooted in the Deficit Model, the Contextual Model theme of Trust was also identified in the discourse, as trust in physicians was also believed to help promote decisions to vaccinate. However, the concept of trust in the discourse is still narrow and needs to be further expanded beyond the patient-physician relationship. For example, parental distrust in vaccine recommendations from physicians may stem from a wider distrust in processes of establishing evidence, as the criteria for what counts as evidence are not always clear. Although the discourse framed the issue of vaccine uptake by parents mainly in terms of risk, the Contextual Model argues that trust, as well as other contextual, non-risk factors, are equally important in parents' decision-making and need to be better understood and addressed in the medical discourse on MMR uptake.

In summary, the major finding of this research was that there was evidence for the dominance of the Deficit Model of PUS in the medical discourse on parental uptake of the MMR vaccination, as demonstrated by the focus on risk in the discourse. However, there was also evidence of the Contextual Model of the PUS through discussions about trust, though it was only weakly present. It appears that the discourse has moved outside the narrow concept of risk as an explanatory factor for MMR uptake by parents, though not very far as the medical discourse is still mostly dominated by discussions about risk. It was shown in this study that the reliance on Deficit Model-based explanations of parental decision-making constrains the ways in which the discourse can frame the problem of vaccine “resistance”. In turn, the possible risk communication strategies for improving uptake of an important immunization are also constrained. Indeed, the presentation of the issue of declining vaccine uptake by parents is consistent and over-simplified. If higher uptake of the MMR vaccine by parents is to be achieved, researchers will need to look beyond risk and consider perspectives offered by the Contextual Model in order to better understand parents’ decision-making.

## 6 Future Directions

As mentioned before, the discourse on parental decision-making about childhood vaccination should not be framed solely in terms of risk. Hence, future research should also investigate other factors that have not been recognized in the medical discourse as “risks” but that could impact decision-making by parents. Although injection pain has been found to adversely affect immunization uptake (Taddio, Chambers *et al.* 2009), there was an absence of discussion within the medical literature about the effect of pain on parents’ decisions concerning vaccination. More research on and more acknowledgement of the impact of pain within the high ranking medical journals may lead to improved vaccine administration procedures and better uptake.

While trust has been recognized in the discourse as contributing to parents’ decisions to vaccinate, the emphasis has only been on improving trust in physicians. However, trust, or the lack of trust, in the government and the pharmaceutical industry is also known to influence parents’ attitudes towards vaccines (Davies 2002; Wolfe, Sharp *et al.* 2002), so future research should also address and explore trust in these areas.

The discourse so far has not focused much on understanding the decision-making processes of parents. Although there were some suggestions to develop messages tailored to parents’ unique needs, there has not been any clear indication as to how experts can identify parents’ needs and how best to tailor messages. There should be more qualitative research with parents to gain a more nuanced understanding of their decision-making about vaccinations, as there is a paucity of studies in the medical literature that actually interview parents about their decisions.

One of the difficulties in allaying parents’ concerns about a putative link between MMR and autism may lie in the fact that the causes of autism are not well understood. In order for medical experts to be able to address parents’ concerns more directly, there should be continued research on autism. Experts cannot present a convincing case to parents against a causal association between MMR and autism if they do not even know what causes autism.

Finally, while this study has looked at the medical discourse as a representation of a particular, formalized system of thought regarding parental vaccination decision-making, and is therefore not concerned with medical practice itself, it would be useful to investigate how discursive

practice relates to the way in which health experts communicate with parents about vaccines. A better understanding of the relationship between the medical discourse, risk communication, and vaccine uptake will allow for the development of more effective public health messages.

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